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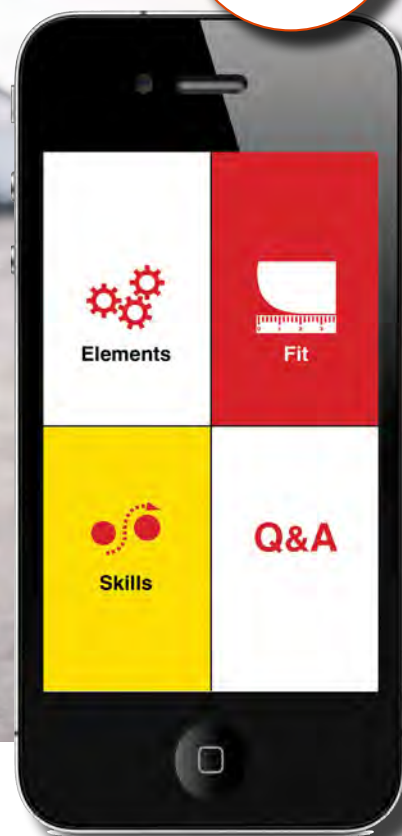
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with the 'My Wheelchair Guide' Mobile App



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SOON!



Finding the right manual wheelchair is hard, we make it easy!
My Wheelchair Guide makes choosing the right manual wheelchair easier and more efficient. (*Search 'MWG Manual' in Google and Apple app stores to download.)

Now, all the necessary tools and resources to guide you through manual wheelchair selection, delivery and maintenance are at your fingertips. This comprehensive app covers the entire process of getting a wheelchair, providing practical information to evaluate your needs, wants, and concerns from beginning to end.

THE MY WHEELCHAIR GUIDE FEATURES:

- Self-assessment & maintenance checklists
- Customizable to-do lists
- Wheelchair skills videos
- Illustrations on wheelchair types, parts, & accessories
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- Ability to take notes within the app using text, pictures, or voice recording
- Q&A section

Whether you're a beginner or advanced wheelchair user, My Wheelchair Guide will help you discover greater health, mobility and independence.

[HTTPS://UNITEDSPINAL.ORG/MY-WHEELCHAIR-GUIDE/](https://unitedspinal.org/my-wheelchair-guide/)

"The app will be a handy reference providing credible and practical information about usage, maintenance, and health issues that wheelchair users face daily."

— Tanya L., Physical Therapist/
Assistive Technology Provider



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COVER STORY

BUILDING A BETTER REHAB HOSPITAL

Not too long ago, rehab hospitals were dark, uninviting facilities that looked and felt stuck in the '70s — but times are finally changing. AARON BROVERMAN reports on a promising new trend of rehabs that incorporate wheelchair users' input to build a better brand of facilities where accessibility is a feature and not an afterthought.

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Cover and Contents Photos Courtesy of Sheltering Arms Institute



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14 SERVICE DOG CONTEST WINNERS

We put out a call for our readers' best pooch pictures, and now it's time to present the prize pup.

28 AN INCOMPLETE DANCE Living with an incomplete injury that sometimes lets you stand or even walk is like having a wild affair with a beautiful yet cruel seductress, writes RICHARD HOLICKY.

32 ISOLATION TO EMPOWERMENT

As the executive director of Magic Wheelchair, Christine Getman enjoys being creative and helping children with disabilities. But a hellish hospital stay last spring showed she is not to be trifled with. CAROLE ZOOM reports.

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BULLY PULPIT

By Ian Ruder

ME AND MY DRAGON

If you follow the tech world, or if you happen to be a huge Microsoft fan, you may have seen that on April 12, Microsoft paid \$16 billion to acquire Nuance Communications, the developer behind speech-to-text stalwart Dragon NaturallySpeaking. Most of the mainstream coverage focused on the impact the acquisition will have on artificial intelligence. But as someone who grew up with NaturallySpeaking and its less-heralded and less-effective sibling, Dragon Dictate, the sale (and the astronomical price) sparked a moment of reflection.

My first introduction to Dragon came in a rarely-used room offset from the main gym where I rehabbed. My parents had urged my therapists to show me how I'd still be able to use a computer, despite not having any arm function and being on a vent at the time.

While I'm sure this conversation is very different 23 years later, thanks to tech advances and the omnipresence of phones and computers, the therapists' reluctance and lack of enthusiasm for demonstrating my speech-to-text options suggested that my parents' request was not common back then. The room where they kept the unit's one computer that ran Dragon Dictate reaffirmed that idea. Surrounded by boxes and empty white walls, the room gave no sense I was using some of the most expensive, cutting-edge speech recognition software on the market.

Despite a somewhat clunky and slow interface, controlling a computer solely by voice gave me hope I'd be able to continue my education, find meaningful work and live a fulfilling, productive life. I remember being so excited to have Dictate on my own computer when, months later, I finally got home for good. I opened the giant box it came in, installed all the CDs and read

the painstakingly dull sample texts to create my voice file ... and then I didn't use it.

Early on in my rehab, someone showed me a video of a quad explaining how she could type just as fast as most nondisabled people with her typing aids. While I'm not sure I truly believed it possible, I vowed that someday I'd be just like her. Once I got off the vent and got some arm function back, I got to banging out all my work with my sticks.

I ignored the fact that Dragon allowed me to dictate at speeds that even the fastest nondisabled typist would envy. Sure, a cumbersome mic and some not-so-brilliant features in the actual software provided easy excuses to avoid Dictate, and later NaturallySpeaking, but my main reason for staying away was simple: In my mind, the less assistance I needed, the closer to "normal" I was.

A few years ago, I revisited Dragon and realized my mistake. While the software couldn't boost my navigation speeds — mouse grids be damned — the dictation had grown so efficient and fast that I felt like an idiot for not using it. It took me a while to find the right balance of sticks and software, but once I did, my productivity immediately increased.

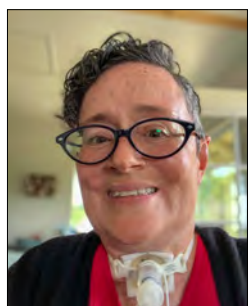
Thinking back on all the deadlines I struggled to make and how many hours I could have saved if I hadn't let my pride hold me back can be a little depressing. Instead, I use my experience with Dragon as a reminder to not be held back by outdated ableist ideas. Inevitably there will be another potentially life-changing innovation, and there's a good chance adopting it will go against some long-held societal conventions, but next time I'll be more ready to figure out what it really means for me.



BEHIND THE STORIES

With Ian Ruder

Catching up with Outdoor Tracks columnist **Kary Wright** is always a blast because he is inevitably planning some cool adventure or building some handy tool to help him on his next excursion. Because of that resourcefulness and creativity, I had no doubt he would rebound from a devastating fire that cost him his home and years of adaptive inventions and aids. Proving me right, he rebuilt his Alberta, Canada, house and, as his column this month mentions, is well on his way to re-amassing his toolbox of tools. "Things are going pretty darn good," he says. "We moved in April 1, the man-cave is set up ... it's a lot of fun."



When you're writing about someone, finding things you have in common is a great way to learn about your subject on a deeper level. In getting to know Christine Getman for this month's feature, **Carole Zoom** found more than just shared interests. "It just felt like I was talking to a younger version of myself," she says. "Christine makes her own way and doesn't take a lot of guff. It made it extra fun to cover her because it gave me a glimpse of how my life might have been different if the ADA had been around earlier."

As counterintuitive as it may be, wheelchair users know rehab hospitals are often maddeningly inaccessible. But what would happen if designers and rehab management actually involved us in the design process? **Aaron Broverman** sought out the answer and found an exciting new wave of facilities striving for a more accessible, inclusive experience. "I thought it was amazing there were so many rehabs that actually cared about what their patients wanted," he says. "I came away impressed by their desire to reach out and truly involve the disability community."



Photo by Agnes Wywrot, Northern Wildflower Photography

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org

United Spinal's Resource Center provides information on any aspect of living with SCI/D. Contact: 800/962-9629; unitedspinal.org/ask-us; 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.



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APRIL 2021

Camping & Glamping

Camping is Awesome: We are big campers! I have ramps into our camper and love every minute of it. This year we are traveling from Georgia to Washington state — stopping at lots of National Parks along the way.

@Jamiagoodwin
Instagram

Ramped-Up Treehouse: Oooh, a treehouse: I'm adding this to my bucket list!

@Curbfreecorylee
Instagram

Accessibility Services Works Behind the Scenes to Bring America into the 21st Century

Right Treehouse, Wrong Sketch: Your articles on glamping and the tree house were very good and gave very good ideas for travel. I thank you for them. The article on accessibility was just a joke. That drawing of a bathroom would never work for my wife. It's the worst design I have ever seen. She is in a power wheelchair and could probably not even get in that room. It just pisses me off when they say they know what they are doing when designing bathrooms. Every accessible bathroom is not designed right in the whole state of Washington. I could say so much more but I am too upset.

Charles Thomas
Spokane, Washington

Accessibility Services Responds: Mr. Thomas is absolutely correct. This

"I'm adding this to my bucket list!"

sketch illustrates a residential bathroom that would not be allowed in new construction under today's accessibility codes and standards. While the Fair Housing Act provides less accessibility than the ADA, this bathroom doesn't even meet the FHA's modest requirements. Good catch, and thank you!

Marsha Mazz
Director, Accessibility Codes and Standards

Zen and the Art of Adaptive Surfing

Ya Missed One: Great article guys, full of legends! But I don't understand how no one is talking about Kyle Richardson, who just smashed the biggest wave record for an adaptive rider last year in Hawaii. The process and commitment to get to this ride was insane, and the media didn't even reach him back.

Pablo Airways
Facebook

Please Remain Seated: Hold the Elevator

My Best Comeback: This is my favorite thing to say when nondisabled folk take the elevator: They say, "I'm feeling lazy today!" And I say, "Me too," and savor the awkward silence.
@freedomofmovement35
Instagram

Faulty Assumptions: Unfortunately, people used to think I was just being young and lazy before my conditions



ended up in full time wheelchair use. I've been yelled at for taking accessible parking spots, for sitting in crowded doctors offices, for "not showing elders respect" out in public, and asked if I was just being lazy or tired once I became a full-time wheelchair user, and so on. The comments people make (both disabled and nondisabled) are sometimes a shocking part of the experience of disability, wheelchair user or not.

@cuddle_zee_critters
Instagram

How Rude: As a quad for the last 44 years, I find this is just "bad manners" and offensive. Being treated well, as a person with a disability, goes both ways — you should treat everyone with respect to get any back.

Colin Johanson
Newmobility.com



www.matbarton.com

NEWS FROM UNITED SPINAL

WIN PRIZES JUST FOR BEING A MEMBER

As a United Spinal member, you already have access to the most comprehensive SCI/D resources and expertise, and now you can win great prizes too. In celebration of United Spinal's 75th Anniversary campaign to Build an Inclusive World, United Spinal members can enter to win prizes at member events throughout the anniversary year (see below). Prizes range from sought-after accessibility accessories to state-of-the-art tech products from sponsors like Amazon, BraunAbility, Cure Medical, EasyHold, Facebook, Google, Microsoft and many more. All the prizes are listed on United Spinal's new 75th Anniversary Member Prize Zone, along with the contest details.

You must be a United Spinal member to enter to win. United Spinal membership is free and you do not need to be present at the drawing.

