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Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Social media is here to stay, and so are a growing number of disabled influencers who are shaping many of the online discussions around disability in ways never seen before. BROOK MCCALL talks with the wheelchair users behind three social media brands to learn why they chose this path, how they built their followings and, most importantly, what life is like on the other side of the screen.

Cover and Contents Photos by Alec Robertson

FEATUES

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Cory Hahn was one of the best teenage baseball players in the world before an awkward slide into second base made him a quadriplegic. Now, he works behind the scenes for the Arizona Diamondbacks. IAN RUDER catches up with him.

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Enjoying the beach is often a question of navigating the sand. JESSICA FARTHING reports on gear and tactics that may be the answer for your next shore visit.

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Booking a hotel for your family is complicated, especially when the only available accessible room inevitably has one king bed. SYLVIA LONGMIRE investigates.

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48 LAST WORD
Humor has always been my chosen weapon for combating depressing news. It helped me cope with my spinal cord injury and has helped me deal with difficult situations many times since. When I posted a photo of a local supermarket produce section that had been stripped bare of kale as local shoppers reacted to the early warnings about COVID-19, it seemed funny:

I’m not laughing anymore. My state is locked down and an in-home quarantine seems a likely possibility.

There’s a good argument the majority of the population should just chill out, wash their hands regularly and use common sense. It appears that for most people, COVID-19 only results in mild symptoms, so the idea of letting the virus run its course and not spreading it to others who may be at higher risk makes sense.

The advice I keep getting hung up on is the recommendation that if you think you are sick or may be infected, then you should stay home and quarantine yourself. That’s good and all, but what about those of us who rely on personal care assistants?

I’ve got a stockpile of meds, supplies and cleaning materials that would make even the most ardent doomsday prepper envious, but without my personal care attendants being able to come to my house, it’s less useful than the blank pages one Australian newspaper printed as a solution to the nation’s toilet paper shortage.

If you think you’re contagious, asking a caregiver to break a quarantine feels kinda shady. Not only are you jeopardizing their health by requiring them to be in your vicinity, but you’re enlisting them in an agreement to act against the common good.

The only guide I could find that speaks to this Catch-22 is published by the Center for Disability Rights. Its “Action Steps for Attendant Service Users in Response to Coronavirus Disease 2019” (tinyurl.com/unxz9zs) lays out 15 steps to prepare for COVID-19. It’s a useful and needed list, but thanks to its first two steps, I can’t help but think it only serves to highlight the conundrum we are facing:

1. Ensure you have sufficient back-up attendants.
2. Ensure that you have the ability to get assistance if an attendant does not show up.

To the CDR’s credit, it acknowledges the difficulty of hiring attendants, but come on … it’s hard enough when the country isn’t deeply anxious about a virus that has shown an affinity for nurses and caregivers.

My coworker and noted humorist Seth McBride imagined the sales pitch: “Have I got the job for you … when the person who’s been taking care of me gets COVID-19, and probably passes it on to me, you come in and help me get dressed while I cough on you … oh, and did I mention you’ll make near minimum wage?”

I see the aerial photos of the empty streets in closed Chinese cities and I can’t help but wonder what would happen here if we are forced down that route. I think about all my friends and all the people like me who don’t fit neatly into the solutions currently on the table.

If COVID-19 has shown us anything, it’s that we need better plans and a larger discussion about how we propose to take care of all of our people.
Trying to keep up with all the projects Sylvia Longmire is working on can be exhausting. This month, she writes for us about accessible hotel limitations. As an accessible travel agent and consultant, she is continually crisscrossing the globe to keep her eyes out for similar issues, but she hasn’t let that stop her from developing a number of travel-related pilots and projects for television or becoming the first wheelchair user to be selected as one of O Magazine’s O Mag Insiders. Oh, and I did I mention she is a mom, too? Longmire, a former Air Force special agent, wouldn’t have it any other way, “My goal is to provide more representation for wheelchair users in the public sphere.” Follow her on Instagram @sylvia_longmire and on Facebook at spintheglobeonwheels.

Spending time on the beach is more than just a pastime for Savannah, Georgia, writer Jessica Farthing, “That’s our thing down here,” she says. “Growing up, that’s what we did all the time.” She and her husband, Paul, an incomplete quad, spend much of their summers on their boat, but they have always been frustrated by the lack of good options to access the area’s pristine sandy beaches together. “He’d always be up on the boardwalk or in some area away from the action,” she says. For this issue, she reached out to wheelchair users to see how they handle the beach and whether there are any products that make navigating the sand and dunes easier.

When Mat Barton isn’t drawing comics with his dry, and often sly, brand of humor, there’s a good chance he is either playing video games or with his almost-3-year-old son. If you’re wondering whether his son serves as the basis for the hilarious, adorable child often featured in “Please Remain Seated,” the answer is no ... well, not exactly. “Some of the jokes have been inspired by things he has said or done, but the character isn’t supposed to be him,” says Barton. Right now, Barton is hunkered down creating and submitting strips to a number of national publications. His work has been featured widely, including in The New Yorker and Weekly Humorist. Follow him on Instagram @matbarton.
“As difficult as our bodies can be after SCI, they are still our bodies.”

Your Body Matters
It took me 15 years to heed the wise advice about taking care of your body that Regan Linton dispenses in her February article (“Self-Image and Intimacy: Beating the Body Rut,” NEW MOBILITY, February 2020). I wish I had listened sooner. As difficult as our bodies can be after SCI, they are still our bodies, and they need our care and respect. Since I started listening to my aches and pains and proactively working to relieve them, everything about my day-to-day life has been better. I only wish I could go back and start sooner.

Tyson Carr
Springfield, Missouri

Love Yourself
I had to love what I had to offer first, and then make it exciting (“Sex is Not Intimacy — A Cautionary Tale,” Blogs, Newmobility.com, Mar. 7). I also make people like or fall in love with me first, and the sex becomes secondary. I make it a point to have fun with it within my limitations, and I may need some help along the way. It is all about acceptance and how you let your partner know you have [learned] to accept what you have and make fun of the situation.

Elizabeth Valdez
Newmobility.com

Honesty is Key
What a truthful and honest story that I hope will inspire both men and women who are facing relationships when a disability is a factor (“Sex is Not Intimacy — A Cautionary Tale”). Thanks for sharing.

Tracy Netherton
Newmobility.com

Those Crazy Walkies
Very insightful and hysterical! Simply marvelous! (“Hilarious Ableist Tendencies in Chat Rooms,” Blogs, Newmobility.com, Feb. 21.) I also get from walkies, “You’re such an inspiration!” Why? For not being dead? Or urinating all over myself? Lol! I mean, I don’t want to be your f***ing “inspiration.” I just want to be given the opportunity to exist.

Sara Sheranian
Newmobility.com

Push the Limits
Awesome article and true in so many ways (“Extreme Sports, Extreme Passion,” NEW MOBILITY, February 2020). I’m excited to see how the adaptive equipment continues to progress, especially with current battery technology.

Kirk Williams
Newmobility.com

Gamers Unite
Thanks for writing this, Michael [Franz] (“Identifying the Game Changers So You Don’t Have To,” NEW MOBILITY February 2020)! Definitely getting the Active Hands. Speaking of video games, I taught myself to play with my mouth! I am limited to Super Nintendo Entertainment System or PlayStation controllers because of their design. It was pretty fun to see me outplay my nephews at Tony Hawk Pro Skater back in the day. Sadly, spasticity has kept me from a lot since approximately third quarter 2004. Thanks again, bud! Much love!

Michael Ecklund
Newmobility.com

The Elbow Grab
This was a lovely job of explaining the situation and possible ways of approaching people (“Daily Dilemmas: How to Handle ‘the Handshake,’” NEW MOBILITY, February 2020). I suspect the person was being considerate because they were concerned a handshake would be painful. Helping them understand it isn’t will allow them to approach people with differences more openly in the future so they can recognize that someone offering their hand means it’s OK to shake with a moderate grip.

I have always liked a firm grip until the last few years when my arthritis and fibromyalgia has caused so much pain in my hands and fingers. Now I often choose to do an arm grip where I grasp their elbow with my hand so they have to grasp my elbow, or I offer my fingers lightly, but in either case I do explain that I have a tender hand and fingers. It’s OK to let people know your individual situation so they are aware of personal differences. I think they will respect you for that.

Deborah Gregson
Newmobility.com
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DISABILITY-SPECIFIC RECOMMENDATIONS FOR COVID-19

In December, the world first started hearing reports of a new strain of coronavirus that seems to have originated in the Wuhan Province of China. In a few short months that virus has spread across the world, causing a public health and economic crisis unlike anything we’ve seen in the past 50 years. While the world’s media has been breathlessly covering every twist and turn of the rapidly-evolving crisis, there’s a frustrating lack of disability-specific information on COVID-19. So here’s what we know so far, including SCI/D-specific recommendations and how to find up-to-date information you can trust. We are updating this information regularly on our website, newmobility.com.

What Is It
COVID-19 is a novel respiratory infection that’s part of a large family of viruses known as coronavirus. Some coronaviruses have relatively mild symptoms, but others, such as SARS and MERS, can cause much more severe symptoms, like pneumonia, kidney failure and even death. COVID-19 can also cause these types of severe symptoms, especially for those with pre-existing health complications, but so far it appears that most people who are infected experience milder symptoms, like fever and a cough. SCI/D on its own doesn’t put someone at greater risk, but some common secondary complications do increase risk of severe symptoms.

Those at greater risk include:
• People with high-level injuries who have impaired lung function, especially those who require the use of a ventilator.
• People with MS or other immuno-compromising disorders, especially those whose treatment includes immunosuppression drugs.
  • People who have underlying chronic health conditions, such as high blood pressure, heart disease or diabetes.
  • People who have underlying acute health conditions, such as skin breakdown or urinary tract infection, are also at increased risk of severe symptoms associated with COVID-19, says Lindsey Freysinger, RN, MSN, who also has a C5-6 incomplete SCI. She explains that if anyone with an acute condition were to contract COVID-19, there would be two separate issues for their immune system to fight, increasing the risk of severe symptoms for both. Freysinger recommends that anyone in this situation be vocal with their health professionals to make sure they are proactively managing both issues instead of only focusing on COVID-19.

How to Prevent Infection and Transmission
The steps that experts recommend for preventing infection from COVID-19 are the same for flu prevention:
• Wash your hands for at least 20 seconds. Some people recommend singing a chorus to a favorite song in your head to help you gauge the time. If you have limited hand and/or arm function that makes hand-washing at a sink difficult, then an alcohol-based hand sanitizer that’s at least 60% alcohol is sufficient. Frequent hand washing and sanitizer use can dry out skin, so you may need to use lotion more than normal to avoid cracks and other skin problems.
• Avoid touching your face. It’s thought that infections like coronavirus can’t enter your system through your skin. They need a more permeable path such as the mucus membranes of your nose, mouth and eyes.
• Cover your cough, but not with your hand. If you cough into a tissue, throw it away. If no tissue is available, cough into your elbow.
• Regularly disinfect surfaces, especially those that are regularly touched. Rubbing alcohol, hydrogen peroxide and bleach are all effective disinfectants. Manual wheelchair users, especially those at higher risk of severe symptoms due to secondary complications, should consider regularly disinfecting their push rims. Bleach wipes are easy and effective.
• Public health officials now recommend social distancing for everyone, regardless of whether you have symptoms of the virus, which is why states are shutting down schools, restaurants, bars and other gathering places. Only go out into public when necessary and avoid close contact with anyone outside your immediate household whenever possible. Emerging evidence suggests that asymptomatic people are a signifi-
cant driver of transmission, so it’s up to all of us to slow the virus’ spread.

**How to Manage Caregivers**

For those who rely on personal assistance services, the COVID-19 outbreak can be especially worrisome. You can’t quarantine yourself to prevent getting the virus when you’re reliant on extra hands to help with your daily needs. Keep in mind you may:

- Ask caregivers to wear a mask if they have been in contact with anyone who has shown possible symptoms of the flu or COVID-19, even if they themselves aren’t symptomatic.
- Ask caregivers to wash their hands or use hand sanitizer before each time they touch you.

But what are you supposed to do if your caregivers stop showing up to work or if your homecare agency cuts hours because of staffing shortages? Unfortunately, we don’t have many brilliant solutions. Most resources suggest making sure you have backup attendants, but that isn’t exactly a realistic option for a lot of people. Even without an infectious disease scare, homecare workers are already in short supply. Everyone’s situation is different, so the best bet may be to plan according to your individual scenarios if you lose personal assistance:

- Are there tasks you could accomplish on your own if you have the proper supplies and advanced preparation?
- Are there family members who could help with some tasks, friends who could help with others?
- Have conversations to prepare anyone you may need to rely on in an emergency.