- **75th Anniversary Member Prize Zone:**

unitedspinal.org/75th-anniversary/member-prize-zone

- **75th Anniversary Homepage:** unitedspinal.org/75th-anniversary

- **Become a United Spinal Member:** unitedspinal.org/join-united-spinal-association



Upcoming 75th Anniversary Events

To celebrate United Spinal's 75th anniversary, we'll be holding prize drawings throughout the year during the following United Spinal Member Events:

Future of Work — June 30, 2 p.m. – 3 p.m. ET

Advocacy Series — Sept. 2021. Date and time to be announced.

Future of Work — Sept. 30, 2021. Time to be announced.

75th Virtual Gala — Nov. 10, 2021. Time to be announced.

Advocacy Series — Dec. 2021. Date and time to be announced.

MEMBER BENEFITS

unitedspinal.org

United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

BENEFITS INCLUDE:

Personalized Advice and Guidance

Peer Support

Advocacy and Public Policy

Veterans Benefits Counseling

Accessibility Advocacy

Local Chapters

New Mobility magazine

Informative and Educational Publications

Ongoing Educational Webinars

Special Offers and Discounts from Partnering Organizations

Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

United Spinal has 75 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.



British Ballers

On April 20, British Wheelchair Basketball announced the creation of the Women's Premier League, the world's first women's wheelchair basketball league and the first professional para-sport league in the U.K.

With 60% British players and 40% internationals, the league will run from January to May 2022, with franchises based at four universities: Cardiff Metropolitan University, Loughborough University, University of East London and University of Worcester.

"To be the first group of girls to pave this way with this premier league — that, honestly, I never thought was going to happen," British team member Siobhán Fitzpatrick told *The Guardian*. "We spoke about it and it was always what we wished we could do and now it's actually happened in two years. It's just phenomenal. It gives me goosebumps just talking about it."

Laurie Williams of Great Britain in action at the Wheelchair Basketball World Championships on August 25, 2018 in Hamburg, Germany.

Visit britishwheelchairbasketball.co.uk or read more about the league in the full *Guardian* article, theguardian.com/sport/2021/apr/20/womens-wheelchair-basketball-makes-groundbreaking-professional-move.

Photo by Moto Yoshimura/Getty Images



Elevated Bathing

Tired of tough tub transfers and hard-to-reach faucets and controls? The Assisto bathtub is a new option on the market for anyone looking for a safer, more accessible bathing experience. With an elevated tub and easy access via a lightweight, no-threshold vertical door, the Assisto removes all the obstacles from transferring and puts all the bath's controls within easy reach. The multitude of options includes heated backrest, air jets, and chromotherapy so you can transform your bathroom into a mini-spa. Currently, the bathtub is sold exclusively by Assisto, a Canadian company that has clearly embraced the principles of universal design and recognized the value of the disabled market. For more information, contact information@collectionassisto.com or call visit assistocollection.com.

Country Roads to an Accessible Hotel

There's never been a better time to book that trip you've been wanting to make to West Virginia thanks to the pending launch of the world's first hotel where every room is adapted for disabled people. John Morris of wheelchairtravel.org reports that The Schoolhouse Hotel is slated to open in White Sulphur Springs, West Virginia, on Jan. 1, 2022. Built in an old high school building, the boutique hotel will feature 28 guest rooms and two suites — all designed for full accessibility. The project is being partially funded by the Disability Opportunity Fund. Read Morris's report at travelabilityin-



sider.com/2021/03/16/worlds-first-all-rooms-accessible-hotel-to-open-in-west-virginia-on-new-years-day-2022 and stay up to date with the latest construction updates at theschoolhousehotelwv.com.



A Pant Iz Born

Izzy Camilleri has designed clothes for Hollywood stars like Meryl Streep, Jason Momoa and Daniel Radcliffe, and she owns one of the most successful and stylish adaptive

clothing lines on the market. But her biggest accomplishment may have come this past February: She solved the wheelchair pants problem — how to build a stylish pant with a seamless back that minimizes possible pressure problems.



After over a decade of designing accessible clothing, Camilleri finally figured it out. She calls it the Game Changer Pant. “The first pant in the collection looks like a classic jean in the front but the back has a revolutionary design called IZ Seamless Technology. This design is free of seams or pockets that a person would normally be sitting on that can result in pressure sores,” says Camilleri.

The Game Changer Pant is available in blue and black denim for \$165, chinos for \$155 and sweatpants for \$105. All are available online at www.izadaptive.com. IZ Adaptive will also be launching Game Changer leggings and underwear. Look for plans to develop a Game Changer Pant line for children.

Vaccine Survey Results

In mid-April, we surveyed our readers to get their thoughts about and experiences with the COVID vaccines. Of the 367 respondents, all of whom said they have SCI/D, 82% (304) had received one or two doses of vaccine, while 7% (25) said they planned to and 10% (35) said they had no intention of getting the vaccine.

- 72% of respondents who had been vaccinated said they had concerns about the safety of the vaccines, compared to 78% of those who had not received a vaccine.
- 60% of respondents said they felt they had adequate information about the safety of the vaccine for people with SCI/D.
- 60% of the people who received vaccines said they had some sort of reaction to the vaccines; still, 94% said they’d be willing to get another vaccine in the future if needed.



WATCH

SUMMER IS ALMOST OFFICIALLY HERE, BUT YOU DON'T HAVE TO WAIT UNTIL JUNE 20 TO ENJOY **BEST SUMMER EVER** ... THE MOVIE. THINK *HIGH SCHOOL MUSICAL*, ONLY WITH ONE OF THE MOST INCLUSIVE CASTS EVER ASSEMBLED AND MUCH MORE GENUINE EMOTION AND CHEER. WHEN SAGE (SHANNON DEVIDO) STARTS A NEW HIGH SCHOOL SO SHE CAN STAY WITH HER SUMMER BOYFRIEND, TONY (RICKEY ALEXANDER WILSON), HIJINKS ENSUE. THE FILM WAS A FAN FAVORITE AT 2021 SXSW FILM FESTIVAL AND SELECTED AS A *NEW YORK TIMES* CRITIC PICK.

THE PRODUCTION TEAM BEHIND *BEST SUMMER EVER* FULLY EMBRACED INCLUSIVITY, GOING BEYOND CASTING TO ASSEMBLE A BEHIND-THE-CAMERA CREW WITH MANY DISABLED CREWMEMBERS.

“FROM WRITING THE SCRIPT TO RECORDING THE MUSIC, TO OUR DAYS ON SET AND MARKETING MEETINGS, THIS FILM WAS CREATED ENTIRELY BY PEOPLE WITH AND WITHOUT DISABILITIES WORKING TOGETHER,” ONE OF THE PRODUCERS EXPLAINED TO RESPECTABILITY.ORG. “*BEST SUMMER EVER* IS A PRODUCT OF THE COLLECTIVE EFFORT, CREATIVITY, AND TALENT OF PEOPLE WITH A VARIETY OF LIVED EXPERIENCES. WE PROCESS INFORMATION, COMMUNICATE, MOVE, AND JUST GENERALLY EXPERIENCE THE WORLD IN WAYS THAT ARE UNIQUE. I CAN'T THINK OF A BETTER RECIPE FOR A TEAM EMBARKING ON A CREATIVE ENDEAVOR TOGETHER.”

BEST SUMMER EVER IS AVAILABLE TO RENT OR BUY ON MOST STREAMING PLATFORMS.



Rickey Wilson Jr. and Shannon DeVido in *Best Summer Ever*.



GEAR HACKS

By Seth McBride

HACKING A HOME, PART 3

It's now been over a year since we last checked in with operation home hack, and ... drumroll, please ... we have a home! As I write this, we're in the throes of moving and it's still surreal that my family's multi-year dream is finally a reality, but we're in, and it is glorious. I'll happily take you all on a tour of the finished product once it has emerged from a sea of boxes. In the meantime, I wanted to look back on a few of the more important hacks I learned through the construction process — from learning how to operate a standard excavator, to insulating our home to quad standards, to finding an inexpensive way to customize our kitchen's accessibility.

Not a Threshold in Sight

Any wheelchair user knows: Door thresholds are terrible. Especially when you're trying to roll with a cup of coffee from your kitchen to the living room and you're barely awake to manage yourself, let alone piping hot liquid. We built our house on top of a concrete slab foundation, and instead of covering the slab with hardwoods in the living room and something more waterproof in the bathrooms, we opted to just let the slab be our floors. Other than a small bump getting in the front door, there isn't a single threshold in the house. Once sealed, concrete is easy to clean, has no problems getting wet and hides dirt like a dream. You have to be cool with an industrial look, but otherwise concrete is an ideal flooring material for wheelchair users.



Playing in the Dirt

So, it turns out that excavators are surprisingly quad-friendly. I found this out by happenstance. We had a general contractor friend, JP, who flew down from Alaska to help us out on the interior of the house just before the 'rona shut down the world. Since he knew how to operate an excavator, we convinced him to help us do some dirt work around the house — setting drain tiles at the foundation perimeter, digging a trench for underground power and even installing a septic tank and drain field.

We rented a John Deere 35G Mini Excavator, and two weeks later JP had almost everything done. Watching him work, I noticed that he never used his legs. Curious, I hauled myself up into the cab. Easier said than done, yes, but once I got the multi-step technique down [see the video at youtu.be/BhuS4XYowzw], it wasn't the most difficult transfer I've ever done. Up in the seat I confirmed that everything could indeed be operated with

no legs and very undexterous hands. If you were ever a kid who played on those sit-on-top, metal sand-scooping contraptions, you'll understand my excitement.

JP gave me a run through on the controls, and I was off — very slowly — chugging across the yard. He sent me toward



a dirt pile, and I practiced moving buckets full of soil from one pile to another. I was herky-jerky and highly unskilled, but sure enough, I could do it.

I extended the rental for another week, and when JP flew back to Alaska, I set about putting our driveway in. Whereas a skilled operator likely could have done it in a day, or two max, it took me a full week of labor. By the end of the week, I had a rudimentary feel for scooping, moving, scraping and leveling dirt — and I had a driveway built with my own two hands. It was damn satisfying. Plus, given the cost of dirt work, it saved us a few thousand dollars and gives us a lot more options as we continue to work on the property in the future. My son, Ewan, for one, has already started petitioning me to rent another one so I can build him a mountain bike track. "Like a pump track?" I asked.

"No. A *jump* track," he corrected. Obviously.

Insulation Situation

For the past three years, my family and I lived in a 100-year-old house with mini-

mal, if any, insulation. As a quad with piss-poor thermoregulation, this sucked. I was either hot or cold all the time. We knew that we wanted a well-insulated, draft-free home. But many of the more modern insulation techniques require either skilled professionals or extensive planning and integration into the building design. Our pole barn shell [see *Hacking a Home*, Part 1] was a standard design with a standard setup process so that we could minimize the labor time and costs to construct it.

After extensive research and waffling, we decided to use a hybrid insulation technique. We hired a spray foam company to coat the entire interior shell of the building — walls and roof deck — in 3-inches of closed-cell spray foam. This was not cheap. For our 1,500 square foot home, the bill was over \$8,000. That didn't even get us up to code — we still had to add another layer of batt insulation to the roof. Instead of standard fiberglass insulation, we chose mineral wool — a byproduct of steel production — because it's denser, less prone to breakdown over time and more fire-resistant.