If you don’t have any other options, contact your local CIL or other disability-support organizations to see if there are any resources available.

**How to Stay Informed**

The COVID-19 outbreak is a rapidly-evolving medical situation. As more data becomes available to health researchers, guidelines and best practices may change. Don’t trust information on social media unless you can verify it through multiple, trusted sources. The following organizations can be relied upon for basic info, but pay attention to dates and times that updates are posted:

- Shepherd Center has already published a helpful, disability-specific guide to COVID-19: [bit.ly/2xQ3BLD](bit.ly/2xQ3BLD).
- The CDC is the official source for up-to-date guidance and recommendations in the U.S.: [cdc.gov/coronavirus/2019-ncov/index.html](cdc.gov/coronavirus/2019-ncov/index.html)
- The Administration for Community Living has information specific for people with disabilities and older adults: [acl.gov/COVID-19](acl.gov/COVID-19)
- We have disability-specific coverage of COVID-19 at [Newmobility.com](Newmobility.com) that we will be updating as new information comes in, including answering readers’ questions (see sidebar). Also, in next month’s print issue we will be doing a deep dive into the various ways that COVID-19 is affecting our community.

**Call for Questions and Stories**

We want to hear about how the COVID-19 outbreak is affecting you, as well as any questions or concerns that you have. We’ll be doing our best to get expert answers to your disability-specific questions and share them across our platforms.

Also, if your homecare has been affected by COVID-19, United Spinal Association is asking that you contact the Resource Center to share your experience at 800/962-9629 or [https://askus-resource-center.unitedspinal.org/index.php?pg=request](https://askus-resource-center.unitedspinal.org/index.php?pg=request). “We may not be able to solve individual problems, but we can tell our stories to our governors and congresspeople to try to get relief,” says United Spinal Association CEO James Weisman.
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.

**MEMBER BENEFITS**
unitedspinal.org

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.

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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.

**30 YEARS OF LEADERSHIP IN SCI RESEARCH**

This year marks the 30th anniversary of the founding of the Spinal Cord Damage Research Center at the James J. Peters VA Medical Center in the Bronx, New York. The Center started 30 years ago out of a desire to focus research efforts on oft-overlooked medical, health and quality-of-life issues for people with spinal cord injury and disorders. The Center, which began with two researchers and one technician studying the impact of diabetes on people living with SCI/D, has grown into an international leader in research with 44 full-time employees, more than 350 published papers since its inception and funding sources that include Veterans Affairs, National Institutes of Health, Department of Defense, New York State and many foundations.

None of that would have been possible without the startup funding United Spinal Association, then known as Eastern Paralyzed Veterans Association, provided in 1990 at the behest of its visionary executive director, James J. Peters. A veteran and a wheelchair-user himself, Peters was always working to develop and improve new ways to help people with SCI/D live their lives to the fullest.

“Peters always wanted the VA to lead the way in SCI research, and he wanted it to happen here,” says current United Spinal CEO James Weisman.

Peters arranged for EPVA to provide $2.8 million over the Center’s initial years while it secured grants and developed its reputation. The Center has been peer review-funded by the VA since 1988.

The Bronx VA was renamed to honor Peters in 2004, and longtime friends and collaborators Drs. William A. Bauman and Ann M. Spungen, the Center’s director and associate director, know he would be proud of the work the SCI Center has accomplished.

“Jim would be beaming,” says Spungen. “With every publication and every grant we received, he always told us how much we had done with the investment and how proud he was of us. He couldn’t have been happier with our achievements. He really would have been blown away and happy to see how much we have done for the field of SCI medicine in the past three decades.”

That feeling is shared by United Spinal Association today. “Thirty years ago, we recognized the significance of investing in SCI/D research,” says Weisman. “We made the investment then, and we’re proud to continue to support the center’s groundbreaking efforts on behalf of all veterans and people with SCI/D.”

— Ian Ruder
**BIG IDEAS IN IMPROVING HOMECARE**

*With James Weisman*

**USE OLMSTEAD TO INCREASE PAY FOR HOMECARE WORKERS**

*Editor’s Note:* The U.S. Supreme Court’s 1999 landmark decision in *Olmstead vs. L.C.* found that the Americans with Disabilities Act gives disabled people the right to live in the most integrated setting possible. If a state funds both nursing facilities and homecare programs, then a disabled person has a right to choose homecare.

But why stop there, asks United Spinal Association President and CEO James Weisman. Why not use Olmstead to increase the pay of home health workers?

**New Mobility:** What’s the Big Idea about leveraging the Olmstead decision?

**James Weisman:** The big idea is that if the responsibility of the government, under Olmstead, is to keep you in the community, then the government must raise the wages of home health workers to attract people to the profession.

Most home care is paid by Medicaid. Both the feds and state governments administer Medicaid, and Health and Human Services, through the Centers for Medicare & Medicaid Services, makes the standards for home care — or what you’re eligible for.

**NM:** Are states required to provide homecare?

**JW:** HHS doesn’t require states to provide home care, but most states do in some way. If a state is providing home care through Medicaid, and decides that it can’t deliver care to you because there are no workers, what’s their responsibility? Is it to put you in a nursing home? Or to keep you in the community? Right now, you can end up in a nursing home, by default, even if you’re eligible for homecare. The default to the nursing home is so much more expensive than home care. That bodes well in our favor, if policymakers begin to listen.

**NM:** How can our readers help?

**JW:** They have to open their mouths. These types of changes don’t happen by themselves, especially now that resources are going to be stretched and we’re saying stretch them even more. They have to tell their elected officials what they expect from them, and if they can’t get what they need, they should let us know. We want to help them to get to their elected officials, and to be their advocates. Squeaky wheels get some grease on this.

from going in, you see states are not doing it. They’re throwing up their hands saying, “That’s all we can do! We’re paying minimum wage or slightly over, and that’s all we can do.” I don’t think Olmstead allows that. Olmstead says figure it out.

So what are the solutions? Obviously, raising wages. Other ways to turn homecare into a real job, as I think Olmstead demands, could be immigration incentives, which this administration, of course, won’t do. But others might. You could prefer people for immigration who want to work in homecare. It’s employment of last resort right now, and whoever the newest immigrants are, that’s who is doing it. Either way, we need immigrants, and we don’t have them.

The other thing to do is make it more of a job — give workers benefits and paid vacations — and virtually none of that happens now.

Creating a job career path, too, would help. You come in as homecare worker, and then maybe you take nursing classes. States have to undertake those planning initiatives to meet Olmstead.

This is a problem that is not solving itself. It’s not going to go away. Now the economy has gone in the dumpster, so people are going to be laid off, and then you’ll get homecare workers again. I hate saying it like that, but if layoffs start, they’ll come out of the woodwork. It’s strictly a job for those people, though. Not a career.

**James Weisman was General Counsel for United Spinal Association for over 40 years and became President and CEO in 2015. He is a recognized expert on disability rights who led efforts on public transit and taxicab accessibility in New York City and other major cities. Weisman was a key negotiator with Congress in drafting and achieving the passage of the Americans with Disabilities Act.**

For the first 26 years of my life as a quad, I couldn’t take full advantage of texting or email. I couldn’t scroll through a list of messages and click on the one that I wanted. I couldn’t search through texts to find the one I needed to respond to. I had to rely on someone else to do all of those things for me.

Then Apple introduced Switch Control in iOS 7 for the iPhone in 2013.

When Apple wanted to create solutions for people with disabilities, they began thinking about functionality — allowing switches (or, more simply, buttons) to manipulate the iOS interface. Switches are physical devices that let you control actions. Examples of a physical switch include Micro Lights or Buddy Buttons. They can be coupled with a Bluetooth interface like the Tecla by Komodo Labs. Most joysticks, sip-and-puff and head array drive controls for our wheelchairs can also act as switches. Drive control can actually function as multiple switches, with each drive direction (forward, backward, etc.) serving as a switch, which minimizes additional hardware and potential points of failure.

I drive my chair with a chin-control joystick. I can use that same joystick to navigate my iOS device via Switch Control, or I can use the four physical switches connected to my Tecla. Personally, I like redundancy and the ability to use either system.

Once the connection is made between the switch and your device, you can use Switch Control to program specific actions to carry out common iOS control functions, like highlight, select, drag or tap. Now that I can complete those common tasks via Switch Control, I have a new world of functionality at the tip of my tongue. I can even use Switch Control to work my laptop, iPad and Apple TV.

As a tech geek, when I got a whiff of Switch Control functionality, I became excited. I started watching YouTube videos and exploring Switch Control with some people I knew. My wife and I purchased an iPhone, a Tecla and some additional switches. Then, we just had to figure...
out how to make it all work together. There was hardly a roadmap or any documentation back then, just a lot of grit and late nights.

Since I began using the new devices, there’s been a quantum leap in my level of tech independence. I can’t tell you how thrilled I was to independently send my wife a text for the first time. There I was, fully controlling my smartphone like a grown man. The potential ripples from this blew my mind. On one hand, I can be on a ferry boat and use my phone to play music or read a book, as opposed to just sitting there. On the other hand, Switch Control creates options for employment and increases independence — something everybody craves, regardless of disability.

After discovering this new world of independence, I applied for and received a grant through a nonprofit to spread the word and install these tools for other disabled folks. I took the information to the Quad Squad, a group of quadriplegics here in the Pacific Northwest with whom I meet to hang and discuss issues important to us.

Initially, after hearing about the benefits of these tools, only one person volunteered to give them a try. Change can be hard, and when navigating a world that’s often not designed for those like us, we cling to what we know. Stepping outside of that might lead to failure or a sense of vulnerability, which only amplifies our disability. Over time, after multiple meetings and continued exposure to what Switch Control could do, others started using it.

I know there are folks out there who think Switch Control will be made obsolete because Voice Control is now available. For me, however, Switch Control will continue to be the foundation of my increased independence. If you’re on a ventilator and your voice is weak, or you have a progressive illness that affects your voice, Switch Control can help you maximize whatever function remains, be it mouth, head or tongue control. Additional capabilities like Voice Control or Mouse Control can sit on top of this foundation and add their own benefits, but by no means will these new features replace Switch Control in all situations.

You need to find the right mobility solutions that work for you. The machine that so often works against us, grinds on. Those of us with disabilities need to grab every tool at our disposal to keep it from robbing us of more independence, more opportunities and more dignity.
What do the Atlanta Chapter of United Spinal Association, Atlanta’s quad rugby team, the Spinal Cord Injury USA Facebook group and a urological supply company called First-Source Catheters all have in common? If you guessed that they benefit the SCI community, you’re right. But for full credit, the correct answer is they were all founded or co-founded by Clint Cook.

As a C5 quadriplegic for 32 years, Cook receives his fair share of “that-a-boys!” and other unsolicited and awkward comments from strangers, but he doesn’t let them get under his skin. In fact, he values them.

“At the end of the day, you don't know what that person who said, 'It's great to see you out grocery shopping' is going through,” says Cook, 52. “They could be a grandma whose grandchild has a brand-new SCI and is going through the same things you've gone through. Or they may have been diagnosed with something and don't know if they'll be able to go grocery shopping again.”

For this reason, Cook spends his time actively trying to connect and motivate people. “I've always made myself available to the community so that people think, 'If this guy can do it, why can't I?''' he says.

Cook participates in all types of sports, including indoor skydiving, wall climbing, curling, handcycling and more. He also dedicates a lot of his time to working with SCI researchers at Georgia Tech’s Rehabilitation Engineering and Applied Research Lab and Atlanta’s renowned Shepherd Center.

But there is no question that peer mentoring and community building are at the heart of his efforts. He works through Spinal Cord Injury USA, a group he started on Facebook and later developed into a nonprofit, to partner with Atlanta-area businesses and host meet-ups and activities.

“The year before last, people [in the Facebook group] were talking about how cool it was to meet people online and then someone mentioned, 'It'd be really cool to be able to meet people face-to-face,' and I thought, well, Atlanta's a pretty cool city, so I decided to throw something together and invite people to come over,” says Cook.

What resulted is Spinal Cord Injury USA's first annual Atlanta Meet-Up where, thanks to Cook, all activities were

**How We Roll**

**It Is Great to See You Out**

As a C5 quadriplegic for 32 years, Cook receives his fair share of “that-a-boys!” and other unsolicited and awkward comments from strangers, but he doesn’t let them get under his skin. In fact, he values them.

“For this reason, Cook spends his time actively trying to connect and motivate people. “I’ve always made myself available to the community so that people think, ‘If this guy can do it, why can’t I?’” he says.

Cook participates in all types of sports, including indoor skydiving, wall climbing, curling, handcycling and more. He also dedicates a lot of his time to working with SCI researchers at Georgia Tech’s Rehabilitation Engineering and Applied Research Lab and Atlanta's renowned Shepherd Center.