I spent a lot of time second-guessing the amount of money we were going to spend on this combo. We were aiming for an inexpensive house, but we didn't want it to be cheap. Putting extra effort and funds into the structure of a house you plan to live in for multiple decades is rarely something you'll regret.

So we went for it, and my quad bod couldn't be happier. We have a heat pump for heating and cooling, and the house is so well insulated that we did something weird when we moved in. We turned the pump off. It hasn't been on for 48 hours now, during which time the outside temperature has gone up to 80 and down to 45. Outside I've gone from shirtless, to a long sleeve with a sweat-shirt over it; inside has been all T-shirt, all the time. This does not suck.

Custom Cabinetry for Ikea Prices

Originally, we were planning to go with Ikea cabinets for the kitchen because they were within our budget. When you're trying to make a kitchen work for a wheelchair user, custom cabinets go a long way,

but after seeing what cabinet makers typically charge, we figured we'd have to make do with what we could afford. After poking around at an Ikea store though, we weren't exactly excited about particle board. Plus, a friend who purchased from Ikea for a kitchen remodel told us that you *have* to spring for the installation option. Have you ever tried assembling a bookshelf from Ikea? Yeah, imagine doing a whole kitchen like that.

After a deep dive into the internet world of "ready-to-assemble" cabinets, I happened on a company, Barker Cabinets, that built theirs out of solid, ¾-inch plywood with sturdy components. What's more, you can customize the measurements however you want. Need to lower a countertop by a couple of inches? No problem. Need to change the depth so items are easier to reach? They can do that.

In our house's division of labor, Kelly does most of the cooking and I do most of the dishes. We opted to keep counter heights and depths the same to easily accommodate standard appliances, but we ordered a 36-inch-wide board in the same wood as the cabinet doors instead of a traditional sink cabinet. The board covers the sink front, giving a built-in look, but allowing me to roll under the sink. After more than a decade of twisting my body to do dishes at a standard sink, I can't tell you how nice this is.

To save money and get the look we wanted, we opted to order unfinished maple for the cabinet fronts and stain them ourselves. All-in, we prob-

ably spent about 20 hours staining and then assembling the cabinets. This was straightforward work that anyone, including me, could do. To stain the cabinets, we set a couple of long boards atop sawhorses and then a row of cabinet doors on top of the boards, putting them at perfect height for me. My mom took over much of the work after we developed a system, but that was for speed, as I could only work on weekends — the whole process was well within my functional abilities. Assembly was straightforward and took maybe a half an hour per cabinet.

We ended up spending less than \$5,000 on our kitchen cabinets, which, absurdly, is less than we would have spent at Ikea. The extra staining and assembly effort was well worth it because we never would have afforded the same quality or accessibility otherwise. The only downside to ordering cabinets this way is that you have to nail your measurements and your design, because any mistakes you make are on you.

That's kind of the deal with DIY house building though. You have to be willing to make mistakes, and put in a whole lot of extra effort, but the rewards are well worth it.

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UNITED SPINAL ADVOCACY MANAGER

Annie Streit



Annie Streit had a career as an interior designer all lined up but found a new purpose when she sustained a spinal cord injury. Today she devotes her time to educating children about disability and building a grassroots advocacy community around SCI/D.



The Path She Was Meant to Go Down

Annie Streit, 38, knows the exact moment she gained some much-needed perspective on her SCI.

The Angola, Indiana, resident was sitting in her room at the Rehabilitation Hospital of Indiana when she looked out the window, noticed the cars driving by on the interstate and had the thought that would guide the next phase of her life: "Life in the world is still going on. It doesn't stop, no matter what I was going through in that moment," says Streit. "That's when I knew I wasn't going to let my spinal cord injury define who I was."

It was that outlook that now allows her to describe her rehabilitation as "a fantastic experience" and helps her maintain friendships to this day with many of those who worked with her on that journey.

Her accident occurred on the night of her college graduation. She was on the verge of taking a job as an interior designer, and a firm held a position for her while she recovered. But dealing with her new injury — C5 quadriplegia from a shallow dive she'd done many times before — made her realize she needed to switch gears.

"I wanted to continue moving forward and make a shift to figure out what I wanted to pursue," says Streit. She liked telling her story and speaking to other newly injured people, so she went back to school for teaching.

She completed student teaching — but getting up at 4 a.m. and then not leaving her chair again until 9:30 p.m. led to issues with pressure sores. That's when she found a job as a youth development coordinator at the local YMCA, working four hours a day.

While there, she started writing children's books to better connect with the younger kids in the program. As her life as an author took off, she sought out a more flexible job. Her current position as manager of grassroots advocacy at United Spinal Association fits that bill.

"I feel more confident now in who I am and what my purpose is — more than I ever did walking on two feet. What I do now is so fulfilling," says Streit. "I loved interior design, but I feel my accident directed me down this path of what I was meant to do."

ADVOCACY APPROACH: Hosting "Meet an Advocate" live streams on the United Spinal Association Advocacy Network Facebook Page has allowed me to see and discuss the issues advocates are working on across the country. When I bring advocates on the stream, it gives them the chance to share what they are working on and educate others and empower them to follow in their tracks.

Join: facebook.com/UnitedSpinalAssociationAdvocacyNetwork



Meet an Advocate!
Wednesday, June 9, 12:00PM ET



Natalie Barnhard
Finn Bullers Advocate of the Year



"I've been a water girl since birth. We have a lift on our pontoon that allows me to get in my raft and float around or get in our lake."

In addition to finding meaning in advocacy, she loves talking with children from elementary school to high school in the Indiana area about her life with SCI, reading them her three children's books and teaching them to not be afraid of disability. She knows she's making a difference.

"Especially when I talk to the younger kids, just the look in their eyes and their questions or how they want to come up and give me a hug," she says. "When I see them out and about and they feel comfortable coming up to me — that means a lot because I want them to have that comfort level around a person who has a disability. I want them to be able to see past disability. That's been my whole goal."

In her first year as a student teacher, her own comfort level was tested. "It was really scary at first, the thought of how am I going to manage this classroom full of high schoolers from a wheelchair?" says Streit. "I felt like I wouldn't have the authority or anything like that, but I just kind of took a deep breath and did it."

That gung-ho approach has served Streit well. "That's kind of how I look at a lot of things in life now: Even if you're not too sure about it, you can't just sit back and let the opportunity pass you by — you've got to give it a try."

TOP ADVOCACY GOAL:

I'm a big proponent of increasing the wage limit in regard to Social Security and Medicaid.



Helping People Grow

Streit's role as an educator doesn't end after a motivational speaking engagement, especially when she faces ignorance and discrimination out in public.

“ If something happens to me, or somebody says something, they don't usually mean it to be rude. I always try to educate instead of getting upset. A lot of people are just unaware. They don't mean to say something in a way that's insensitive, but sometimes it comes out that way. I've always tried to educate, help people grow and understand. I think a lot of times it works. It's funny



Streit's books give her a way to connect with younger children and teach them about the importance of accepting differences, overcoming obstacles and acting with kindness.

because people often get really fired up when I'm in a parking lot and they've parked in an area where my ramp is supposed to come down. My mom and I have kindly explained it to them. We weren't upset with them. We were just trying to explain, 'That area is for the lift.' Even though they got upset with us, I bet that's the last time they park in a striped area.

”

WHAT I DO AT UNITED SPINAL: As the grassroots advocacy manager, one of my top priorities is to manage all the advocates across the U.S. for United Spinal. It's a way for me to connect with the advocates and relay information and resources to them. On top of that, it's how we build a national advocacy network that can fight for the changes our community needs.



Winner

► Brianna Heim and her pup, Emily, love to bowl, as this winning photo by Wendy Heim captures.

SERVICE DOG PHOTO CONTEST WINNERS

Service dogs enrich the lives of their handlers by performing a myriad of tasks that mitigate disability, and since dogs thrive on having something to do, performing these tasks is akin to a never-ending game of fetch. Better still, a service dog gets to be with their human 24 hours a day.

Service dogs also enhance mood and motivation. They sense when a gentle nuzzle or cuddle is needed. Having a rough day? Your dog needs a walk, which means taking them out in the neighborhood. And observing a dog's Zen vibe of being in the here and now is a contagious and frequent reminder of what dogs instinctively know — life is grand.

Service dogs are extensions of their humans and are empathic listeners — and it can seem as if the team reads each-others' minds. And a service dog's person is always on their mind, which manifests in very cool ways, like heading to their person's bedside several times a night to check on them by giving a few light taps of their paws and waiting for a gentle pat on the head to make sure their person is all right.

Like any best friend, a service dog shares your great times and is there for you in tough times. Most of all, they forge a bond in your heart. We asked you to share your favorite photos of your K9 companions and we were blown away by the response. Here are a few of the best submissions, along with the contest winner.

— BOB VOGEL



► Michaela Devins shows school spirit while Chicory doesn't look so sure.



► Cindy Ranii and Hollis mask up for safety in this snapshot taken by Shelly James.



► Cobalt pulls Max Woodbury up Mount Tabor in Portland.



► Art Blaser relaxes with Ollie in this photo by Isaac Larios.



► Photographer Tyler Hawley captures Griffin napping while Britany Hawley celebrates her graduation.



► Lori Friedman's husband, Michael, captured this intimate portrait of the bond between service dog and handler that persists even when the pooch is off duty.



▶ Sean Goral smiles enigmatically while Spirit looks off to the side.



▶ Loki's primary job is to pull Jesse Little, but the two also like to play and do yard work together, as these photos by Darlene Robillard show.



▶ Jojo comes to her handler, Paxton Williams, for a hug.



▶ Jesse Figueroa's pooch, Susie, jumps up for some love.

▶ Rachel Hargis and Dylan enjoy the serenity of Tucson's Mount Lemmon.



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DRIVING *Toward* INDEPENDENCE



Matt Abisamra, OTR/L, CDRS, the adapted driving program supervisor at Shepherd Center, shows a client how to transfer from his wheelchair to his car.

Shepherd Center's Adaptive Driving Program in Atlanta helps people with disabilities get back on the road.

For most people, the ability to drive means much more than just a way to get from point A to point B. It means convenience, opportunity and most of all – independence. Just ask Ben Elstad.

"Imagine not being able to drive independently or having to count on other people or public transportation to go anywhere," says Ben, a U.S. Army veteran who sustained a C-4 incomplete spinal cord injury in a car crash in 1989. "Public transportation isn't always reliable, and I didn't want to inconvenience my family and friends by asking them to drive me everywhere I needed to go."

Fortunately, Shepherd Center's Adaptive Driving Program, which is part of the Assistive Technology Center, aims to help drivers like Ben remain independent while keeping them and other drivers safe. The adapted driving team, consisting of certified driver rehabilitation specialists, including a certified driv-

ing educator and two occupational therapists, helps clients evaluate, understand and use available transportation options while also addressing safety and accessibility issues after experiencing a loss in mobility.

When clients first come to Shepherd Center Adaptive Driving Program in Atlanta, they undergo an in-center evaluation, typically lasting three hours. The first hour-and-a-half is a clinical assessment of the client's arms, legs, vision, cognition and balance for driving. The last hour-and-a-half is an on-road assessment.

"We begin by evaluating clients' physical capabilities like eyesight, reaction time and brain function," says Matt Abisamra, OTR/L, CDRS, the driving program supervisor. "We also look at their current level of function and how their disability may affect driving."

Next, it's time to hit the road. Abisamra takes clients out on the road and films the entire trip. He looks at their awareness of traffic, street signs and intersections. He also assesses how clients negotiate turns and hills. When they complete the assessment, Abisamra shows the video to the client to illustrate what tools

may help them drive independently, or sometimes to show them why driving is not a safe option. If the team determines a client can continue moving forward with driving, training can begin with one of Shepherd Center's driver specialists.

"At Shepherd Center, they have seven practice vehicles to use, so I would do two hours of training in the morning and two hours more in the afternoon several times a week," Ben says. "I was a little nervous at first, but the longer I was driving, the smoother and more confident I got. The team was amazing and really inspired confidence."

Program specialists provide information on obtaining a driver's license, purchasing modified vehicles and using adaptive equipment. Then, if the client purchases their own adaptive vehicle, the team at the Adaptive Driving Program goes to work making recommendations to outfit the vehicle with any adaptations needed and then orients the client with their new purchase.

For example, clients may need a device to help them accelerate and brake. This can be a lever that connects the pedals to a hand control, where the hand control works most commonly by pushing toward the dashboard to brake and pulling back to give it gas. These can be devised as an electronic system if the client needs help moving those levers.

For clients who have minimal function in their upper body, the team at the Adaptive Driving Program can offer recommendations for advanced technological solutions, like a joystick, touchpad controls, and brake and steering wheel modifications. Ben, who recently



Shepherd Center Adapted Driving Program client Ben Elstad demonstrates the adapted features of his truck that helped him return to driving.

purchased his own vehicle, benefitted from Shepherd Center's access to the most technologically advanced driving systems on the market.

"I have quadriplegia, and I have limited use of my arms and hands, but I can still drive," Ben explains. "I have the highest level of high-tech driving controls and use a joystick to drive."

While a doctor's referral is required before scheduling an appointment for Shepherd Center's adaptive driving services (a doctor's order requesting a PT/OT driving evaluation is sufficient), it is not required that a client be an existing Shepherd Center patient. The Adaptive Driving Program is open to anyone who needs to be evaluated for safe driving. That includes people with spinal cord or brain injuries, as well as those who have cognitive, behavioral or physical disabilities or concerns related to aging.

"When we hear from patients and community members, one of the main things they want to continue doing or get back to doing is driving independently," Abisamra says. "It opens their world up beyond their homes so that they can continue doing the things they love."

And Ben is living, driving proof.

"Now, I can get into my car and go get groceries when I want to," Ben says. "I can drive myself to the state park and push myself around on the trails to exercise on my own. I can drive to my daughter's house to meet my second grandchild. I can visit friends and do anything anyone else can do. Getting this ability back has been a life-changing experience. It's freeing."

For more information, visit shepherd.org/driving or call **404-350-7760**.



Many Shepherd Center patients have an opportunity to try out adapted vehicles with hand controls so they can return to driving.

BUILDING A BETTER REHAB HOSPITAL

BY AARON BROVERMAN

As soon as David Estrada rolled into the construction zone that was set to become the new gym at the heart of a \$225 million renovation of Spaulding Rehabilitation Hospital Boston, he could see something was wrong. Actually, it's what he couldn't see that was wrong.

The panoramic windows intended to provide a striking view of the Mystic River were too high off the ground for wheelchair users to see out. "I said, 'You guys must really want people to walk again because I can't see the view,'" says Estrada, a T3 paraplegic.

It's the kind of oversight that contractors might not have noticed and never would have changed. Thankfully, Spaulding took the time to get feedback from Estrada and a group of stakeholders with SCIs.

Oswald Mondejar, senior vice president for the care network that manages Spaulding, remembers being stunned by Estrada's observation. "I knew right away that we had to fix this," he says. As a person with a disability of his own, it was personal. "I raised [the argument for lower windows]. It was a significant retrofit with a lot of dollars behind it, but our president ultimately stuck by us. That took a little bit of ... not coercing, but really explaining why it was important for us to not only provide access, but symbolically make this shift."

Using his background in hospitality, Mondejar framed the discussion as a customer-first mentality where simply complying with the minimum requirements of the ADA wasn't good enough. "Our tagline here is, 'beyond compliance,' so how we approached this whole project was very targeted," he says. "We offer patient-centered care, and we want to reflect those who come through our doors in everything we do."

"Patient-centered care" means that Spaulding treats the people it serves according to what they want and feel is important. To do this well, the rehab needed facilities that worked for them — and to make that happen, it needed input from stakeholders like Estrada.

The remodeled hospital opened in April 2013 — with the redesigned windows — and stands as a prime example of a growing trend of rehabilitation facilities going beyond ADA requirements and incorporating input from the disability community to build more accessible and inclusive buildings.

WHAT TO DO WITH AGING FACILITIES

Twenty-five years ago, when Estrada was undergoing rehab at the old Spaulding Rehabilitation Hospital after a motorcycle accident, he re-



David Estrada



members overhearing people as they toured the hospital.

“There were seven different hospitals to choose from back then. When people would enter the old Spaulding building, they’d say, ‘This place looks gross. It looks like it’s the 1970s,’ and they would go to some other place. Even though they would receive great care and treatment, people would literally not go to Spaulding because of its appearance,” says Estrada.

Built in the 1970s, the building featured little natural light, making it difficult to navigate. Many of the existing accessibility features were retrofitted, rather than being seamlessly integrated into the design from the beginning.

As one of 14 SCI Model Systems Centers recognized for providing the highest level of care, Spaulding felt a responsibility to represent the accessible ideal for its patients, staff and students in its remodeling plans. Not only that, but it knew becoming radically inclusive would give it a competitive edge over other rehab destinations.

A few years after those discussions, a team of planners in Richmond, Virginia, faced similar dilemmas as they looked to bring three smaller hospitals — Sheltering Arms Hanover, Sheltering Arms South and Virginia Commonwealth University Health — under one roof as a state-of-the-art inpatient rehab facility.

In place of dated facilities where accessibility had been retrofitted as an afterthought, they envisioned a one-stop shop that combined the experience and research power of VCU Health with the technological innovations of Sheltering Arms. They dubbed their vision Sheltering Arms Institute. Like the team behind Spaulding’s remodel, they wanted to



Boston’s Spaulding Rehab is now bright and cheery, and goes far beyond ADA requirements.

foster collaboration between clinicians, therapists, patients, vendors and community partners like United Spinal, so that everything was run from a central hub.

Both Sheltering Arms and Spaulding identified the importance of innovative thinking and centering their plans around patients’ needs. One example of innovative thinking came when Spaulding’s CEO asked the project’s designers to navigate the old Spaulding building using wheelchairs.

“That was an aha moment for us,” says Jessica Stebbins, former senior principal and associate project manager for Perkins + Will, the architecture and design team on the Spaulding project. “Not having the independence or control

over where we wanted to go was revealing. We tried to get into the patient room bathroom, but the door was too narrow so we couldn't get in."

Spaulding also gave Stebbins' team wheelchairs and walkers to take back to the office to help them with mock-ups, such as testing knee clearances for sinks or designing more ergonomic faucets that wouldn't put stress on users' shoulders. Stebbins would go on to share many of these insights with the team planning Sheltering Arms Institute as a consultant, but she says the most valuable insights came from listening to the experiences of those who live with spinal cord injuries.

"Involving those with SCIs of various levels was important to the design team because we wanted to design a facility that was truly inclusive from an experiential standpoint and broke down physical barriers, so everyone has more parity in experience and access," she says.

The medical and hospital experts at Spaulding knew that the real expertise needed had to come from community members. "We went beyond the voice of the patient at Spaulding Rehab because we wanted to engage advocates. Folks that are challenging the status quo. Folks that know what the challenges are, that have been doing the work for many years or have been compelled to advocate for themselves in the community," says Mondejar. "We didn't shy away from being challenged. We wanted those voices."

A BAR IN A HOSPITAL?

In addition to town halls and traditional outreach, Spaulding asked leaders of Massachusetts' SCI community like Estrada, the late Travis Roy and the late Betsy Pillsbury what the disability community would like to see in an ideal rehab center.

Similarly, the Virginia team reached out to local YouTuber Cole Sydnor and Richard Bagby, director of the Virginia Chapter of United Spinal Association, who rehabbed at VCU.

"We threw everything out there. Nothing was too extreme," remembers Bagby, who attended one of the three initial workshops that were attended by about 150 people each. "In those initial meetings, people were talking about different pieces of technology. A big idea was single-patient rooms, and I think a couple folks asked for a rooftop bar."

A bar in a hospital may sound odd, but Sandra Tkcaz, vice president and healthcare principal at HDR, who helmed the design of Sheltering Arms Institute, says her team was guided by the underlying idea that people in rehab and their families needed space to relax that didn't necessarily look like a hospital.

"One really important thing we learned from those early



Craig Hospital's newly-renovated rooms feature lots of turning space and state-of-the-art electronics.



TWO CRAIGS ON THE CUTTING EDGE

Spaulding Rehabilitation Hospital in Boston and Sheltering Arms Institute in Virginia serve as beacons of possibility along the East Coast's I-95. But out west, the new Craig H. Neilsen Rehabilitation Hospital in Salt Lake City and the renovation of the stalwart Craig Hospital in the Denver suburbs provide equally insightful windows into the benefits of listening to, and incorporating input from, the disability community.

Craig Hospital

Craig Hospital has been on the cutting edge of SCI/D and brain injury rehabilitation since its foundation in 1956. But after almost 60 years, the facility was in dire need of a facelift.

From 2012-2016, the Craig Hospital Foundation spent nearly \$90 million on an 84,000-square-foot renovation of its west building because the HVAC unit was dripping water on people's heads. However, once the HVAC was fixed, Craig decided to take the renovation further to include feedback from those it serves. The hospital took patients through mock-ups that included inpatient rooms and bathrooms in search of ways to make their stays more comfortable and productive.

"We involved both brain injury and spinal cord injury patients in giving us feedback," says Dana Polonsky, Craig's vice president of clinical services. "It wasn't as formal as having a panel, picking out specific people or reaching out to the wider community for specific feedback." Instead, the renovation took place in the midst of everyday activities so therapists could take patients through and get their feedback. The end result was 52 private rooms with sip-and-puff and eye-and-motion controls for TVs, window shades, lighting and audio. The facility also now has two pools, two gyms and completely-overhauled elevators and electrical systems.

"The focus was way bigger than improving our HVAC — it was about improving the experience. We want a family atmosphere, and we don't want people to feel like they're in a hospital," says Polonsky.

The Craig H. Neilsen Rehabilitation Hospital

The new Craig H. Neilsen Rehabilitation Hospital opened in May 2020 on the University of Utah campus. It took incorporating former patient input to a whole other level, as it was funded by the foundation of its

namesake, Craig H. Neilsen.

Neilsen held two degrees from the University, and he received care in the campus' old rehabilitation hospital after he was paralyzed in 1985. In 2017, his foundation donated \$47.5 million to fund the 172,000-square-foot campus. His son, Ray Neilsen, is the chairperson of the board of directors for the foundation and explained the massive investment to the *Daily Utah Chronicle*, "My dad wanted to make a difference," he said. "He knew the challenges of living with spinal cord injury."