But there is no question that peer mentoring and community building are at the heart of his efforts. He works through Spinal Cord Injury USA, a group he started on Facebook and later developed into a nonprofit, to partner with Atlanta-area businesses and host meet-ups and activities.

“The year before last, people [in the Facebook group] were talking about how cool it was to meet people online and then someone mentioned, ‘It’d be really cool to be able to meet people face-to-face,’ and I thought, well, Atlanta’s a pretty cool city, so I decided to throw something together and invite people to come over,” says Cook.

What resulted is Spinal Cord Injury USA's first annual Atlanta Meet-Up where, thanks to Cook, all activities were

**Can’t Live Without:** My Quickie 7R. It’s a lightweight manual wheelchair, and I chose it because it was the lightest available.

**What You Get Out Of Volunteering:** Just the fact you might’ve changed someone’s life, just like someone might’ve changed your life. There’s no greater feeling than that for me.
You can’t be in here,” said the bar owner.

“I’m fine,” replied Cook. “I’m 21, and I’m legal to drink.”

The owner checked Cook’s ID and replied, “No, I don’t have insurance for you.”

“What do you mean you don’t have insurance for me?”

“If you get hurt in here, I don’t have insurance for you because you’re in a wheelchair.”

“I about fell from my wheelchair and passed out,” recalls Cook. “I thought, ‘what are you talking about?’ But I was young and newly injured, so I thought maybe insurance was a thing. I said, ‘Can you give me back the money I paid for my beer and game of pool?’

I didn’t know I’d been discriminated against. I was so green and I thought maybe he was telling me the truth. To this day, I have no clue what his reason was. I really think he felt he would be liable.

Years ago, Cook had time to kill before his car stereo was repaired. He rolled into a bar expecting a beer, a game of pool and a warm reception. The owner’s response was anything but welcoming.

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Why I joined United Spinal: My dad always said, “You can’t keep it if you don’t give it away.” Really what he meant was someone gave me the tools to live my life, so I needed to do the same for someone else.

DREAM GARAGE: It would have a later-model Corvette, a BMW M5 and a Maserati. Those are my dream cars.

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DREAM GARAGE: It would have a later-model Corvette, a BMW M5 and a Maserati. Those are my dream cars.
The Arizona Diamondbacks decision to draft Cory Hahn in the 34th round of the 2013 Major League Baseball draft was the kind of feel-good story local news broadcasters love. Hahn was one of the top college baseball players in the world in 2011, when he sustained a C5 spinal cord injury on an awkward slide into second base in the third game of his freshman year at Arizona State.

The Diamondbacks were essentially Hahn’s hometown team, and selecting him in the 34th round — chosen because Hahn always wore number 34 — was a low-risk PR win for a savvy organization. Not many 34th round picks ever see the light of day on a major league roster, so what was there to lose? Indeed, the stories that documented Hahn being drafted congratulated him and the team for adding “another touching layer” to an “inspirational” story. And while it definitely was both touching and inspirational, Diamondbacks President and CEO Derrick Hall knew it was much more than that. He knew that with the 1,020th pick, he’d just gotten a steal.

A spinal cord injury might have ended Hahn’s playing career, but the Diamondbacks understood that many of the same skills and traits that made him successful on the field could translate to the front office. “We already knew in the back of our minds that when he was finished with school, we were going to try and get him in the organization because we thought he could help our team,” says Hall.

What Hall couldn’t have known was that Hahn would exceed all of the team’s expectations, using the same “bulldog” mentality that brought him success in center field to quickly work his way up the organizational ladder and establish himself as one of its rising stars.

Less than seven years after being drafted, Hahn is the Diamondbacks coordinator of pro scouting. He manages the organization’s 21 pro scouts, evaluates players and helps the team formulate its roster. “If I can’t play the game anymore, I’m doing the next best thing, and that’s working within the game and being a part of it still,” says Hahn.

“Not being able to play the game anymore definitely leaves a void in my heart and in my mind,” he says. “I think that’s a void that will never be filled, but the fact that I’m still in the game, and I still get a chance to be around baseball 24/7, it’s the next best thing.”

A ‘Baseball Rat’

Like any parent, Dale Hahn, Cory’s father, worried about his son’s future in the immediate wake of his injury, but amidst all the uncertainty, Dale was certain baseball would remain a part of Cory’s life. “Knowing how he was before, he loved baseball. He was a baseball rat,” says Dale. “That was going to be his life, and nothing was going to change that.”

Hahn returned to Arizona State, and it was like he never left. He re-
joined the baseball team as a player-coach. He kept a locker in the clubhouse, dressed for games and sat in the dugout and lived with his teammates. With Dale helping take care of him, and his friends and teammates supporting him, Hahn graduated with a business degree in 2014.

He wasted no time getting to work for the Diamondbacks and started his career off the field as an amateur scout, traveling to high school and college games to evaluate talent. Hahn had honed his evaluation skills from the bench at Arizona State and took pride in analyzing players’ strengths, weaknesses and areas for improvement. While he trusted the intuition he had building baseball, he gained confidence hearing how his advice improved his friends’ games.

It’s important to note that his friends weren’t some rag-tag group of baseball nobodies, but a high-powered group that included Philadelphia Phillies star Bryce Harper and San Diego Padres slugger Manny Machado, two of the highest-paid players in the history of baseball. Harper and Machado are among many MLB stars who played on an elite traveling team with Hahn in high school and still stay in touch.

“The fact that some of the best players in the world trust my baseball knowledge to identify some of the things they’re doing right and some of the things they’re doing wrong is a really cool feeling,” says Hahn. “It’s a really rewarding feeling, given what I do on a daily basis.”

Despite his high-profile friend list, Hahn still had to deal with the mundane and often infuriating realities of scouting in stadiums where accessibility wasn’t even an afterthought. Scouts traditionally sit together right behind home plate so they can have the best view of the pitcher and talk shop, but those seats are rarely accessible.

“I didn’t get the opportunity to sit down in game and ask a scout, ‘Hey, how do you evaluate this pitcher, or how do you do this?’” says Hahn. “At the end of the day it forced me to really trust my own gut fast.”

Hahn also learned to improvise. “I’ve had to go to some high schools where I’m literally in left field because it’s all grass or dirt behind home plate, and I can’t get back there. Or it’s all bleacher seating, and I don’t have a view. I’ve had to watch games from some really, really crazy and unfortunate areas, all of which I think personally have made me a better evaluator, because I’ve been forced to look at the game a different way, and I’ve been forced to be unique and creative in the way that I evaluate a game.”

Make no mistake, Hahn isn’t simply watching games, he’s documenting every aspect, something that can be tricky with quad hands. “I’ve had to create my own code words,” he says. “I don’t want to say that I’ve created my own alphabet, but I’ve created my own lingo where I know what certain trigger words mean and I know what I need to expand on.”

Dale accompanies Hahn on scouting trips to help with his care, but leaves him to work during games. He says some of the same adaptation skills that helped

**New Responsibilities**

Four years ago, Hahn took on new responsibilities when he moved to the professional side of the scouting department. He still spends a good deal of time on the road — he estimates around 50 nights last year — but gets to avoid some of the least accessible amateur destinations. He has offices at Chase Field, the Diamondbacks’ Phoenix home and Salt River Fields, the organization’s nearby training facility.

Hahn’s travel responsibilities and daily schedule vary depending on whether the MLB season is going on, but either way, he is on the go. The off-season means less travel and more rehab, and the season means longer days and lots of baseball. Whether he is swamped with work or on the road, Hahn always finds time for the gym, even if it means

Since being drafted by the Arizona Diamondbacks in the 34th round of the 2013 MLB Draft (top), Hahn has honed his player evaluation skills by putting in long hours (above).
early mornings and late nights (see sidebar). “That competitive fire and confidence to push myself to my limits every day still burns,” he says. “Baseball really brought that out for me, and I think if I didn’t have those characteristics, or I didn’t work hard every day, I would not be as successful as I am.”

Hall says the organization is happy to keep expanding Hahn’s responsibilities because of the impact he injects wherever he works. “He sees the positives,” says Hall. “He sees the light that most wouldn’t. And he puts it into perspective in a very refreshing way.”

“We’re in a very numbers-based game now; it’s very results driven. Our emotions go with the ups and downs of winning and losing. Hahn is so even keel, and he rubs off on others. His perspective on life — he’s so fortunate, so happy, so content — and it definitely is contagious. It’s something that we all feel and see and feed off.”

Hahn’s positive impact isn’t limited to the world of baseball. In 2018, he teamed up with his childhood friend and longtime teammate, Trevor Williams, now a pitcher for the Pittsburgh Pirates, to launch Project 34, a nonprofit to raise money and support for people with SCI/D.

“I realized that I’ve been very lucky to have an incredible support group,” says Hahn. “But along the way I’ve met some other people who don’t necessarily have that, and we want to be able to be that bridge to somebody. We’re all capable of doing incredible things. We just need the opportunity to do so, and not everybody has that opportunity.”

Williams developed a deeper appreciation for the realities of SCI/D watching Hahn push himself in rehab. As a professional, he was used to the idea of rehabbing an injury intensely for a set period of time and then returning to the field. What he saw with Hahn was different. “It’s a day-to-day process where you could easily fall into despair,” he says. “If you don’t have that community built up around you, then I think it can be really, really tough for some people.”

Still, the two are confident that MLB players will identify with the struggle and are working to grow the nonprofit. They held their second annual Dingers in the Desert fundraiser this winter and are working with MLB teams to host Project 34 days in stadiums across the country.

“Raising money is one thing,” says Williams. “People will always give money. But when you get down to the root of it, we created Project 34 to build community. If building community means helping people with rehab costs, great, but what really goes the furthest is telling someone that you love them and that you’re not alone in this. I think that’s what we wanted to create.”

A Bright Future

For now, Hahn is in a waiting pattern like the rest of the world, thanks to COVID-19, but the novel virus won’t dim the exciting prospects he has on the horizon. “I think whatever he decides to do, sky’s the limit — because he’s qualified, and I think he’s talented enough to do so,” says Hall. “If Hahn
wants to switch gears and go down another avenue at any point in the future he can. He could be a broadcaster — he's got the voice, he's got the looks. Or he could be a coach — he knows the game so well. But I think he's enjoying the scouting right now.”

Hahn has a long list of both personal and professional goals that he intends to keep checking off, and he makes no bones about his dream job. “My ultimate goal is to eventually find myself as a general manager of an organization,” he says. “I know that in order to get there, I have to dominate the job I’m in now, and then dominate the next job, and dominate the job after that.”

He’ll continue to work toward that end a day at a time, but that hasn’t kept him from discussing the general manager possibility with Williams. “We give each other a hard time because he’s got the front office vibe, but he’s promised me as soon as he’s a GM that I’m going to be his first transaction, either with a trade or a free agent signing or, really, anything,” says Williams.

Williams joked that Hahn promised he wouldn’t let Williams’ medical history hold up any deal, but turned serious when the conversation came back to his friend’s prospects. “The way he’s going about his professional career now with the Diamondbacks, there’s no doubt that he’s going to be a general manager someday. I believe that,” he says.

Hahn can’t wait. “Despite the challenges, I’ve been given this incredible opportunity to keep baseball in my life, and I wouldn’t want it any other way,” he says.

CORY’S TOP THREE STADIUMS FOR WHEELCHAIR ACCESS

1. Chase Field, Phoenix: I’m a little biased there, but it really is great for access.
2. Nationals Stadium, Washington, D.C.: They’ve done a great job with accessibility at a lot of the newer stadiums and that’s one of my favorites.
3. Petco Park, San Diego: Incredible ... probably the best scouting view for me that I can get from the big league fields.
Gear Up For The BEACH

BY JESSICA FARTHING

Freedom Chair by GRIT
Slick Skis

Andrew Hippert, a C6-7 quad, founded the online healthcare store LivingSpinal.com to help his fellow wheelchair users find logical solutions to wheeling problems. He and his crew tackled the difficulty of pushing through sand and developed Slick Skis, a caster attachment, as an affordable option.

“The Slick Skis make both sand and snow so much easier to navigate by allowing your front caster wheels to sit on top of the surface and glide with ease,” says Hippert. You install these lightweight, plastic paddles by sliding your casters into brackets and then pulling the straps tight to lock them into place. Now, instead of dragging and becoming buried, the front of your chair floats on top of the sand. Also, Slick Skis help to protect your bearings from becoming packed with sand and snow. “This is a big concern when you put your chair in that kind of environment,” he says.

The Slick Skis work best with a companion product, the all-terrain Sumo Beach and Snow Wheels, which are manufactured by Box Wheelchairs for Living Spinal. The 4½-inch-wide tires work with chairs that have a 2-inch axle sleeve, and there are optional super-grip vinyl push rim covers for an easier trip across the sand.