The desire to alleviate these challenges is evident throughout the hospital's design. It features 75 "smart" patient rooms that allow iPad or voice control of the HVAC, lighting, blinds and television. In addition to all the standard rooms and labs a rehab center has, there are two indoor gyms and an exterior balcony gym with a garden and putting green. That's not even mentioning the first-in-the-nation, climate-controlled mobility garage where patients can drive in any vehicle, including their own, and practice skills like transferring and using hand controls. There is also adapted recreational equipment available for therapeutic purposes.

"We can literally put people using ventilators on indoor Alpine or Nordic ski simulators, or on an electric-assist handcycle, and they can use it in a controlled way, in this garage," says Jeffrey Rosenbluth, medical director of the Spinal Cord Injury Acute Rehabilitation Program at the University of Utah Health Sciences Center. "We got some of these ideas from the other rehab centers we visited and certainly from our patients but brought it all together in this unique building."

Neilsen also built a fabrication lab where University of Utah engineering students and staff can build any adaptive equipment, from braces to cervical collars, and test them with people in real time as soon as they are built. "Instead of basic core research, we're doing real-time innovation — deploying students every day and actually listening to and prioritizing patient needs," says Rosenbluth. "Not just inpatient, but out in the community — recognizing that they're in the hospital for such a short part of their life."



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Sheltering Arms Institute's gym features plenty of natural light, as well as space to recover and practice new skills.

design sessions was that people with new complex spinal cord injuries may not be ready to enjoy the rest of the institute until the latter part of their stay. Their unit needed to be bright, supportive and welcoming, while having a satellite dedicated gym, as well as lift technology in every room," she says. "Also, they need all the rooms and support spaces, like the family lounge, to have a lot of room to maneuver and enjoy,"

"It was refreshing to have people come to me and ask what was ideal. They were aware they don't experience what a wheelchair user experiences."

Once those initial meetings ended, Bagby and Sydnor continued to make their voices heard as part of a 20-member design steering committee. They helped push the committee to go beyond ADA requirements in several instances, including installing low-effort, sliding barn doors for bathrooms. They also found compromises that wouldn't overly dilute access for wheelchair users.

"There was a discussion about installing flooring that was softer for the nurses and folks who were on their feet all day long. But, as wheelchair users, we prefer something that's harder and creates less friction," says Bagby. "So we took those ideas from both groups and married them together."

Alan Lombardo, a physical therapist on an SCI unit for six years before becoming CEO of the Sheltering Arms Institute, highlighted the value that Bagby and Sydnor brought to the design. "The world is uniquely different for people with SCIs — or anyone with mobility impairments — so even though I've worked directly with members of those populations, I can't possibly see the world the way they see it," he says. "It was critically important to have folks with lived experience in the early stages of planning to ensure the facility was accessible for the SCI community.

Bagby was equally pleased with the process. "It was refreshing to have people come to me and ask what would be ideal. I didn't have to frame the discussion around it," he says. "Instead, it was, 'Hey, would this work for you? How could it be better?' They were so aware that they don't experience what a wheelchair user experiences that I'd be honest and say, 'it could be better this way' or 'it's fine.'"

A DEPTH WE WOULD HAVE MISSED

When Spaulding opened its new 262,000-square-foot, 132-bed, \$225 million facility in 2013, it immediately became the standard-bearer for rehab hospitals that it sought to be. Natural light permeates the building, the hallways have ample width, the sinks in the public washrooms have a higher clearance underneath than what is required by the ADA and all the stalls are big enough for a wheelchair user to turn around in. The patient rooms are designed to be navigated by wheelchair,

with custom cabinetry at seated level. Also, they feature automated shades, lifts, private bathrooms and amenities such as private refrigerators, Wi-Fi and sleeping accommodations for family members.

Other highlights include a street-level entrance, a lower and rounded reception desk, a pool for aquatherapy, two state-of-the-art gyms and an activities-of-daily-living suite. There are also transitional apartments and satellite gyms embedded on two inpatient floors. The environment lends itself to making it easier for wheelchair users to be directly involved in their care.

"If you're in a regular hospital, there are places where clinicians can write their narrative on each patient. Typically, they're not accessible, but for our floors, they're all accessible," says Mondejar. "You can bring the screen and keyboard down just with a slight movement."

All of the effort to collaborate with the community paid off with a forward-thinking facility that continues to deliver dividends to this day. "The involvement



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Above is the exterior of Sheltering Arms Institute and below is a peek into a therapy session, where a woman is able to simulate walking down a street.

of people with SCIs gave a depth to our work that we would've missed otherwise," says Mondejar.

Seven years after Spaulding's opening, and about 550 miles southwest on I-95, Sheltering Arms Institute followed suit in June 2020, opening its doors and transforming the Virginia region's rehab options. Built on 212,000 square feet, the hospital offers 114 beds, a 9,500 square foot therapy gym, three satellite gyms, and contemporary research and care facilities with wheelchair-friendly touches all around.

Take the ceiling tracks that run throughout the building. Seventy percent of patient rooms come equipped with a lift system that can get a person out of bed and transport them right into the washroom. Still, Lombardo is quick to point out, this is just the beginning for Sheltering Arms Institute.

"We're situated on a 46-acre campus, and we've only used

about 12 acres of that," he says. "Right now, we only provide inpatient rehab services. We're thinking about the future where we would provide outpatient services that are on par with some of the inpatient services we provide, so that when people come here, they feel a sense of community and belonging."

Lombardo hopes to nourish that sense of belonging by giving space in the planned outpatient building to community partners like United Spinal's Virginia Chapter and Sportable, Richmond's local wheelchair sports nonprofit. Spaulding took a similar approach, providing an in-facility office for United Spinal's Boston Chapter.

A rehab with space for the local SCI community is exactly the point, says Bagby. "The goal wasn't to build this state-of-the-science building and rest on our laurels," he says. "The goal, which has not been realized yet, is to develop and build a campus and community. At some point there should be an outpatient gym where people who have been through SCI come back to the same campus to do their outpatient therapy, and so you have people who are fresh into their injuries seeing what is possible down the road."

INCLUSION PAYS DIVIDENDS

That plan, though in development, is still in the future. In the meantime, both Sheltering Arms and Spaulding recognize the importance of taking what they've learned about building accessible, universally designed spaces and evangelizing those

lessons to the wider community.

The designers from both Perkins + Will and HDR tell NEW MOBILITY that they're constantly emphasizing the importance of making spaces accessible. Most clients are receptive and don't cite cost as a barrier to access, but Stebbins says making things accessible is cheaper than they think. "If you're starting from scratch, it's much easier to open things up and think universal design and accessibility than if you were trying to retrofit an existing structure," she says.

Bagby and Estrada also learned a lot by participating in this collaborative design process. "My takeaways were the inclusivity and the progressive mindset. You need that from leadership," says Estrada. "The other part is, if you've grown up as a nondisabled individual and haven't had a personal relationship with someone with a disability, your mindset may be, 'we need to get



Wheelchair users were involved at every stage of planning for Sheltering Arms.

this done,' and you're not thinking about accessibility. You need to put yourself through a multi-factor process as a leader to even start thinking about access. These people made the right decisions and planned accordingly in including us."

Both he and Bagby realize that despite their experience, the world is still a long way from a reality where these kinds of collaborations are the norm and access is universal. Estrada maintains it starts

with the leadership, and Bagby says it ends with the will and motivation.

"I'll be really hopeful when someone just does universal design without there being anyone with a disability who requests it," says Bagby, "when it's something that's just done automatically." NM

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SHIFTING SANDS: Life with an INCOMPLETE INJURY

BY RICHARD HOLICKY

Because my incomplete spinal cord injury sometimes lets me stand and even walk, I was seduced by the possibility of more — more function, more normalcy, more of what I used to have. I'm not alone in this, as many people with incomplete injuries are beguiled by the thought of maybe, just maybe, they will be able to undo bad fortune and restore, in some small measure, what was.

Looking back at the past 30-plus years, I see my life with incomplete injury as a wild affair with a mistress who's been by turns voluptuous, jealous, sultry and vengeful. I call her Mistress Incomplete. At her best, she is an incredible seductress. At her worst, she's hell-bent on making me pay for any transgression, such as tricking myself into believing my SCI will continue to improve when, more often, the opposite is true.

When I got to rehab, I couldn't touch my chin with either hand. Five years later I was spending my days doing the stuff of life — cooking, cleaning, dressing and working — more often than not on my feet. Regaining function and sensation “gifted” me with a panoply of emotions: I was ecstatic when I got more and depressed when I didn't. Each step meant more hope with no guarantees, enormous expectations built on sand and more distance from my SCI friends and our collective shared experience.

As I approached what seemed to be maximum function, depression and anger began to set in. As long as I was experiencing return, I could stay in denial and avoid depression. Conversely, when I was doing well, the uncertainty bred anxiety.

After a year with no significant changes, I decided to throw in the towel. I wanted a life, not more therapy; a job,



Kyle Pearson's “obsession with walking” led to lots of time spent in rehab working on treadmills and crutches.

not an endless series of exercise sessions. I wanted some certainty about my future.

What tempered all the negatives for me was the realization and acknowledgment of how truly lucky and blessed I was and still am. My depression and anxiety gave way to gratitude.

“What the hell do you have to be grateful for?” asked incredulous friends and family.

I often responded with a laundry list of blessings and luck: walking short distances with crutches, doing stairs,

having some trunk muscles for balance, getting through narrow doorways, standing up to get dressed.

I'm not alone. Following are the stories of some others who live with incomplete injuries that sometimes let them stand and take some steps — and tease them with the possibility of more.

Kyle Pearson: It's OK to be Different

Kyle Pearson, a 60-year-old engineer with Pearson Adair & Co. from Dallas, Texas, sustained a T10-11 injury skiing



in Colorado in early 2013. Before he even got to rehab, he was visited by Craig Rehab's research physician, who suggested that walking might be possible.

"That was all the incentive I needed to begin my obsession with walking," says Pearson.

After two and half months of rehab at Craig, during which he experienced a good deal of functional return, he went home to Dallas somewhat adept at using a walker. Later that year, he returned to participate in the NeuroRecovery Network treadmill walking program pioneered by The Christopher & Dana Reeve Foundation. Pearson spent time on the treadmill five days a week for four months. As he saw his function increase, he says, "I began to think I would be 'normal' again."

Over time, Pearson's seemingly-positive mindset proved to be problematic. "Back home, the onset of cold weather was accompanied by high levels of spasticity. In addition, I had never properly grieved my accident. Nevertheless, I left Denver beginning to walk with a cane and feeling a profound sense of gratitude."

He wasn't prepared for what came next.

"I wasn't as active that fall. The weather was colder, and I began experiencing high levels of spasticity, which at first I didn't understand," he says. "One day I could walk, but the next day I couldn't.

I began to realize how emotionally challenging the unpredictability of all this is. It can drive you nuts if you let it."

Soon, Pearson had to accept that walking wasn't always worth it. "Early on, using crutches was a point of pride with me — trying to appear 'normal,'" he says. "But that just set me up for a big fall when the pain came on. I'm finally learning that I'm not defined by whether I can walk or make it to the second floor. I'm a work in progress, learning to manage my emotions." He does squats throughout the day to stretch and work his quads,

hamstrings and glutes to try to manage his debilitating neuropathic pain.

His chair use has varied over the years, generally in a downward direction. "In 2015, I vacationed in Ireland and worked in London for two weeks without a chair. More recently, I've used my wheelchair for longer distances and whenever I need to get somewhere fast. This stems from four back surgeries in late 2019 and early 2020 that left me extremely weak." He's spent the past year regaining strength and estimates he uses his chair about 80% of the time.

Rather than expressing disappointment at his increased use of his chair, he says, "I think I may have finally matured into this. I've had two major negative events — unexpected spasticity and neuropathic pain in 2013-14, and four surgeries in 2019-20. Each time I felt I was a failure, as I could no longer act 'normal'. Now I understand that it's OK to be different."

He credits his wife of 35 years, Leann, for being his rock, saying she's been and remains a source of incredible support. A family man, he has three grown children and recently became a grandfather.



Pearson and his wife, Leann.

Megan Wemmer: Still Regaining Function

Megan Wemmer, 39, sustained a T12-L1 injury six years ago when she fell



from a ladder to a loft in a Colorado backcountry ski lodge.

“There were too many trees for a helicopter to land, so my boyfriend had to leave me on the floor and ski out to get a mountain rescue crew. I was in shock, alternating between shivering from the cold and burning hot. In the back of my mind, I already knew I was paralyzed but wasn’t ready to confront it.”

Rescuers sledged her out to a waiting ambulance that transported her to the hospital. Her T12 vertebrae was pushed into her spinal cord and her L1 was shattered. After 12 days in ICU, she was off to Craig Hospital where she spent two months rehabbing.

“I had enough movement for doctors to instill hope that I would recover some function, but I never had a clear picture of what that might look like. If I asked, all I got was ‘you may be able to ...’ or ‘we don’t really know,’” she says.

Most rehab docs put the window for recovery of sensation and function at 18 to 24 months after injury. Wemmer says she’s been actively recovering function and muscle use for the past six years. Recently she learned how to activate muscle groups that were absent two years ago, then found ways to strengthen and integrate them into movement.

“I’ve been trying to use the muscles I have for their intended function and not compensate,” she says. “I certainly compensate for muscle groups that are still absent, but I truly think that I have had significant neuromuscular return well outside the 18-month recovery window that they tell people to expect.”

She is continually learning to activate new muscles. “To maximize return, I’ve never stopped doing physical therapy, regaining strength in these weak muscle groups and learning how to integrate them into movement. It can

be exhausting,” she says. “I used a wheelchair exclusively for about a year, before progressing to less supportive devices.” Also, she still does a bowel program, complete with a suppository, and she still cath.

Wemmer is able to walk but since

she has very little sensation below her right knee and can’t feel her right foot at all, she continually looks down at her feet. “I have to stay focused, constantly monitoring my body, and it’s a lot of mental effort,” she says. “Uneven surfaces are difficult because I have no ankle stability. My balance isn’t great, so if someone bumps into me, I can’t always recover.” She relies on braces and does skin checks every day.

She remains active in outdoor sports —

rafting, snow shoeing, camping — and she credits adaptive sports camps with people with a variety of other disabilities for showing the way. “I have been to a number of adaptive sports camps, and I’ve met people with all types of disabilities. I’m in awe of what people with disabilities are capable of.”

And what about the emotional journey? “That’s hard to convey, as my body is still changing. I can’t just accept and reconcile myself to the way things are and move on. I’ve been building



Balancing the demands of physical therapy and living an active life keeps Megan Wemmer busy and sustained.

strength, endurance and function, doing everything I can on my feet. I have hope that I'll still be able to accomplish more physically," she says. "I know that I will have to face the reality of a decline, regression and losing what I have been working so hard to regain. I know I'll need a wheelchair again eventually. I'll have to come to terms with that."

Christy Quinn: Acceptance and Gratitude

Christy Quinn, a 61-year-old grandmother of three, joined the SCI club in 2012 following a bike accident that left her with a C6-7 injury. Following five weeks at Portland's Legacy Rehab Institute of Oregon, she discovered Adapt Advanced Physical Therapy (formerly Project Walk). She calls the once-a-week sessions a "game changer." A few long breaks from PT took a toll on her physical abilities and she now sees PT as essential to maintaining function.

Early on, as her progress slowed, Quinn became concerned. "I started to get discouraged and even depressed at times," she says. "I'm super-competitive, but now I give myself grace."

Since then she's progressed from wheelchair, to walker, to forearm crutches, to a cane, on which she now relies. But it's not easy as she must be hyperaware of every step she takes, which requires concentration. "I can never relax while walking," she says. "I'm thinking about moving a certain way, not dragging a foot, being sure to lift an ankle, not recruiting muscles I



Christy Quinn has progressed from wheelchair to cane, but walking requires all of her concentration. "I can never relax while walking," she says.

shouldn't recruit. I'm also in significant pain. It's a lot."

She says walking reminds her of scuba diving. "You breathe slowly so as not to use up the oxygen too quickly, you move slowly so you don't miss something hiding under the coral and you take your time coming back up to the surface so you don't burst your lungs," she says. "I now walk with purpose, yet slowly so I don't miss something or get hurt, all the while enjoying things I've never seen before."

Quinn no longer needs to do a bowel program, but because of a neurogenic bladder is prone to frequent UTIs. "I recently had back surgery and watched an overnight stay become five days because everything shut down — bowel, bladder and even some function," she says. Cold also presents a problem, as she has difficulty with temperature regulation; her body stiffens up, making movement difficult.

"I'm learning to go easy on myself.

I still struggle at times with wishing this hadn't happened. This new and different lifestyle requires a commitment to find ways to enjoy life differently," says Quinn. Fortunately, she is learning how to navigate these activities from others with SCI and says it helps to know she's not alone. "Finding others with similar challenges has helped me discover new activities such as kayaking, riding adaptive bikes in the summer and hiking," she says. "Swimming is the one activity where my body doesn't have to struggle; it's easier to balance, and I can't

fall in the water, so I'm not afraid. Nothing I do now looks or feels the same as before, but that doesn't mean I can't enjoy or benefit from those activities."

The most difficult challenge for Quinn is the tension between not giving up hope for continued improvement and being thankful for what she has. "Accepting where I'm at doesn't mean I've given up. The tension is what keeps me alive," she says. "I'm content with where I am today regarding my physical abilities while continuing to hold out hope for continued improvement."

That's the essence of life with an incomplete injury: hoping for more return while practicing gratitude.

Because, let's be honest, if my dear Mistress Incomplete came knocking on my door, I'd probably go all wobbly and starry eyed and say, "Please come in, please."

I'm a sucker for seduction. I suspect we all are.

MM



Christine
Getman

FROM ISOLATION TO EMPOWERMENT: A Nightmare Hospital Stay That Led to Change

BY CAROLE ZOOM

A FEISTY GIRL

Getman has never been one to quietly suffer injustices. Thanks in part to living with SMA, she learned the value of speaking up for herself at an early age. One of her first childhood medical memories is lying almost nude on a table in front of a bunch of people. “It was like I was just a specimen. I was hospitalized and people were not listening to me. I had to raise hell to force them to listen to me,” she says. “That was one of the turning points where I learned the effectiveness of being feisty.”

At an early age, she had to make serious life decisions that other children her age didn’t have to consider. “Doctors were always reminding me I wasn’t supposed to be alive,” she says. “That definitely affected my decision-making and my planning in my early adult life. I had to ask myself, ‘Do I want to get into this eight-year program? Or will I even make it to the end of that? Those are twisted thoughts to have.’”

Between negotiating with doctors in her tween years, standing up to school officials in her teens, and confronting other people’s opinions on how she should live her adult life, Getman developed a self-assured style that is part humor, part bravado and part targeted anger.

“I grew up very fast,” she says. “I was able to converse with adults by the time I was 12. And everyone said, ‘Oh wow, you’re so mature.’ It’s like, you have no other choice. You have to.”

“She’s got this fierce punk edge, but in this really approachable way,” says longtime friend Nickole Cheron. “She’s incredibly charismatic, and people feel really comfortable and drawn to her ... it’s a unique blend.”

That blend has helped Getman, 33, lead a busy life outside of Portland, Oregon, with her fiancé, Scottie Foertmeyer, three dogs, four cats, three bearded dragon lizards and a python. As the executive director of the national nonprofit organization Magic Wheelchair, she helps children with physical disabilities live out their fantasies by creating epic costumes they can enjoy from their wheelchairs (see sidebar). The job also allows Getman to embrace her passion for nerd culture, as the organization has become a mainstay at events like Comic-Con.

“I love that I can go from geeking out in a spreadsheet, to nerding out at Comic-Con or a Halloween trade show, all in a day’s work. Never in a million years did I think my career

As the pandemic raged across America in April 2020, Christine Getman found herself in the last place any person without COVID-19 wanted to be: trapped and alone on a hospital floor that was dedicated to treating people sick with the novel coronavirus. Dreading just that outcome, Getman had done everything in her power to avoid visiting the emergency room, but when an infection related to treatment for her spinal muscular atrophy simply wouldn’t go away, she had no other choice.

While you might think a hospital would take extra precautions to protect a power wheelchair user who relies on a full-time caregiver and has a trach, Getman’s experience suggests otherwise. Despite needing assistance with most daily activities, including moving her hand to her trach to help her talk, her pleas for access to her PCA were denied. She asked if the hospital would assign a staff member to work with her one-on-one and even offered to have her PCA stay confined in her room — all to no avail.

In the end, Getman found herself isolated in her room in bed, unable to access her phone, relying on nurses and staff who were constantly mingling with COVID-infected patients. “When you can’t hit the call button, you can’t feed yourself and you can’t use your phone, the hospital isn’t a safe place,” she says. Getman swore to herself that if she survived her hospital stay, she wouldn’t let anyone else live the same nightmare.

would lead to knowing about the competitive fake blood market or the chemical reactions that happen during prop building, but I'm here for it."

Getman also sits on the board of the Wheel to Walk Foundation, a nonprofit organization that provides needed medical equipment and therapeutic services, and serves on the Multnomah County Animal Services community advisory committee.

THE HOSPITAL WOULDN'T LISTEN

The possibility of increasing her strength, improving her movement and stabilizing her breathing convinced Getman to sign up for a clinical trial that led to early access to Spinraza, the first Food and Drug Administration-approved treatment for SMA. She received her first dose via lumbar puncture in Sept. 2017. The results were encouraging. Even though her fourth dose led to bacterial meningitis, a splitting headache and hospitalization, Getman continued forward. "Spinraza was amazing," she says. "It did something for my energy. I was able to travel as much as I wanted. I definitely felt stronger and more resilient. My breathing and core felt stronger."

At the beginning of the pandemic, Getman was working to help others with disabilities. "I was focused on connecting Magic Wheelchair's volunteer builders with PPE creation opportunities, supporting families and just staying healthy," she says. "I think many of us were traumatized by the critical care triage guidelines and visitor policies that were circulating in the headlines, and the onus was on us to stay out of the hospital because of them."

After her 11th Spinraza dose in spring 2020, Getman started feeling lousy. She had a headache. Not just any headache, this headache felt just like the one that resulted from spinal meningitis. With the pandemic swirling outside, she tried to recover at home but quickly ran out of options as her infection worsened. She had to go to the hospital.