Box Wheelchairs also uses its tires on its own beach wheelchairs. Slick Skis are $149 per pair, and Sumo Beach Wheels are $1,399.

Beach Trax

Access Trax co-founders Kelly Twichel and Eric Packard were tasked in their graduate school occupational therapy class with creating a product to improve the everyday lives of their clients. They invented Beach Trax, which are portable, lightweight panels that easily attach to each other to form a stable path on uneven terrain. Because the 3-by-3-feet, 5-pound squares allow for customizable configurations, they are often used by adapted sports organizations and event planners, as well as individual wheelchair users.

Twitchel says the portability of the product is ideal for travelers who plan to visit a beach. “You can check it as luggage on an airplane because it’s assistive technology, which is typically free. With panels and a carrying strap, we duct-tape the open end and don’t even use a bag,” she says. “Travelers can rely on it and feel empowered. They don’t have to ask around or be limited to one small spot with an existing mat. They can go where they want to go.”

Dave Foster traveled with five panels of Beach Trax checked as luggage to Costa Rica last November. “They happily checked it all the way from the San Diego check-in counter, free, as an accessibility aid to Liberia, Costa Rica,” he says.

With help from his daughter, who moved the panels as needed, Foster was able to enjoy the beautiful water at Carrillo Beach. “It’s a wonderful innovation for mobility,” he says.
Beach Trax cost $68 per panel and the carrying strap is $29.99. The company now offers panel rentals for events where organizers don’t want to commit to a purchase.

**Freedom Chair by GRIT**

There are over 200 Spartan obstacle races that take place in 42 countries, and the makers of the Freedom Chair partnered with Spartan to become the official equipment of its Para Spartan Race division. The first Para Spartan Elite Heat took place two years ago in Laughlin, Nevada, where the terrain includes deep desert sand, and the Freedom Chair was put to the test. “The chair performed really well in the toughest of scenarios,” says Alex Guarco, GRIT’s operations manager.

Tyler Rich has raced about 15 Spartans in his Freedom, but values the chair for its other all-terrain capabilities as well. “I’ve used my Freedom Chair on the beach a handful of times, though I live in the mountains of Virginia, so my opportunities are somewhat limited,” he says. “I have used it in the desert extensively, and can say with the utmost certainty that it is vastly superior to a conventional manual chair over sand. It still bogs down to a degree, but the additional torque provided by the drivetrain affords the ability to move without assistance, albeit slowly.”

The way the chair works is a bit different. GRIT developed the product with a mountain bike in mind, and it has a patented lever-drive system designed at the renowned Massachusetts Bowel & Bladder Basics are our Business!

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Institute of Technology. There are two handles, pushed by the rider, that are designed to conserve shoulder function and maximize energy for a boost of speed on normal terrain, or to provide more power on challenging surfaces. Equipped with wide mountain bike back wheels and one large, extended front caster, the chair resists sinking in the sand.

Guarco appreciates that the chair is easily transportable. “I have a Toyota Corolla, and it goes in the trunk, no problem,” says Guarco. “There are quick-release axles for the wheels, and the back is also quick release. The front plate slides right off. Everything compacts pretty tightly. That’s one of the problems we were trying to solve when we designed the chair.”

The most popular Freedom Chair model costs $2,995.

**Hippocampe**

The Hippocampe from Vipamat was initially developed so that Patrice Faucogney, a career soldier who became a paraplegic after a snowboarding accident, could independently push himself on beaches and trails in France. Along with a physical therapist and an orthopedic prosthetist, Faucogney designed the self-propellable Hippocampe to be long and sleek like a surfboard.

Bruno Tateossian, managing director for Vipamat in North America, touts the chair’s all-terrain capabilities. “On the beach, you can go right into the water. Someone comfortable enough to get out of it can swim and then get back into it,” he says. “Also, we have a front ski attachment for it to be used on trails, grass and snow. It’s really usable year-round and on all types of terrain. That’s how it’s been designed.”

The Hippocampe’s all-terrain tires have a special outer coating to reduce hand slippage, though a little help from friends might be needed to push the chair in softer sand. The chair comes with colorful blue or pink material that covers metal parts to keep them from becoming hot in the sun, and the foam seat allows for quick drying and no water retention, in case the user decides to swim. For transport purposes, the chair’s backrest folds down, and its wheels and push bar are removable. The Hippocampe weighs around 37 pounds and costs $3,379. It is offered in four sizes based on the user’s height.

**Resources**

- Hippocampe, vipamat.us/hippocampe-beach-and-all-terrain.php
- Beach Trax, accessstraxsd.com
- Freedom Chair, gogrit.us
- Slick Skis, livingspinal.com/active-mobility/slick-skins-the-affordable-caster-attachment-for-snow-and-sand

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This May, Richard Corbett will find out if his YouTube channel, Wheels2Walking, has won the Shorty Award for the top Health and Wellness influencer of 2019. Unfamiliar with the Shorty Awards? Corbett will likely forgive you. Until recently, Corbett, 31, an incomplete L2 paraplegic, wouldn’t have known the Shorty is the most prominent award for annual social media and digital achievements either. Less than three years ago, he didn’t have a single social media account. In fact, he didn’t want to exist online in any capacity — he wanted to be invisible.

With only one barely-used Facebook account between them, Cole Sydnor and Charisma Jamison were basically invisible on social media when they created a YouTube channel two and a half years ago. Today their channel has over 230,000 subscribers and millions of combined views, but back then they simply aspired to educate friends and family about the ins and outs of Sydnor’s life as a C5-6 quadriplegic.

Shane Burcaw, 27, started blogging on a lark, looking to share his humorous take on living with spinal muscular atrophy. He hoped his honest prose would launch him into a career as a writer — four books later, it’s safe to say it has — but he likely never could have imagined it would also lead him to his future wife or that the two of them would be nominated for the 2020 Shorty Award “Best YouTube Ensemble.”

Together, these three stories provide insight into the unique and unpredictable ways our community is embracing social media to entertain, educate and, yes, pay the bills. Beyond the fake news, targeted advertising and questionable tracking, social media has shown a genuine ability to unite by allowing people to share and discuss questions, issues and their daily lives. You’d be hard pressed to find a community that has benefitted from this more than ours.

If you were injured 20 years ago and wanted to see what other people with similar injuries were up to, or how someone with a similar disability did something, your main options were New Mobility and Rutgers’ Care-Cure forum. Today, a quick search of YouTube returns hundreds, if not thousands, of videos, ranging from homemade to professional, documenting every which way to do pretty much anything with a disability.

Whether it’s Corbett’s in-your-face approach, Sydnor and Jamison’s personal appeal or Burcaw’s humor and wit, each of these content creators has figured out how to increase awareness and elevate conversations around disability in ways they find rewarding and fun to create.
Richard Corbett runs Wheels2Walking.
The seven years between Corbett’s injury in 2010 and when he joined social media were a bit of a roller coaster. “I had a number of things I was really ashamed of, having a spinal cord injury being one of them,” he says. “I went through a really tough addiction to opiates. I didn’t want anyone to know me online, I wanted to be a ghost.”

That began to change in 2017 when his nephew came to visit for a couple of weeks. The two of them made a few videos about their adventures to show his mom what they were up to. Corbett posted the videos online and came away with an unexpected response. “It was fun,” he says. “After my nephew left, I stayed on. I got addicted to the scroll and enjoyed looking around at what people were doing. At that time, I only had Instagram, but I started filming myself doing workout videos.”

Initially, Corbett kept his wheelchair out of the videos and held back on sharing his personal story. “It was a good ego pump,” Corbett says. Between jobs, Corbett had been looking for a creative endeavor he could take charge of. A production artist by trade, he quickly picked up video editing by watching other professional video makers that didn’t have disabilities. “At first, I wasn’t sure what story to tell, so I just started filming everything that I did differently because of the disability,” he says. “So, anything from going to concerts to grocery shopping. Just the basics.” The response shocked him. “Even early on, my videos got a few thousand views. People with and without disabilities were saying how helpful it was and that they were cool to watch. I just thought, ‘This is wild and unexpected!’”

The surprising response and the accompanying circumstances led Corbett to a decision he could not have imagined just months earlier. “I wasn’t busy and feeling bored creatively, so I figured, let me try doing this for real,” he says.

For Corbett, doing things “for real” meant looking at the project like a startup, and understanding that the business and marketing elements were as important as the video production. “I contacted a friend of mine who helps people set up the backend of things — the website, the email list, photography and branding for Wheels2Walking to make it a full thing,” he explains.

As much as he enjoyed the buildup, Corbett found himself overwhelmed and frustrated with the realities of how long quality video production took on his own. He set out to find someone to help shoot and edit the kind of videos he needed when he was first injured: “Real nitty-gritty and descriptive stuff to explain the gravity of decisions and consequences in a way that is usable with resources and suggestions to help alleviate the kind of struggles I had to learn the hard way,” he says.

A Story Worth Sharing

Where to Watch and Follow
Richard Corbett
YouTube: Wheels2Walking
Sample YouTube Video: How to Fly Independently in a Wheelchair, youtu.be/PasQHVplqs0
Facebook: /Wheels2Walking
IG: @Wheels2Walking
Website: Wheels2Walking.com
Podcast Link: Wheels2Walking.com/podcast
Patreon: /Wheels2Walking

On his social media, Corbett strives to share information he wishes he’d had when he was first injured.
Corbett found the perfect person to help him realize that vision in Andrew Deitsch. The two met when Corbett was a guest on Deitsch’s podcast. “It was during that first interview I had with Andrew that I opened up publicly about my disability, my past, my addiction,” he says. “It’s a story I hadn’t told before, and it was a huge step for me. All of a sudden, I felt like, ‘I do have a unique angle to share with the world and now I have a way to do it that people seem to dig.’”

“I wanted Andrew to come on as my Wheels2Walking partner because he’s talented and helped me find my inspiration. I knew he wanted a podcast studio, and I had an extra room, so our collaboration started basically as a bribe,” adds Corbett with a chuckle.

The two have now committed the bulk of their professional lives to the project. Beyond their successful YouTube channel, they have a Wheels2Walking podcast that they live stream on video, as well as a number of popular social media accounts. From the start, the two pooled their knowledge and educated themselves on social media best practices, and these decisions were validated by the rapid growth of viewers and subscribers. “We thought about hashtags and best ways of cross promoting. Something from YouTube would go viral on Facebook weeks later, and people would come over to Instagram,” says Corbett. “Suddenly, we had videos getting 1.7 million views.”

**Turning Love into Likes**

Sydnor and Jamison didn’t care much about online visibility when the two began noticing one another across the rehab gym where she worked and he worked out. Despite some subtly flirtatious moments between reps, it was a mutual follow on their seldom used individual Instagram accounts and some strategic photo “likes” that prompted Sydnor to, as he puts it, “Slide into Charisma’s DMs [direct messages].” So technically, the pair didn’t meet on the Internet. But online is where they found a way to connect, not only with each other, but with fans from across the world who have enjoyed the intimate and educational Roll With Cole and Charisma social media content they produce about living as a couple affected by spinal cord injury.

Less than a year into their relationship, Jamison suggested that she and Sydnor start a collaborative YouTube channel. “I brought up the idea of starting a vlog one day randomly in the car, and really, I think he kind of just said yes to make me happy,” says Jamison of the man who is now her fiancé. “The reason it crossed my mind was because people kept asking me, ‘How does your relationship work?’”

“It made me think. I hadn’t really been able to look up much to answer some of the questions my friends and family were asking me now about spinal cord injury for myself initially, either. There is a lot of curiosity around what it’s like to have a disability and to be in an intimate relationship with someone who has an ability that is different than I do.”

**The Troll Toll**

The level of entrepreneurial hustle needed to sustain social media is not the only downside of being visible. As anyone who has been on the Internet knows, negative backlash lurks within every active comment section. People with disabilities can be targets for ableist vitriol or hateful words from an angry keyboard bully.

Shane Burcaw and Hannah Aylward have learned to twist the negative comments their Squirmy and Grubs content generates to their advantage. “We get hundreds of rude and hateful comments every single day that we try our best to ignore, but it’s hard. Over time, it’s just become motivation. Clearly, there is still a lot of ignorance about disability and relationships out there, so we use the comments as fuel to remind us to keep sharing our story and change the narrative on uninfomed ideas,” shares Aylward.

As a part-time crutch user, and low-level para, Wheels2Walking creator Richard Corbett notices the negativity he gets comes from a crowd that may surprise some: other wheelchair users. “I get a lot of hate,” he says. “Often, it comes from other chair users who have different mobility than I do. Half of that I like, because it’s criticism that I can use and learn from about things I may be getting wrong, but the other half of the hate is just hate.”

As someone giving information and opinions from his perspective about sometimes controversial disability related subjects, Corbett finds accolades and a generally supportive tone from his nondisabled audience, but gets a mixed bag of fans and flak from other people with disabilities — wheelchair users specifically. “Half of them are all in, but the other half loves to loathe me. I get called lazy because I’m semi-ambulatory, but use my wheelchair a lot,” he explains. “Or, I get called the fake and not even paralyzed. People get hypercritical of my abilities.”

“I kind of like that people talk trash because it sparks a conversation. Sometimes I reply, and other times I don’t. You can’t feed the trolls. The cool part is, my community often steps up and goes to battle for me. I like that because, you know, maybe they were me five years ago. I can’t be mad because I was upset and lashing out at one point in my life.”

Cole Sydnor, 24, and Charisma Jamison, 26, are the creators of Roll With Cole and face an additional type of negativity: racism. “We didn’t expect that one, since it’s not anything we have ever faced in our day-to-day with being an interracial couple, but it’s been bad,” says Sydnor.

So bad, in fact, that the couple were forced to block certain ugly racial phrases and words so that they were no longer visible to them or anyone else. “That helped a lot, but before it was easy for us to get down from a comment. Feeling hurt gave us opportunities to confide in each other and confront things that may not have been said otherwise. We’ve been able to reinforce that no one knows us better than we know ourselves,” says Jamison.

“It’s been a weird realization about the racial tension in the nation,” says Sydnor. “I think a lot of times when people see our channel, they don’t even notice the wheelchair, because they can’t see past the fact that we have two different skin tones. I like to think when they do, they see that interracial or inter-abled, it doesn’t need to be a big deal.”
about how Cole does certain things and what is possible for us as a couple. So, it started out as a way to answer and educate by showing people we knew some perspective on our life together.”

Friends and family grew to a few hundred people, then to a following that blew up to thousands over a relatively short amount of time. “We continued, because we felt like it was helping people realize something important,” says Sydnor. “People valued us sharing about the activities we did and how we can travel. We were having fun working together as a team, and it challenged us in a way that felt rewarding and adventurous.”

What started off as a hobby and a fun project began to evolve after they posted a video that showed Sydnor walking in an exoskeleton. Allowing their audience an eye-level view of their first standing hug paid off. The view count shot up to 10,000 views, and then more than 100,000, within a couple of days. “It was wild, but it felt good and brought in a ton of subscribers. We actually hit the thresholds enough at that point to monetize our channel,” says Jamison.

As the channel’s viewership grew, so did the team’s commitment. “It made us start putting more time into things,” says Sydnor. “We started planning so that we could elevate our idea development and execution to take our education potential to the next level. We reinvested with better equipment and time spent editing. I think that has helped to bring in more people, because they know we’ve taken our time. In return, they invest their time and stick with us as engaged fans.”

When Burcaw started his blog nine years ago, he hoped some of his ridiculous stories and vignettes about life with spinal muscular atrophy might resonate with others, and even early on, it was clear they did. He quickly built a large, growing fanbase and attracted literary agents and publishers. Among those fans was Hannah Aylward, 24, a self-professed introvert and social media neophyte.

Long before anyone knew her as Squirmy — a nickname Burcaw would later give her for her restless sleeping style — in 2016 she sent him a late-night email with the telling final words: “P.S I think you’re cute.” Thus began a year-long internet romance that led to the two moving in together and her dubbing him Grubs because of his sweaty hands. They

Engaged and Engaging

Charisma and Cole

share their romance with their viewers.

Where to Watch and Follow

Cole and Charisma

YouTube: Roll with Cole and Charisma
Sample Video: Quadriplegic’s Night Routine, youtu.be/heocaJ_GV7E
Facebook: @rollwithcoleandcharisma
IG: @roll.with.cole
Patreon: /user?u=13109819
introduced the public to Squirmy and Grubs in 2018 by rolling out their branded YouTube and Instagram accounts.

Today, the future husband and wife reach a growing community of fans together, casually engaging viewers with their easy chemistry, abundant smiles and a shared plucky sense of humor. With charm and wit, the pair finds creative ways to inform strangers about subjects that run the gamut from intimate facts about Burcaw’s condition, to revelations about the frequent insensitivities the couple encounters from strangers, to simple posts about what made them smile that week. “The biggest driving force in our work is a desire to correct the damaging misconceptions that exist about disability. The size of our platform places us in a position to influence the way society thinks,” says Burcaw. “Beyond our message and purpose, we get to film our adventures every day and call it a career. Plus, making our videos is also just a lot of fun.”

Both Burcaw and Aylward feel humbled by their fans’ support and the increased credibility it has given them to speak up about accessibility and inclusion. The couple has enjoyed numerous opportunities to travel and speak about their work and disability. In 2019, a production team from the Today Show flew out to Minneapolis and filmed them for a day, allowing them to share their story with a nationwide network TV audience.

**Return on Investment**

Thanks to their 550,000-plus subscribers on YouTube, Burcaw and Aylward are drawing a steady income from YouTube AdSense. Still, it’s not something they feel comfortable enough with to rely on as a forever plan. They also receive income from other sources, including Patreon, a membership platform where subscribers can directly support creators financially, often in return for unique benefits. “Diversifying our income has been super important, so that if AdSense revenues are low one month, we have speaking engagements, brand deals, Patreon and book royalties to rely on,” says Burcaw.

YouTube AdSense has been a strong revenue source for Sydnor and Jamison, but they feel the fluctuations and know that the money is not guaranteed. “On strong months, we start thinking, ‘Oh my gosh, we’d be able to buy a 2000 square foot home!’” says Jamison. “But then, the next month, the money is not there and we go stock up on ramen.”

Sponsorships have helped even out the couple’s income, but they are selective about with whom they partner. “We try to focus on sponsorships that align with what we are actually able to use and that benefit us uniquely as an inter-abled couple,” says Sydnor. “If it helps improve a quad or caregiver’s life and makes sense from all sides, we feel good about promoting something to our viewers.”

With a wedding later this year and a desire to grow their impact through freelance and other projects beyond YouTube, the couple feels the heat. Luckily, they like a good challenge. They are thrilled with cool gigs that have stemmed from their social media presence, like a TedX talk they did this fall and a current collaboration where they are helping produce content with a local hospital.

Corbett and Deitsch are also relying on AdSense and Patreon, and also looking to expand with partnerships that align with their core values. They are still in the red in regards to Wheels2Walking, but Corbett sees gains and is comfortable
with the deficit. “That’s how startups usually work,” he says. “You gotta put in a huge chunk in the beginning and work, work, work for a couple of years until you are profitable.”

A Full-Time Job
Making a living by posting videos of your daily life may seem like a dream job, or at least a fun endeavor, and while everyone in this story makes a point of saying they are enjoying the pursuit, they were all adamant about the same thing: it’s no cakewalk. “We love having a channel, but it does take up a significant amount of our time,” says Burcaw.

Aylward explains, “I think our biggest low is just the overall struggle to constantly create. Having a YouTube channel is like an exciting dream 95% of the time, but there’s a very real mental and emotional side effect that comes with sharing our life so much.”

Managing social media and writing projects is a full-time job for the couple. They aim to upload one video every other day, which requires at least three to four hours filming or editing. Beyond that, around five hours per day is spent answering emails for backend planning from potential partners and engagement clients. The growth of their following has corresponded with a growing number of invites to events and appearances. “We can get worn out,” says Burcaw. “There are times when we just don’t feel like having the camera pointed at us, but you have to push through those moments to be successful.”

Learning to push through the grind is something Sydnor and Jamison can identify with. “Creating content that reaches and helps others’s understanding has been a fulfilling privilege, but it’s definitely a full-time thing for us now,” says Jamison.

Early on, Sydnor and Jamison hadn’t nailed down set hours, so they ended up working every day of the week and sometimes staying up till 2 a.m. to complete a project. “It wasn’t really healthy for us or our creativity, so we now force ourselves to work only from 10 a.m. to 6 p.m. Monday through Friday,” notes Sydnor. He now does the edits on Tuesdays and Thursdays only, is enjoying it more, and has realized he has a knack for it.

Corbett and Deitsch have also discovered the benefits of a regimented schedule. As things stand, the team has designated shoot days, podcast days and regular planning meetings. Working more than full-time on things, Corbett

ARE YOU ELIGIBLE FOR AN ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) SAVINGS ACCOUNT?

If your disability occurred before your 26th birthday, you may be eligible to open a tax-exempt savings account that won’t affect your eligibility for federally-funded benefits such as Medicaid and SSI.

Funds saved in an ABLE account can be spent on qualified disability expenses such as housing, transportation, personal support services, assistive technology, education, health care, and employment training and support.

To learn more about how to open an ABLE account, visit ablenrc.org/get-started.

Where to Watch and Follow
Hannah Aylward and Shane Burcaw
YouTube: Squirmy and Grubs
Sample Video: Why We Turned Down Dr. Phil, youtu.be/prjdlTVT5uk
IG: @shaneburcaw and @hannahayl
Website: laughingatmynightmare.com
Blog: laughingatmynightmare.tumblr.com/
Patreon: /squirmyandgrubs
finishes up at the gym around 11 a.m.,
gets to business soon after, and works
until 8 or 9 p.m. On Fridays, he makes
a point to end the day by 6 p.m. and to
spend the weekend with his girlfriend,
unplugged from social media and his
work altogether as much as possible.

As the editor and behind-the-scenes
guy, Deitsch does a lot of the time-
intensive heavy lifting, which Corbett
admits is a godsend. "It’s sick what he
does, and so crazy good because he’s in
it for the equity too. We both know that
we are building something for a legacy
that will pay off for both of us in the fu-
ture,” says Corbett.

#WhatsNext

For Corbett, the future is in commu-
nity. "I want to change the dialogue,
and I can use the platform of Wheels-
2Walking to better unite people with
disabilities and work around some of
the dead-end quarreling amongst our-
selves just because we are all different," he says. "I’d like to be a voice that helps
rally people and says, ‘Hey, wait, let’s
talk about some things we have in com-
mon and unify on some of the big is-
sues and make some improvements in
things like accessibility, healthcare and
getting the equipment we need.’"

He and Deitsch are excited about
expanding their offerings and trying
new things in their videos. “One of my
favorite things to do is collaborate, so I
want to meet up with others as I trav-
el,” says Corbett. "I love learning new
things about the ways other people with
disabilities live, plus we get to mutually
influence and introduce each other to
our networks.”

Along with planning their wedding
and hanging out with their new pup,
Burcaw and Aylward are looking for-
tward to continuing the growth of their
YouTube channel and their social me-
dia audience. The pair are also hugely
excited to be collaborating on a book,
Burcaw’s fourth published work and
Aylward’s first. “We are interviewing 30
inter-abled couples and profiling their
love stories. It’s a huge project, but we
are honored to be the ones writing it,” says Aylward.

In a similar vein, the future Sydnors
are anticipating an exciting future to-
gether, both personally and profession-
ally. They are looking at expanding be-
yond their social media roots to engage
in more live community engagement.
Having seen the potential impact of their
storytelling, they want to use their skills
to help others share their experiences.
Still, their YouTube fans are huge in their
lives and they will continue to share their
experiences and raise awareness.

As Sydnor explains, "People are cu-
rious about spinal cord injury, relation-
ships, caregiving and unique lives, and
that’s OK. At the core of everything we
do, is love. We want to do anything we
can to support and show someone that
it doesn’t matter what your circum-
stances are, that love is possible. That it
comes in all different forms, and that’s
how it should be. It’s beautiful.”

ABLE ACCOUNTS HELP YOU SAVE
MONEY WITHOUT LOSING BENEFITS.
HOW CAN WE MAKE THEM BETTER?

United Spinal supports the ABLE Age Adjustment Act, which
would expand eligibility for ABLE accounts to allow people
whose disability occurred before their 46th birthday to sign up for
these life-changing savings plans. This would allow another 6 mil-
lion Americans the opportunity to open an ABLE account.

To contact your members of Congress, please visit unitedspinal.
.org/save-the-able-act. To learn more about ABLE accounts, visit
ablerc.org/get-started.
Twelve years ago, I was blessed with a beautiful baby boy. Two and a half years later, my second amazing son came into this world. They were born after my multiple sclerosis diagnosis, but before MS would require me to use a wheelchair. Fast forward to today, and I’m traveling around the world in my power wheelchair, almost always by myself. I’m also a part-time single mom, and now that my sons are 11 and 9, I made the decision that they’re old — and responsible — enough to travel with me.

I was nervous the first time I brought my boys with me on a trip. My mother traveled with us just in case I needed help with anything from pumping gas to child supervision while I used the bathroom. I picked Atlanta for a road trip in June 2018 because we could reach it in a day’s drive from my home near Orlando, and it’s filled with family-friendly and wheelchair-accessible things to do. I had already spent hours planning our activities, and all I had left was to find a hotel room. Little did I know how challenging this would be.