The hospital admitted Getman, gave her a COVID test and placed her on a floor with people being treated for the virus, despite the fact that she and her fiancé had been quarantining together for three weeks. Even after her test came back negative, Getman would spend two more days on that floor as doctors and administrators refused to pay any attention to her disability-related needs. Most importantly, the hospital's COVID no-visitor protocol did not allow Foertmeyer to stay in her room to help her. "People were not listening to me," she says.

The hospital was oblivious to what was so obvious to Getman: An overwhelmed hospital staff had no way to see to her needs, and without dedicated, round-the-clock assistance she would be in danger of developing more complications, or, God forbid, catching COVID.



Magic Wheelchair designs and delivers elaborate costumes for kids who use wheelchairs.

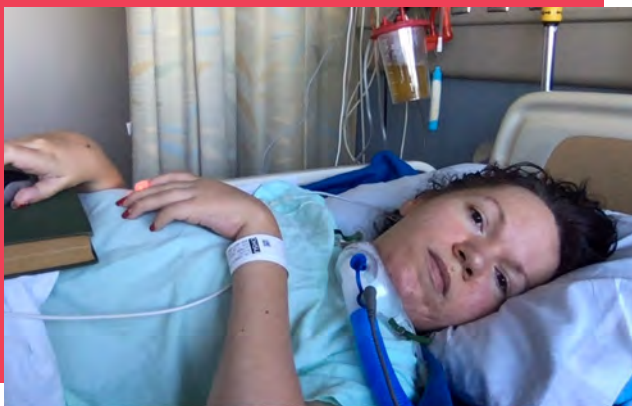
MAGIC WHEELCHAIR

Getman's colorful personality and passion for helping the disability community blends perfectly with her expertise in marketing and communication and her role as executive director of Magic Wheelchair. The nonprofit builds elaborate costumes for children who use wheelchairs, at no cost to them. These are not your typical homemade, cardboard costumes. Magic Wheelchair partners with makers and designers who, in Getman's words, "take Hollywood special effects and make them accessible to anyone. The idea is for these to be as quality as a movie prop."

Getman grew up making her own costumes — "a John Deere tractor and a Pepsi box. And a mermaid!" — and knows that life as a child with a disability can be tough. "These kids face a lot. Everything is so serious around them. Let's just have some fun," she says.

In addition to fun, Magic Wheelchair is about empowering children to think outside the box. "Having your imagination valued early on can teach you how to use your voice to fight for other things later in life. I grew up where my ideas were always valued. I'd say something crazy, and Grandma would say, 'Let's do it.' So that has shaped me and how I create programs." The costume-build leads children through a creative process where they have agency, give direction and participate in decision making. This teaches children with disabilities and their families one way to explore the kind of self-expression that helps children develop into fulfilled adults.

For more information, visit magicwheelchair.org.



Alone on a floor of COVID patients, Getman resolved to take action so other disabled people wouldn't end up in the same situation.

Needing help with simple activities of daily living, such as going to the bathroom or getting a drink of water, placed Getman at risk of contracting the virus from nurses and aides who were working directly with people who'd tested positive for COVID. On top of that, given that Getman can only lift one finger on one hand, she needed to have someone familiar with her physical and communications supports to assist her. The hospital made exceptions to the no-visitors policy for children and people with intellectual disabilities, as well as for women giving birth, but the hospital would not make a

reasonable modification to the no-visitors policy for Getman.

On Sunday, April 5, Getman updated her status on Facebook, posting a photo of herself lying in a hospital bed and sharing details of her ordeal:

Supposedly not much could be done on the weekend, but tomorrow I'm starting more fights. It's hard to fight when you're 75 pounds lying in a hospital bed and dealing with an egotistical attending doctor, but I will.

That's the short version. I have moments of optimism and lots of losing my mind.

Send all your good vibes (and a little rage for Monday) my way.

A CALL TO ACTION

Getman's Facebook post galvanized her friends and followers. Cheron, who works as an ADA compliance officer for the city of Portland, was among the many who were outraged.

"My first response was that they were totally violating her rights," says Cheron. "It was atrocious. And I think what was really hard in general about the pandemic was that it was such a new territory for everyone."

For Cheron, who also lives with SMA, Getman's plight resonated even more deeply.

"My biggest concern was just getting someone in there with her, because I think for all of us, we all knew that if we had to go to the hospital, if we got COVID, we weren't coming back," she says. "No one was going to take care of us in a hospital the way we would need to survive COVID."

After two days on the COVID floor, Getman finally won her transfer to a trauma unit that specialized in working with people with trachs. The next day she got a PICC line, a prerequisite for administering her needed antibiotics at home, and a new doctor who listened to her needs. A day later she finally broke out and returned home. With Foertmeyer administering her antibiotics, Getman recovered from the infection and set her sights on ensuring no one else would have to go through what she did.

"Even while I was in the hospital, I was thinking, 'I know how to navigate the system, and even I can't crack these policies,'" she says. "I was imagining folks who haven't learned that you have to keep fighting — what that could have done to them in the hospital. People don't always know they have a right to fight these injustices."

Getman connected with Disability Rights Oregon and shared her story in a front-page story in the *Oregonian* newspaper and on NPR. She passionately argued that people with disabilities who require assistance to function should have access to their care team if they end up in the hospital, even during a pandemic.

Oregon State Senator Sara Gelser read Getman's story in the newspaper. As the mother of an adult son with intellectual and developmental disabilities, Gelser had a personal interest in working with health authorities to change visitor policies and clarify crisis care guidelines. When informal conversations made little progress, Gelser took the lead in drafting SB 1606 to legislatively address the problems.



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Disability Rights Oregon connected Getman with Gelser, and soon she was testifying in the state capitol on behalf of the bill. DRO and Gelser had collected stories from other people with disabilities across Oregon, but Gelser says Getman's impact was strong. "It made it real. I think that's the most important thing that can happen, especially with issues like this that people just don't want to believe are true," says Gelser. "Christine's a natural speaker and advocate and was just incredibly compelling to people."

Propelled in part by Getman's testimony, SB 1606 passed the House and the Senate and was signed into law in July 2020. It established that hospitals in Oregon must allow a patient with a disability to designate at least three support persons to assist them while they are in the hospital.

Looking back at her testimony and the emotions she was



Getman and Foertmeyer.

feeling, Getman sees the value of the anger she felt. "Anger is an energy. You can get things done when you are angry," she says. "If you listen to my testimony, I was angry when I gave it. And you can hear it." Channeled properly, Getman's anger and feistiness led to significant changes that will benefit Oregonians with disabilities in the future.

She's not stopping, either. This May, the Oregon Health Authority hired Getman to be the accessibility coordinator for the Coronavirus Response and Recovery Unit. Additionally, she has worked with Gelser on vaccine education and issues affecting people with disabilities around the rollout.

"We've done a lot of public education around disability visibility and cross-disability work, and Christine has been phenomenal in helping to put that forward," says Gelser. MI

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OWN IT

By Regan Linton

IT HAPPENS — SO GIVE US BETTER BEDPADS

I remember the first time I had a bowel accident after I was paralyzed.

I was at a movie with my best friend a few days after leaving rehab. Apparently, the thrill of being out of rehab and back in a movie theater gave my body a great sense of freedom. I thought someone behind me was passing a lot of gas. Near the end of the film, I realized my rehab constipation had ended and stool softeners had finally worked their magic — yay! Ugh.

Transferring in and out of my friend's adorable VW Jetta, I smeared all sorts of bodily waste, trying to wipe it off as I went — with no success ... poop gets everywhere. My friend graciously insisted that it was totally fine, no big deal, she'd go get it washed.

When I finally got to the hotel room where I was temporarily living during house renovations, a tsunami of emotion overwhelmed my 20-year-old self. As my sister helped with logistics — pants, transferring, rinsing, cleaning, wiping — every moment felt like a thousand hours, especially accompanied by my uncontrollable sobbing.

I was shaken by the reality of newly unpredictable physical processes, and fear that poop now ruled my life.

Fast-forward almost 19 years. The emotional impact of that event still occasionally bubbles up if I have a bowel routine that isn't very "results oriented." ("Does this mean I'm gonna shit my pants today?") Or when I have unexpected stomach rumblings. Or when I'm with a sexual partner, and I'm

not sure if this is gonna be the time that my body finally goes "whoopsiedaisies!" while he's on top of me or — yikes — staring my lady-parts in the face.

But now I've learned to manage my body so that these scenarios are few and far between. I can recognize odd stomach feelings. I monitor my non-feeling parts with my feeling hands to identify unexpected bodily fluid before it gets out of hand. I have the extra cushion covers, bed pads, pants, wipes, all of the elements for a seamless cleanup.

With all of this comes power. One of my favorite Buddha quotes is, "Everything we are arises from our thoughts. With our thoughts, we make the world." Now I have agency over the mess — the knowledge to change how I perceive it, to know it doesn't consume who I am, and the power to deal with it.

When it comes down to it, bodies have natural processes like pooping that we should never feel ashamed of, especially when we have completely reasonable circumstances — like a catastrophic injury — that cause an occasional hiccup. And let's be honest, people poop their pants all the time for much more frivolous reasons.

Why don't we have an overall more affirmative culture around bodily mess and accidents? I'm not saying we should intentionally go around pooping our pants in public, but maybe we could have less anxiety around it. Beyond a car seat shampoo, it's really not a big

"From wheelchairs to bedpads, we often settle into how they were first presented to us. We get stuck in 'this is what we have.' But we have the power to turn them into 'this is who I am.'"

deal ... better to laugh about it and be open and honest about the fact that it can and will happen.

This means we have to identify the little elements in our lives where we can reclaim power over shame, embarrassment or apprehension. Hence, bedpads.

Make Bedpads Attractive Already!

I love bedpads. They are a simple and brilliant tool for managing the aforementioned human messes with alacrity. When my bladder occasionally leaks unexpectedly in the middle of the night, I can swiftly pull the bedpad off the top of my sheets, throw a new one on, and voila! Back asleep within 10 minutes.

But bedpad designs leave a lot to be desired. The bedpad industry has decided that bedpad users should apparently be style-less, feeling like we are still in the hospital being pumped full of stool softeners. The common bedpad is white with pastel pink or blue backing and easily stained and tarnished. A search for more stylish designs yield uninspired options: Grandpa's dark navy plaid or

Grandma's pink flowers. (Just because I occasionally pee on myself doesn't mean I am ready for the 80-year-old fashions. Grandma and Grandpa probably hate those options, too.) Worst of all, if you look up pee pads for dogs, it is literally the exact same product. I love dogs, but come on.

We deserve better. Design them in a way that doesn't reinforce any shame or embarrassment about our bodily functions but makes them a source of style and confidence — a way to say when you pull down the blankets, "This is who I am, mofo. Take it or leave it." Or a way to still look put together in your wheelchair without bits of bright blue chux popping out from under your butt.

I was overjoyed when I was recently on Etsy and came across QuiltyConscienceME, the brainchild of Carin Morse, a mom, medical assistant and granddaughter of a master quilter who retreats to her sewing machine at the end of the day. She was inspired to start sewing bedpads after working as a nurse. "I remember I would get the chux off the laundry cart when I was 19 or 20. I'd say, 'These are horrible! Why are we putting these under people?' And I was told, 'This is what we have.'" After becoming a mom, she also realized the necessity to create something that wouldn't be a source of embarrassment for her autistic daughter to take to sleepovers.