I’ll admit I was being too greedy while searching for an accessible hotel room that would accommodate all four of us. I hoped to minimize the bed-sharing in particular. Since I can’t move my legs or roll over easily, if I’m sharing a bed, I need at least a queen-sized one so I can sleep and move comfortably. And, have you ever tried to put two adolescent boys in a double bed together with the hope of a good night’s sleep for all? Once I shared a king with my 9 year old and had to duct tape a rolled-up mattress cover between the two of us so he’d stop kicking me!

THE QUEST FOR A ROOM THAT WORKS

The odds of snagging an accessible hotel room that can accommodate more than two people are considerably higher in the United States than in other countries. However, those odds are diminished if you need a roll-in shower instead of an accessible tub, since bathrooms with roll-ins often take up more space. This means the bathroom encroaches on the bedroom, which leaves less room for beds.

The Americans with Disabilities Act has rules for how many accessible rooms a hotel must have based on its size, and how many of those rooms must have roll-in showers as opposed to tubs. Additionally, the law requires that accessible rooms be dispersed among various categories (such as standard, deluxe and suite) and that a variety of choices be offered for the size and number of beds. In practice, these requirements are rarely followed. This is why finding an accessible hotel room with a roll-in shower and two queens can be like finding a unicorn. Add a sofa bed to the mix and you just won the lottery.

I sort of won this lottery in Atlanta at a Staybridge Suites by the airport. Our accessible room had two queens and a sofa bed, so my mom and I shared a queen, and my boys each had their own bed. On the downside, the room had a tub instead of a shower, so it was washcloth baths for me for three days. The
room was also ridiculously expensive and located far from the city center.

I didn’t quite win the lottery while planning our next road trip in June 2019. I needed accessible hotel rooms, including one with a roll-in shower, for four people in Tallahassee and Fernandina Beach, Florida. I found such rooms after a considerable amount of searching, but ended up paying over $300 for one night at the Residence Inn in Tallahassee and over $500 for the night in Fernandina Beach. I considered myself lucky that I was able to get these rooms at all, because finding accessible rooms for more than two people in other countries is an absolute nightmare.

In June 2020, I’m taking my boys on an Alaska cruise without any help. We took two cruises and two plane trips in 2019, just the three of us, so I know we’re all ready. The cruise planning was the easy part. The hard part was finding an accessible hotel room in Vancouver for the three of us.

Canada doesn’t have a federal accessibility law like the ADA. Each province has some accessibility provisions, but the rules are not standardized or enforced equally across the country. This means you generally can’t find and book an accessible hotel room online. Instead, you have to call every single hotel you’re interested in. I called one hotel in Vancouver after another, asking the same three questions: Do you have an accessible room with two beds? What size are the beds? Does the room have a roll-in shower?

I called 10 hotels before I found the Fairmont Vancouver, which has the unicorn combination of two queen beds and a roll-in shower. It is also close to the cruise port and centrally located. However, I’m paying $400 a night for that pretty little horse.

Europe is a different animal altogether. Many countries have their stuff together when it comes to accessibility, but because there are few accessibility laws or national standards, you’re never really sure what you’re going to get when you open that hotel room door. Also, European hoteliers are even less likely than their American counterparts to believe wheelchair users travel with their families. Just try finding an accessible room with more than one bed in London (which I’m still trying to do as I type this).

European hotel rooms — especially those in large cities — tend to be smaller than their American equivalents, and European hotels don’t do sofa beds or roll-aways. However, they do have twin beds in their rooms, which sometimes provides options for families of three. But if you’re looking for two queens in a European accessible hotel room, especially one that also has a roll-in shower, you’re going to need help from the CIA, the FBI, the Navy SEALs and possibly NASA.

These are just some of the issues I’ve come across, and I only have a family of three, two of whom are strong, nondisabled adolescents. There are plenty of other families with at least one member in a wheelchair with travel challenges much greater than mine.

**DUPED AND DISPLACED**

Jeana Berron of St. Charles, Missouri, has a family of five, including her 18-year-old son, Joe, who uses a wheelchair. She described a trip to Scottsdale, Arizona, over an Easter weekend where her family had to book two separate hotel rooms, one accessible and one standard, to accommodate everyone. “While the JW Marriott couldn’t guarantee the rooms would be next to each other, we were assured that they would be close together,” she said. “When we arrived, the only rooms they had were in separate buildings.” Berron explained that the hotel is a large resort made up of several separate buildings scattered across the property, and it was a five-minute walk between rooms.

“The trip involved my husband and two sons. I stayed with Joe in one room, and my husband and other son stayed in the other room,” said Berron. “This made it very difficult for my husband to help with Joe. It was as if we were on separate vacations.” The accessible room was also very inconvenient at the back of the resort, at the farthest point from the restaurants and lobby. “Because of this, we were unable to take advantage of the resort the way we had planned,” she said.

Another huge source of frustration for families is checking into a hotel and finding out that their room isn’t what they paid for. Jenny Smolinski of Clawson, Michigan, and her husband have two adolescent daughters. Twice in the past six months, she reserved accessible hotel rooms with a king and sofa bed — or so she thought.

“There were no other room configurations with roll in showers, but that setup would have worked fine for us since my kids are still young,” said Smolinski, who has ALS. “Both times, upon check-in, we discovered there was no sofa bed — only a chair.”

In clear violation of the ADA, neither hotel did anything to accommodate her family. They offered to allow the Smolinskis to pay out of pocket for an additional room, since the properties were not full. But an appropriate ADA accommodation would have been to let them have an additional room for free.

“The first time my husband had to
sleep on the floor, and my daughters and I slept together in the king bed,” said Smolinkski. “Most recently, my daughters slept on the floor.”

GETTING IT RIGHT

There are some hotel chains and companies that get it right, and it should come as no surprise that theme parks are leading the way. For example, Walt Disney World has several resort hotels with accessible rooms that can accommodate more than four people. A quick search using my Disney travel agent reservation portal showed an accessible room at the Caribbean Beach Resort with two queen beds, a child-size pull-down bed, and a roll-in shower. The Fort Wilderness resort has accessible cabins that can accommodate six people with a double sofa, a queen and two bunkbeds. Another resort chain that gets it right is Great Wolf Lodge. I have visited one in North Carolina and one in Georgia, and both experiences were amazing. In both cases, I was traveling with my mother and my two sons. In North Carolina, we had an accessible junior suite with a queen, a double sofa and two bunkbeds. In Georgia, we had an accessible junior suite with a queen, two bunkbeds and an additional twin.

I’ve also had luck with some non-resort hotel chains. The Residence Inn brand is a subsidiary of Marriott, and it caters to families and long-term stays. Often the suites have separate living and eating areas, along with small kitchens. In many locations, the chain offers rooms with two queens and a double sofa bed, often in separate bedrooms. Its larger rooms also have two bathrooms — one accessible and one standard.

While it’s good to know that there are some accommodations out there for larger families with wheelchair users (at least, in the U.S.), the news isn’t all sunshine and roses. Most of these rooms tend to be much more expensive than standard rooms, even though they lodge fewer people. Some would say that’s fair, as we need more rooms in order for our whole families to be accommodated. But the ADA says that we are entitled to pay exactly the same price for an accessible accommodation as a standard room in the exact same category. Unfortunately, it’s up to us to make sure hotels are abiding by the law.

A WAY FORWARD

I’m not one to complain about something without having solutions in mind. So, what suggestions can we offer hotel chains to better cater to families with wheelchair users? For starters, I find it curious that American hotel rooms don’t utilize twin beds arranged to form a king bed. This configuration is common in Europe, and it’s very easy to separate the larger bed into two smaller ones. The American answer seems to be the sofa bed, which, conversely, is not a “thing” in Europe.

While sofa beds offer additional sleeping space, they’re not common in accessible rooms outside of those found in long-term suite hotels like Residence Inns or Staybridge Suites. They’re also uncomfortable and not fun for two people to share since they’re usually the size of a double mattress. Because hotels aren’t required to offer rollaway beds, many don’t. I would be very uncomfortable booking a room for my family without guaranteed sleeping space. Offering rooms with an additional twin bed might help.

There also seems to be a lack of accessible hotel rooms with two queens and a roll-in shower. They do exist, but usually accessible rooms with two beds either have queens and a tub, or doubles and a roll-in. I’m sure this is partly because of construction and size limits, especially in buildings that were retroactively modified to comply with the ADA. But the forced choice between sleeping comfortably or bathing safely is very unfortunate.

While some wheelchair-accessible hotel rooms connect to standard rooms, there should be more that do so. It’s definitely pricier to book two rooms instead of shoehorning your whole family into one, and if you reserve an extra as a last resort, you want to at least be in a connected space with your family members.

Before we can even start battling hotel chains to make their accessible accommodations more family-friendly, we have to fight the societal notion that wheelchair users don’t have families. It’s incredibly disheartening to be separated from your family members during a vacation simply because you couldn’t find a place that let you sleep close to each other. It’s heartbreaking to get the message that you’re not welcome at a destination because there’s no place for you and your two children to sleep comfortably.

To all hotel owners, managers, franchisers and franchisees, allow me to introduce myself. I am a wheelchair user, I have a family and we travel together. Our money looks and spends the same as that of so-called “standard” families. We enjoy vacations and leisure time spent together, just like anyone else. Please work harder to help make this happen — for us and for millions of families with wheelchair users around the world.
2000: What’s next for the ADA? If I were a betting fool, I’d bet the ADA will be found to be constitutional — for “the disabled.” Its integration mandate will also endure and slowly dismantle institutions, forcing states to quit putting people in nursing homes solely because they need personal assistance. The access requirements will remain largely untouched, too; eventually both stadium architects and mom-and-pop contractors will wake up, and new construction — including websites — will be accessible the first time out. But existing structures will rarely be changed without a fight.

— Mary Johnson, June 2000 issue

2003: I had discovered the cost of activism, the paradox. Those of us who call attention to our disabilities in order to publicize the needs of the group to which we belong must pay a price. In seeking societal independence and freedom from restrictive stereotyping, we unavoidably sacrifice personal independence and individuality. The more we seek to break free from an outdated stereotype, the wider the stereotypical net stretches. At first we were seen as meek, polite, unfortunate cripples seeking what was rightfully ours. After activism became radicalized, the stereotype grew to include pushy, rude, ungrateful cripples demanding more than they were entitled to. It seems we are either one or the other.

— Tim Gilmer, September 2003 issue

2010: Having that sense of [disability] identity leads into a sense of community. And then, with a sense of community, we tend to get more collective action. Within the broader culture, disability is still perceived as a negative, but there are a lot of cracks being made in that perception.

— Mark Johnson, director of advocacy at Shepherd Center

2007: Carrie Ann Lucas wasn’t looking to sue Kmart. She simply wanted to shop there but couldn’t do so without running into accessibility hassles such as blocked aisles, tightly spaced clothing racks, seldom opened accessible checkout aisles, inaccessible restrooms, fitting rooms and parking lots.

Lucas, a chair user due to congenital myopathy, spent years going to the store managers to point out the accessibility problems and how they violated the law. When she’d return to the same store a few weeks...
later, she’d find the same problem still there. She filed numerous letters with the Department of Justice, but Kmart repeatedly claimed all the problems had been fixed. She even requested mediation, but Kmart said no.

Most of us would have bailed at this point, perhaps not so silently kvetching that we’d take our business elsewhere. We’d feel like victims, businesses would continue to break the law and nothing would change. But Carrie Lucas isn’t most people, and rather than give up, she sought help and began a crusade. In the end, she prevailed and won a victory for all of us.

The settlement agreement, which United States District

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**2000-2001: ADA LAWSUITS WE LOVED**

**A VALENTINE’S DAY MASSACRE**
This year, [Valentine’s Day] will be wonderful. I’ve ordered roses from the same florist that sent me away last year. I’ve ordered champagne from the same store that charged me for breaking the bottle I couldn’t reach. I’ve made reservations at the same restaurant that charged me gourmet prices for take-out. But I tell you, this year will be different.

The florist settled my ADA lawsuit against them and has built a ramp. The wine store settled my ADA lawsuit against them and has a written policy mandating assistance to people with disabilities. The restaurant settled my ADA lawsuit against them and has a fully accessible front entrance. I won’t even need help to use their restroom.

Two months and a few unsuccessful matches later, when I show up at the bottom of the stairs, I’m met by the same guards who’ve been lugging me up and down, but something has changed. I see it in their faces. “We just got word,” says the leader, “that the market owners won’t let us do this anymore.” I’m not surprised. Up to this point I’ve been relying on their casual goodwill, but all along I’ve felt that fear of injury or lawsuit could put an end to the whole arrangement. This means shifting gears. I’ll have to propose other ways of keeping my face in Matchmaker’s files.

But McLane doesn’t see it that way. With no more than a blunt note she returns my check and informs me I can no longer be her client. I’m not one to be put off so easily, so I email her different options — accommodations — for dealing with the problem.

None of my suggestions seem unusually demanding or inappropriate according to ADA guidelines, but McLane ignores them. I send her a second email, which she also ignores. For the second time she says, “there’s no feasible solution” to the problem. Now I’m getting pissed.

**ENTER ATTORNEYS**
The negotiations become a show of anger and bullying for McLane’s consigliere-style attorney. But the court negotiator is not fooled by his antics. He orders McLane to pay all of my legal fees and expenses, the full refund of my original Matchmaker membership, and a negotiated amount for causing “emotional distress.”

In truth it’s a modest settlement, much less than I’ve asked for, but this is not about employee discrimination for wrongful termination. We’re talking dating. The Matchmaker’s penalties are certainly no threat to her thriving business — in the low five figures. I am still merely an annoyance who will now finally go away. As for myself, the satisfaction of a legal victory, not to mention modest compensation, feels good. I didn’t find what I was looking for from Matchmaker, but I found something of equal value: a greater sense of who I am, of what I represent, and of my valid place in the world.

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**DATING SERVICES — ADA COMPLIANT?**
Matchmaker in the Market is located up two long flights of hard-tiled stairs in a 100-year-old building with no elevators. The business requires clients to visit its office to fill out questionnaires, conduct video-taped interviews, and scope out the files and videos of other clients who’ve been chosen as potential matches. I suppose the Matchmaker — a woman in her 60s named Noel McLane — fancies herself a modern yenta of sorts, using computer files and her own intuition to pair off her clients.

Two months and a few unsuccessful matches later, when I show up at the bottom of the stairs, I’m met by the same guards who’ve been lugging me up and down, but something has changed. I see it in their faces. “We just got word,” says the leader, “that the market owners won’t let us do this anymore.” I’m not surprised. Up to this point I’ve been relying on their casual goodwill, but all along I’ve felt that fear of injury or lawsuit could put an end to the whole arrangement. This means shifting gears. I’ll have to propose other ways of keeping my face in Matchmaker’s files.

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**JEFF SHANNON, MAY 2001 ISSUE**
Judge John Kane termed the "gold standard" for disability access class actions, ensures sweeping accessibility improvements at more than 1,400 Kmart stores nationwide, along with damages totaling $13 million dollars, four times as much as the next largest disability access class action suit.

More important, the settlement provides a template for taking on an entire store chain, and a model of what compliance can and should look like — for the courts as well as other chains. If Kmart, one of the least prosperous outfits in the country — and just emerging from bankruptcy — can find a way, surely more upscale and affluent retail chains can also be compelled to do so.

What began with one person’s struggle to improve wheelchair access in an inner-city discount department store turned into a seven-and-a-half year saga resulting in the largest and most far-reaching accessibility settlement ever. If you’ve seen some changes at your local Target, Sears or other chain outlet, just remember, one person — Carrie Lucas — got the ball rolling.

— Richard Holicky, November 2007 issue

2010:

I can still remember when discrimination based solely on disability was as socially acceptable as the attitudes toward blacks in the era of early civil rights. The ADA gave us a voice and brought to our culture a new level of activism that, until then, nobody had been able to imagine. The ADA cemented the permanent foundation of our disability rights movement.

We all know the ADA was no perfect child. She had to be taught and cared for, nurtured and allowed to grow. We were first-time parents who rejoiced at the birth of this promise of equality, this promise of hope, this promise of independence and access for all.

— Maria R. Palacios, July 2010 issue

Want more? See “ADA: A People’s History” by Josie Byzek, at newmobility.com/2015/07/ada-a-peoples-history

2005: THE VIEW FROM THREE GENERATIONS

My husband, George, and I got our first van in 1977. We called it our Independence Van and we had a little camper potty put in because every place we went we couldn’t use the bathrooms. [When the ADA passed] it was very crude at first. You never knew what was accessible and what wasn’t right after the ADA was passed. Businesses were slow getting accessible and we’re still working on that. But now because of the ADA I can go to restaurants, go to a motel and sleep over or whatever I want to do. And I don’t have a potty in my van anymore.

— Mary Ann Beckley, 68 at the time, Harrisburg, Pennsylvania

“Here you go,” says the waitress, a slender woman in her late 30s, placing my coffee and croissant to the right of my computer. “Can I help you with anything else?”

“Actually, it’ll be great if you’ll please set my coffee over to my left,” I say, needing the mug placed to the side where I can most readily lean.

“Sure thing,” she says, moving my coffee, intuitively opening a straw, placing it in the mug, then readjusting it toward me. “Give me a holler if you need anything else.”

The waitress’ gracious, helpful nature impresses me. Public acceptance of my disability still feels new. It seems like it wasn’t more than several years ago when few places were welcoming and accessible to those with disabilities. …

Yet, as time passed, I noticed fewer and fewer inaccessible establishments, a subtle but meaningful movement toward equal access. And here I sit today, almost 15 years after the passing of the ADA, living in an era where there are not only ramps, but also cultural and legal assurances that equality now starts at whatever doors I approach.

— Mark E. Smith, 34 at the time, Philadelphia, Pennsylvania

The Americans with Disabilities Act passed shortly before I was born. I guess we are maturing at the same pace. There is still a lot of learning and change to occur before it is fully grown and acknowledged. Individuals with disabilities need to be the enforcement agency and power behind this law. Starting from an early age, I learned that there were some places and experiences I could not fully participate in. …

I recently asked my friends what they thought about inclusion. Most didn’t know what I was talking about. They were surprised to learn that my presence in school is not the norm. We go to parties, movies, shopping and use up phone time. I went to a holiday party at a classmate’s home this year. The few students I knew were great at helping me get around the house and dance to the DJ. To them, I am just “Alli,” their friend.

— Allison Cameron Gray, 15 at the time, Southern California
One of SCI research’s biggest and most heated disagreements may be nearing a resolution. At issue is: After a spinal cord injury, what exactly prevents a surviving axon from making its way through the injury site to reconnect with surviving axons on the other side?

Over years of heated debate, two camps have emerged. We’ll call them Team Scar and Team Poison. Team Scar is positive the problem is molecules produced by astrocytes, which are one of the three main kinds of spinal cord cells. Team Scar asserts these molecules form a barrier that is both physical and chemical — a scar.

Team Poison is just as certain that the culprits are different molecules found in myelin, the white coating that serves as a wrapper around healthy axons. Team Poison’s proposition is that these myelin-made molecules are toxic to growing axons.

Both kinds of molecules, those being studied by Scar and Poison, are part of a normal, healthy nervous system and, after injury, one or both of them act to prevent recovery. In my last column (“Three Molecules and a Mom,” January 2020), I told you about a company called NervGen, which was recently formed specifically to deliver a treatment based on the scar theory.

This column is about another company — named ReNetX — also recently formed specifically to deliver a treatment based on the scar theory.

Meet Emily

Because I have trouble sometimes wrapping my head around the long time frames of research, I’m going to introduce a child to help me keep track of the passing years. Let’s call her Emily. In 1988, while Team Poison scientists are beginning their long, frustrating effort to figure out exactly which of the hundreds of protein molecules in myelin are poisoning axons, Emily is born. The scientist leader of Team Poison is in Zurich, Switzerland; his name is Martin Schwab.

In 1994, after six years of effort, the scientists in Schwab’s lab have found nothing. Emily is entering first grade. During that time, other labs have begun to look for the toxic molecule. That year, two of them hit the jackpot. They find a molecule they believe is the culprit, and they name it MAG. At first, the Zurich team panics because they believe they’ve been beaten to the goal. Soon, though, they produce evidence that MAG is not the only poison in the myelin. Sadly for us, there are multiple varieties of toxic molecules in myelin.

By the time Emily enters sixth grade in 2000, another one of those axon-poisoning molecules has finally been identified in Switzerland and simultaneously at Yale University in New Haven, Connecticut. It’s taken 12 years to get from the initial search to the publication of a paper in Nature that maps the molecule’s genes and gives it a name: NOGO.

A year after that, scientists at Yale produce a paper that identifies a receptor for NOGO; this receptor is a particular molecule that acts as a sort of lure for the toxin. It’s January 2001, and in a few weeks Emily’s father will fall and break his neck. Emily is real, of course. She’s my daughter, and that year she will celebrate her 13th birthday with our friends in the cafeteria of a trauma center.

The finding of the receptor is a hugely important step, because it invites our Team Poison scientists to get to work finding a way to neutralize that receptor, to make it chemically invisible. The theory is that if the NOGO can’t see the receptor, it won’t bind to it, and the axon will be able to grow safely past.

But how does a theory — even one backed by solid science — go from scientists publishing papers to treatments for real people? The simple answer is, it takes money. Lots of it.

Wings for Life

Two years after the Yale team discovered that NOGO receptor, a young Austrian named Hannes Kinigadner broke his neck. Hannes, though, was the son of a two-time world champion motocross racer named Heinz. In 2004, Heinz Kinigadner and a friend formed a nonprofit called Wings for Life. The friend was Dietrich Mateschitz, and
Mateschitz is the man who founded the company that produces the energy drink, Red Bull. He has, to put it mildly, lots of resources.

Wings for Life has only one mission: to find effective treatments and cures for spinal cord injury (see sidebar). In 2017, Wings for Life committed to supporting Team Poison’s NOGO Inhibitor project via the newly formed company, ReNetX, with $7 million — enough money to build and carry out a clinical trial on people with chronic spinal cord injury. A November 2017 press release explained the critical role the funding would play:

“Our mission is to find a cure for spinal cord injury,” says Jane Hsieh, executive director of the Wings for Life Accelerated Translational Program. ... Hsieh describes the funding as a critical bridge to help ReNetx Bio cross what is known as the “valley of death,” to advance programs to key proof-of-concept milestones needed from a large-scale clinical trial to spark additional investor and industry engagement to advance promising treatments for patients.

Let’s slow that down.

First, “cross the valley of death” means to get proof-of-concept milestones in place. That involves, among other things, showing that this treatment, which has restored full mobility to one-third of the rats that got it, works in at least one human being.

Second, set up a large clinical trial that will bring in investors willing to place bets on that treatment.

Third, use the investors’ money to build the medical infrastructure that can deliver treatments.

You can be part of this project by volunteering to be in the safety trial (see Resources).

“Are we there yet?” It’s a sentence my young Emily must have asked a thousand times on car rides. By the time her 33rd birthday comes around in 2021, she just might be able to read about a person who was successfully treated with a therapy that has been in the making since the day she was born. And then we’ll know whether it was Team Scar or Team Poison — or both — that was on the right track.

Resources
- NervGen, nervgen.com
- ReNetX, renetx.com
- ReNetX Clinical Trials, renetx.com/c clinical-trial.html
- New Mobility, “Three Molecules and a Mom,” newmobility.com/2020/01/three-molecules-and-a-mom
- Wings for Life, wingsforlife.com/en

The World Run

When one of the founders of your nonprofit is known for founding a company with a reputation like energy drink giant Red Bull, there is an expectation that you will host creative fundraisers. Wings for Life has surpassed that expectation with the World Run, the innovative annual race it launched in 2014. In the Wings for Life World Run, there’s no set time and no set distance; instead, each runner starts their race at exactly the same moment all over the planet, at one of the 35 designated starting points for each 100km course.

The runners get a 30-minute head start. Half an hour after the race begins, a “catcher car” leaves each starting point, traveling the course at just under 9 mph. When the catcher car passes a runner, that runner has been “caught” and is eliminated. The race ends when there is only one runner left on each course, and the distances covered by each are compared to find the overall champion.

The World Run is a bit of a metaphor-generator. It’s a race to get to a treatment before one more person gets “caught” by paralysis. It’s a global example of the kind of tight scientific coordination that will be necessary to get a therapy to market. It’s a visual reminder that efforts are underway to find those therapies in every corner of the planet, simultaneously.

All the costs of mounting this elaborate international event are born by Red Bull, and all the entry fees go directly to support the science the Wings for Life scientific board has identified as most promising.
Most disabled people have heard of the Medicaid Buy-In program, but they don’t know how to enroll, stay enrolled or capitalize on the financial freedom the program can bring.

As a C4-5 quadriplegic and full-time medical malpractice attorney, I rely heavily on my state’s Medicaid Buy-In program so I can simultaneously work and maintain my healthcare benefits. Medicaid Buy-In allows employed workers with disabilities to keep our benefits while earning above a particular state’s Medicaid income limits. Considering that these limits are low no matter where we live, Buy-In programs are often the best way for us to earn a living wage without losing needed medical coverage.