She makes bedpads that are everything we deserve. The materials pleasing to the touch and non-irritating to skin. They're absorbent, holding up to 2.5 pounds of liquid, sustainable and environmentally friendly, since they can be reused for years. They're also affordable and, best of all, stylish. Her bedpads are anything but bland and embarrassing, with every kind of design — Yoda, horses, Red Sox, cacti, or custom designs of your choosing. "We shouldn't be ashamed of the things our bodies do naturally," she says. "It's just an added safety net, another piece of fun linen on your bed."

For those of us with disabilities, our lives are filled with unique items and

ways of doing things that aren't the norm for many nondisabled folks. And with many of these items, from wheelchairs to bedpads, we often settle into how they were first presented to us. We get stuck in "this is what we have." But we have the power to turn them into "this is who I am." Time to pull that raggedy, ugly, stained white bedpad off your sheets, and replace it with a gigantic Wonder Woman logo, or whatever

will make you laugh and feel pretty cool, even when you pee all over it.

Like all humans, we are living, evolving, growing beings. We deserve to throw away old notions of ourselves that don't serve us anymore — such as the 20-year-old who smeared poop in a friend's car after a movie — and move on to the confident embodiment of all that we can be ... the person who will laugh about it.

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OUTDOOR TRACKS

By Kary Wright

TINKER, TRIGGER, HUNTER

In the spirit of helping us carry on and get back to normal after our house fire, and having better foresight than yours-truly, my buddy Dave contacted me in early last summer about the fall hunting season.

"So, have you thought about rifles yet? Now is the time to prepare."

"Pshaw," I thought, "it'll only take a day." Then, after implementing one of my newly acquired skills — namely giving the situation some careful thought and considering others' opinions before opening my foot-trap — I realized he's right. I usually assume a project will be quick and easy. Then I allow just enough time for a best-case scenario, only to be stressed and have to come up with a for-now solution that I make do with forever.

"What kind of gun are you getting?" asked Dave.

"Dunno," I replied. "Good question."

"What caliber?" he asked.

Same reply. Hmmm.

"How are you going to pull the trigger?"

See above.

I guessed I'd better get on it — four months will pass fast. I mentioned this time I'd like a bolt-action, smaller-caliber rifle that is accurate and fun to shoot. My old rifle, "The Cannon," was a Browning semi-automatic 300 Winchester Magnum. It was large, heavy and booming. The noise made it less than comfortable to target shoot with, although its aim was accurate for the 20 years that I used it. Dave let me know that his nephew is a good researcher, and he chose a Browning 6.5 Creedmore rifle.

Being old as dirt, I hadn't heard of this relatively new caliber. I did some reading — imagine that — and it



Wright and friend Dave spent months testing various iterations of the trigger puller on the range he has set up on his property. "I was having trouble getting the trigger to reset after a shot, and we wanted to be very, very careful."

looked good. It is a little slower than the 300, a little more bullet-drop until long range, and it uses smaller ammo. The recoil, or "kick," is much less — as is the noise. The accuracy is exceptional, and it is chosen quite often for long-range target shooting, which is something I've always wanted to get into. Our little town is blessed with a first-class sport shop, and a call to the owner, Pud, was in order.

"Hi, Wheels," said Pud. In a small town everybody has a nickname, and some have real names, too ... I think. "Sorry about the house fire. What can I do for you?"

"I need a rifle that's smaller and more fun than the 300 and was think-

ing a 6.5 Creedmore bolt action," I said. "Whutcha think?"

"It's getting to be a popular caliber, with its light recoil and accuracy. What're you doing with it?"

"Targets and deer hunting, nothing that needs a cannon," I reply. "The 300 was getting to be no fun."

"Sounds good. Come to the back alley and I'll show you a few different models," he says.

After looking at the different models, I settled on a bolt-action Browning with a Nightforce scope suitable for long-range plinking, and I took it home the next day. I didn't have a trigger-puller yet, so another friend, Joe, offered to sight-in the gun since

we were both camping at the farm and had targets set up. Soon he was hitting bullseyes regularly.

Over the summer, Dave and I devised and 3D-printed many different ideas for a trigger-puller. Most worked, but the bicycle cable that pulled the trigger would not reset after shooting, creating a dangerous situation when a fresh cartridge is loaded in. I got quite a bit of shooting in while we tested and could unfailingly hit a 4-by-4-inch plate at 200 yards, but I was always concerned with the safety factor.

A Breakthrough

One day while searching the internet, I read a post about a quadriplegic who uses a BMF Activator, which fires the gun when you turn the crank. These are illegal now where I am, but after some searching, I found a pattern online to 3D print it. This pattern allowed me to look at the innards and design a single-shot version that accommodates my bicycle-cable and clothespin setup.

Dave and I printed, tested, swore and tinkerbleeped in that order. Finally, a week before hunting season, we had it. We tried dry-firing indoors, and the trigger reset. Several more tries later and it still went perfect.

Then, as I pretended to line up on something, my hand slipped. The gun fired accidentally! I sent off a volley of expletives to solidify my displeasure — words like “shucks” and “darn it,” or maybe even worse.

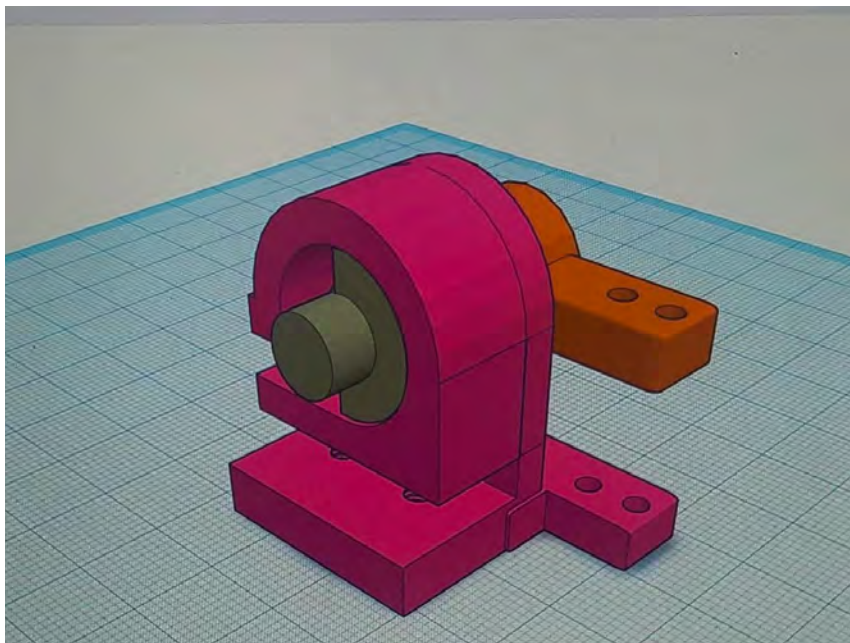
My hand had set off the gun by sliding the whole mechanism back, a situation that was totally unforeseen by us, even though we tested lots to try and expose flaws. Then Dave had to go and couldn't return until the opening day of hunting.

Opening day arrived.

“I can come by at 3,” Dave texted.

“I think I've printed a solution, making it impossible to accidentally fire. If it works, it'll be a quick add-on with a glue gun,” I replied.

Dave showed up at 3 p.m. By 3:30



It took more than five tries designing, redesigning and 3D printing the mechanism before Wright felt safe using it to fire his new rifle.

the piece was glued on and appeared to prevent any movement.

“If we get 10 safe dry-fires, let's go hunting,” said Dave.

We commenced mimicking real-world shooting, complete with all of the obligatory fiddle-farting I must complete before placing a shot.

“One,” said Dave.

More fiddling.

“Two.”

Bang trigger with my paw on purpose ... no misfire.

“Three.”

And so it went, until we reached 10. No accidental firing and no problems firing it when I wanted.

“Let's go! Only a little time left for today,” he said.

We decided to hunt in our never-before-setup-blind (of course) to “quickly” be hunting. The blind turned out to be a tad short and small for two

full-size-and-then-some guys, and a power chair with a rifle mounted. I situated myself, and Dave set the blind over me with the zipper undone. I had a crack to poke the barrel out of. We left my bolt open to be safe — Dave would close it if a deer came by.

“It'd be nice to get one while it's warm out, since we have no heated garage this year,” said Dave.

“Agreed.”

At 4:30 or so I looked through my little crack and saw something move.

“Dave, there's a deer. Crank one in!” Dave bolted my rifle.

It was a nice whitetail with three points on each side. I lined up like we practiced and the trigger-puller worked perfectly. It was the first time ever that we scored on opening day! We went from afternoon tinkering and testing to harvesting a nice deer, all within a couple of hours.

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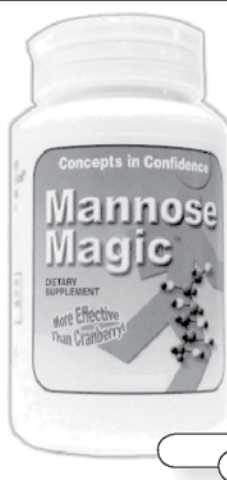
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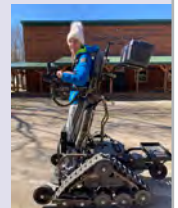
PATHWAYS TO EMPLOYMENT

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www.unitedspinal.org/pathways-to-employment/

Meet New Member Heidi Wachtel

Age 44, from Merkel, Texas
C6 complete spinal cord injury
Former firefighter/critical care paramedic
Pursuing a social work career



Why I joined United Spinal: I joined United Spinal association to learn how to live this new life. Learning from others who have excelled and are enjoying life will help me move forward and begin to truly live.

What is the one product you couldn't live without?
My track chair from VR. It allows me to live in a very rural area and work with kids at a Christian camp.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? I would educate people better to see me as a person and not just my chair or my disability. I'd also teach them about not parking in accessible parking spots.

Meet other members or join United Spinal at unitedspinal.org

LAST WORD



SPINOUTS



WHERE IS OUR 2017 PERSON OF THE YEAR TODAY?

Sommelier Yannick Benjamin (pictured here with chef Oscar Lorenzzi) gave foodies a sneak peak of Contento, his authentic and accessible New York restaurant, when it hosted the Copa Jerez chef/sommelier competition April 19. Contento opens to the public this month.



Lauren "Lolo" Spencer attends the 2020 Film Independent Spirit Awards.

Photo by John Shearer/Getty Images

NM LIVE VIDEO SERIES with Teal Sherer

JULY'S GUEST: ACTOR AND MODEL LAUREN 'LOLO' SPENCER

Lauren "Lolo" Spencer will soon grace our screens in the HBO Max series *The Sex Lives of College Girls*. Though much about the show, which Mindy Kaling created, is under wraps, Spencer shares some details about it and her character "Jocelyn" in our interview. She also talks about her breakthrough performance in the film *Give Me Liberty*, which garnered her a Film Independent Spirit Award nomination and put her on the *Hollywood Reporter* film critics' list of the 25 best performances of 2019.

As a model for brands like Tommy Hilfiger and Zappos Adaptive, Spencer gives tips on how to "work your wheelchair" in photos. She also talks about her lifestyle brand, *Sitting Pretty*, and why she's dedicated to creating content that showcases disability in an authentic way.

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