In the late 1990s, Congress passed two laws that allow states to create their own Medicaid Buy-In programs. States can choose limits on an enrollee’s age (typically 16 to 64), how much they can earn (income) and save (assets), whether or not their spouse’s income and assets are counted, and the amount they pay in monthly program premiums.

Below are answers to five frequently asked questions about Medicaid Buy-In.

1. How do I know if I’m eligible?
   First, your state must have its own Medicaid Buy-In program. As of 2020, the only ones that don’t are Alabama, Florida, Hawaii, Oklahoma and Tennessee. The District of Columbia doesn’t have one either. Then, you must have a qualifying disability that meets Social Security’s definition, such as most spinal cord injuries. Finally, eligibility is determined by whether you meet your state’s unique Medicaid Buy-In rules and requirements.
   For example, I live in Maryland and our program is called Employed Individuals with Disabilities. The 2020 rules require an enrollee to:
   - Be between 18 and 65 years old.
   - Be a U.S. citizen or qualifying non-citizen.
   - Meet Social Security’s disability definition.
   - Work for pay and earn less than $3,123 per month if single, or $4,228 per month if married.
   - Have less than $10,000 in countable resources if single, or $15,000 if married.
   Examples of countable resources include cash, bank accounts and investments. Examples of exemptions to countable resources include your home, most items in your home, and your car.
   - Pay a monthly premium based on earnings. These typically range from $0 to $25, $40 and $55.
   Some states, such as Virginia and New Jersey, have very limited time and income windows for enrollment. This makes it even more important to know the eligibility rules prior to gaining employment.

2. How much can I make?
   To answer this question, it’s important to understand the difference between earned income and unearned income. Earned income is your salary and unearned income is everything else, including your Social Security benefits. Both types are treated differently during the monthly income calculation process. Most states deduct 50% of earned income and 0% of unearned income. This means that if you have zero dollars of unearned income and 100% of earned income, then you can earn twice the allowed amount.
   Those enrolled in Maryland’s Medicaid Buy-In with 100% earned income can make around 2 x $3,123 = $6,246 per month if single or 2 x $4,228 = $8,456 per month if married. There are a few other smaller deductions applied to the calculation and other ways of reducing earned income through impairment related work expenses. As of 2020, a non-married person in Maryland with zero unearned income can earn up to $77,556.

3. How do I stay eligible once enrolled?
   Once again, most states create their own unique rules and requirements for their programs. Maryland does an annual checkup on me and requests my previous year’s tax returns, monthly salary, bank statements, any other money-related accounts and all deductions that apply. By providing all of this required documentation, I have remained enrolled in my state’s Medicaid Buy-In program for the last six years.

4. How can I learn about my state’s Medicaid Buy-In program?
   Visit SPINALpedia.com/Employment/MedicaidBuyInList.

5. Can someone help me enroll in my state’s Medicaid Buy-In program?
   Yes, you can email me at josh.basile@gmail.com to receive free job mentoring and to be matched with a free disability employment benefits counselor. I am here as a resource, so you are not alone in your pursuit of employment. You can find more resources about Medicaid Buy-In programs at SPINALpedia.com/Employment/MedicaidBuyIn.
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ARIZONA
Barrow Neurological Institute at Saint Joseph's Hospital and Medical Center, Phoenix, AZ; 602/406-3747
HealthSouth East Valley Rehabilitation Hospital, Mesa, AZ; 480/567-0350
Encompass Health Valley of The Sun Rehabilitation Hospital, Glendale, AZ; 623/878-8800
Honor Health Rehabilitation Hospital, Scottsdale, AZ; 480/800-3900

CALIFORNIA
Dignity Health - Northridge Hospital Medical Center, Center for Rehabilitation, Northridge, CA; 818/885-8500
Encompass Health Rehabilitation Hospital of Bakersfield, Bakersfield, CA, 661/323-5500
Rady Children's Hospital San Diego, San Diego, CA; 858/576-1700
Shirley Ryan Ability Lab, Chicago, IL; 312/230-1000
The Spinal Cord Injury Program of Marianjoy Rehabilitation Hospital, part of Northwestern Medicine, Carolstream, IL; 217/788-3302

COLORADO
Colorado Acute Specialty Hospital, Denver, CO; 303/264-6900
Craig Hospital, Englewood, CO; 303/789-8800

CONNECTICUT
Gaylord Specialty Healthcare, Wallingford, CT; 203/284-2800
Hospital for Special Care, New Britain, CT; 860/827-2671
Mount Sinai Rehabilitation Hospital - a Trinity Health of New England, Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA
Medstar National Rehabilitation Hospital - SCI Program, Washington, DC; 202/877-1000

FLORIDA
Brooks Rehabilitation Hospital, Jacksonville, FL; 904/345-7600
Pinecrest Rehabilitation Hospital at Delray Medical Center, Delray Beach, FL; 561/498-4440

GEORGIA
Emory University Hospital Center for Rehabilitation Medicine, Atlanta, GA; 404/712-7593
Rehabilitation Hospital Navicent Health, Macon, GA; 478/201-6500
Shepherd Center - Southeastern Regional SCI Model System, Atlanta, GA; 404/350-7645

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

ILLINOIS
Shirley Ryan Ability Lab, Chicago, IL; 312/230-1000
The Spinal Cord Injury Program of Marianjoy Rehabilitation Hospital, part of Northwestern Medicine, Carolstream, IL; 217/788-3302

INDIANA
Parkview Rehabilitation Hospital, Fort Wayne, IN; 260/373-4000
Rehabilitation Hospital of Indiana, Indianapolis, IN; 317/329-2000

IOWA
Childserve, Johnston, IA; 515/727-8750

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

KENTUCKY
Cardinal Hill Rehabilitation Hospital, Lexington, KY; 859/254-5701
Frazier Rehabilitation Institute, Louisville, KY; 502/582-7490
Gateway Rehabilitation Hospital Florence, KY; 859/426-2400

LOUISIANA
The Gilda Trautman Newman Rehabilitation Center, New Orleans, LA; 504/899-9511
Touré Rehabilitation Center, New Orleans, LA; 504/897-8560

MASSACHUSETTS
Spaulding New England Regional Spinal Cord Injury Center, Charlestown, MA; 617/573-2770

MARYLAND
Adventist Rehabilitation Hospital of Maryland, Rockville, MD; 240/864-6132
International Center for Spinal Cord Injury at Kennedy Krieger Institute, Baltimore, MD; 888/554-2080
Medstar Good Samaritan Hospital Spinal Cord Rehabilitation Program, Baltimore, MD; 443/444-8000
University of Maryland Rehabilitation and Orthopaedic Institute, Baltimore, MD; 410/448-2500

MICHIGAN
Mary Freebed Rehabilitation Hospital, Grand Rapids, MI; 800/528-8989
DMC Rehabilitation Institute of Michigan, Detroit, MI; 313/745-1055

MINNESOTA
Essential Health Miller-Dwan Rehabilitation Services, Duluth, MN; 218/727-8762

MISSOURI
Ability KC, Kansas City, MO; 816/751-7812

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

NORTH CAROLINA
Cone Health Inpatient Rehabilitation Center, Greensboro, NC; 336/832-8153
Vidant Medical Center, Greenville, NC; 252/975-4100
Wake Forest University Baptist Inpatient Rehabilitation Program, Winston-Salem, NC; 336/716-2011
WakeMed Rehab Hospital, Raleigh, NC; 919/350-8861

NEBRASKA
Madonna Rehabilitation Hospital SCI Rehabilitation Program, Lincoln, NE; 402/489-7102
QLI - Spinal Cord Injury Program, Omaha, NE; 402/573-3700

NEW JERSEY
Bacharach Institute for Rehabilitation, Pomona, NJ; 609/748-5480
Kessler Institute for Rehabilitation, West Orange, NJ; 973/252-6367

NEVADA
Renown Rehabilitation Hospital Reno, NV; 775/982-5000

NEW YORK
Helen Hayes Hospital, West Haverstraw, NY; 845/786-4000
Mount Sinai Medical Center, New York, NY; 212/241-6500
Orange Regional Medical Center, Middletown, NY; 845/333-1000
Rusk Rehabilitation at NYU Langone Medical Center, New York, NY; 212/263-6012
St. Charles Hospital Rehabilitation Center, Port Jefferson, NY; 631/474-6011
St. Mary’s Hospital for Children, Bayside, NY; 718/281-8987
Strong Memorial Hospital of the University of Rochester, Rochester, NY; 585/275-2100
Sunnyview Rehabilitation Hospital, Schenectady, NY; 518/382-4560
The Burke Rehabilitation Hospital - Spinal Cord Injury Program, White Plains, NY; 914/597-2500

OHIO
Metrohealth Rehabilitation Institute of Ohio, Cleveland, OH; 216/778-3483
Ohio Health Outpatient Neurological Rehabilitation, Columbus, OH; 614/484-9600
Summa Rehabilitation Hospital, Akron, OH; 330/572-7300

OKLAHOMA
Integris Jim Thorpe Rehabilitation Network, Oklahoma City, OK; 405/951-2277
Valir Rehabilitation Hospital, Oklahoma City, OK; 405/609-3600

OREGON
Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151
Interested in becoming a hospital or organizational member? Please contact Nick LiBassi at 718/803-3782, ext. 7410 or nlibassi@unitedspinal.org

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EMPLOYMENT OPPORTUNITY

Job Title: Americans with Disabilities Act (ADA) Coordinator (Part-Time)

Description: The Americans with Disabilities Act (ADA) Coordinator will build upon and administer the ADA accommodation program from start to finish. The position will also be involved in the Light Duty/Return-to-Work program. Other duties include but are not limited to the following: Identifies and performs outreach to employees possibly requiring accommodations; educates management and employees to develop and provide employees effective and reasonable accommodations; develops written materials and other informational pieces regarding the ADA program; develops and maintains internal measures to track ADA status and compliance and maintains and documents records of all disability and accommodation issues; ensures compliance with applicable laws, regulations, and policies; assures that workers with disabilities are provided effective and reasonable accommodations allowing them to work productively and safely; assure Township-Sponsored activities, Township Facilities and events address accessibility and accommodation concerns.

Requirements: Bachelor’s degree in social sciences, human resource management, business administration or related field and two years of personnel administration experience are required (or a combination of education and/or training and/or experience which provides an equivalent background required to perform the work of the class); a minimum of eighteen (18) months of experience in a position that involved evaluating and administering reasonable accommodation issues subject to the ADA or §504 and completion of a course on barrier-free design or ADA accessibility guidelines which was sponsored or approved by the New Jersey Department of Community Affairs or a department which oversees the Uniform Construction Code in any other State, the American Institute of Architects, the Paralyzed Veterans Association, or the United Spinal Association, within twelve (12) months of hire.

Salary: DOQ

Hours: Part-Time, three days weekly (not to exceed twenty one hours per week).

Apply: Send resume or application to: Ms. Braedon Gregory, HRIS Coordinator, Human Resources Department, Township of Montclair, 205 Claremont Avenue, Montclair, New Jersey 07042 or email: bgregory@montclairnjusa.org

Closing Date: Job posting will remain open until position is filled.

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Meet New Member Randy K. Ferguson
Age 65, from Sunnyvale, Texas
T1 paraplegic
Retired Dallas Police Officer

Why I joined United Spinal: I joined United Spinal so that I could connect with people with a similar disability. I thought it would be a good way to “stay in the loop” and not feel so isolated once I returned home from rehab.

Can’t live without: I couldn’t live without my Raz shower chair. It allows me to access my shower stall easily and safely. For me, it’s the most critical piece of equipment I own.

What I would change: More accessible parking! Able-bodied people are using spaces reserved for wheelchair users. I wind up having to park at the end of the row so that I can operate and use my ramp. Also, restaurants need to have more tables that can accommodate a wheelchair.

Meet other members or join Spinal at unitedspinal.org
When I’m on the FES arm cycle at my gym, I have my hands wrapped up in gloves that allow me to go pretty hard sans grip. One morning, while working out, I was waiting for an email confirmation from my doc about a last-minute appointment I hoped to get that afternoon.

About 20 minutes into my workout, I heard my email chime, but didn’t want to disconnect all of the pads from the machine until my time was up. I’m not super private about my email generally, because it’s almost always junk and boring stuff. I asked my 50-something PT, “Hey Carol, can you look at my new email? I need to see if I have an appointment after this.” After a little instruction, we got my inbox open. She clicked on the top bold message and started to read it out loud.

Turns out it wasn’t from my doctor. Carol read the first sentence, “I can’t stop thinking about how hot the other night was…” I literally gasped, and shrieked out, “Never mind, never mind, never mind!” A blushing Carol seemed pretty scandalized, but played it off OK.

The doctor emailed about an hour later saying the appointment was a no-go and I never actually saw that email casanova ever again. I don’t have people check my email for me anymore.
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