

AXIS

A NEWSLETTER OF SHEPHERD CENTER
PROVIDER OF MEDICAL TREATMENT, RESEARCH AND REHABILITATION



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SUMMER 2019

All the Important Information You May Have Forgotten



BY EDELLE [EDEE] FIELD-FOTE, PT, PhD, FAPTA,
DIRECTOR OF SPINAL CORD INJURY RESEARCH, SHEPHERD CENTER

The time that immediately follows a spinal cord injury (SCI) is often a whirlwind of education, with so much to learn in such a short period of time. From how to use a wheelchair and perform skin inspections to directing a bowel program and recognizing autonomic dysreflexia, the list seems endless because inpatient rehabilitation education programs are packed with an incredible volume of information. Additionally, beyond the information that is important for the person with SCI, there also is information that is important for family members and supporters to learn.

Fortunately, in this age of digital media, people with SCI, as well as their supporters, have easy access to essential information. Among the most useful of these is the SCI Model Systems Knowledge Translation Center (MSKTC), which you can find at <https://msktc.org/sci>. As you may recall from prior issues of *AXIS*, the SCI Model Systems program is a consortium of 14 centers, each of which provides a multidisciplinary system of high-quality rehabilitation care. In addition, the SCIMS centers provide education and disseminate information with the goal of improving long-term functional, vocational, cognitive and quality-of-life outcomes for individuals with SCI. Each of the SCIMS centers also has ongoing research studies related to SCI, as well as research projects on which the SCIMS centers collaborate. The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funds both the MSKTC and the SCIMS program, and their efforts complement each other.

The MSKTC website offers a remarkable amount of valuable informational resources for people with SCI. The resources on the SCI MSKTC represent the products that have been developed through collaboration between the

MSKTC and the SCI Model Systems centers. These resources are provided in a variety of formats, including videos, slideshows, hot topic modules and fact sheets. The list below illustrates the range of health and wellness related topics that are available to persons with SCI and other consumers:

- Adjusting to Life after SCI
- Aging & SCI
- Autonomic Dysreflexia
- Bladder Health & Management
- Depression & SCI
- Driving
- Employment after SCI
- Exercise & Fitness after SCI
- Gait Training & SCI
- Managing Bowel Function
- Managing Pain after SCI
- Pregnancy & SCI
- Respiratory Health & SCI
- Safe Transfer Techniques
- Sexuality
- Skin Care & Pressure Sores
- Spasticity & SCI
- Understanding SCI
- Urinary Tract Infection
- Wheelchair Information

As an illustration of the types of information that can be accessed, by clicking on the link for the resource topic "Exercise & Fitness after SCI," the user opens a list of materials in different media formats. (See screenshot on page 7.) For example, there are 22 videos (such as: *Breaking Down Barriers to Exercise*, *About Hand Cycling* and *Components of a Good Exercise Routine*), two fact sheets (such as: *Adaptive Sports & Recreation*), a hot topic module (*Exercise and Fitness after SCI*) and a slide show (*Gait Training after SCI*).

For researchers and others who are interested in exploring these topics in more detail, the MSKTC website also offers research-related resources from the SCIMS centers. These include Quick Reviews (brief reviews of research studies funded by NIDILRR), Research Database (a web-



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Five Questions About Peer Support at Shepherd Center

Meet new peer support liaison Curran Brown.

BY DREW JUBERA

A head-on car collision resulted in a spinal cord injury that paralyzed Curran Brown from the waist down.

She was six years old.

Now 23, Curran joined the team of the Spinal Cord Injury Peer Support Program at Shepherd Center in November. It's

one way, she says, for her to give back to the rehabilitation community that helped her growing up.

Raised in Johns Creek, Georgia, Curran graduated with a degree in kinesiology from the University of Illinois. She attended Illinois on a wheelchair basketball scholarship and continues to play for the Shepherd Stealers, which is one of the 11 sports teams sponsored by the Fred, Shaler and Andrew Alias Sports Teams program at Shepherd Center.

We caught up with Curran to talk about what she jokingly calls her first “big-girl job” and its role in helping patients at Shepherd Center.

What do you remember about those who helped you when you were injured as a kid?

Coming from someone who was six, I really didn't know what was going on. For the team of nurses and therapists who worked with me (at Children's Healthcare of Atlanta), their goal was for me to get better. I just knew these people didn't know me but they were helping me anyway. That stuck with me. I was going from a super traumatic accident and having to learn, basically, a whole new life, and there were people there for you like you were special. I want to help people have that same experience, show them that life still goes on, post-injury.

How do you begin talking with a patient?

A typical first session is me letting them hear my story, being vulnerable. We both let our guards down so that anything they want to talk about, we can talk about.

How does that fit in with other therapy?

Physical therapists and occupational therapists can show them how to do things, but it's reassuring for a patient to see someone who can't move her legs and is in a wheelchair show them, too. A physical therapist can show them how to transfer but the patient might be thinking, “But you can move your legs.” It's nice to see someone who's in the same position.

They see me and know, “I'm here now but eventually I can get to that point.”

What concerns do patients talk most often with you about?

Bladder and bowel issues are a huge piece of what patients have a hard time with. When they come to peer support, I tell them my experience, we talk about our frustrations, they ask about

techniques. I don't think anyone really understands that whole side of spinal cord injury unless you absolutely experience it.

What's the best part of your job?

I love when patients notice their own progress. When they first get here they're really closed, not really knowing what's going on – that time right after a traumatic accident is definitely hard. Then after just a few weeks, they've grown to do so much, they have a more positive attitude. I love seeing the joy in their face after they do something they didn't think they could do just a week ago.



PHOTOS BY LOUIE FAVORITE

FUN FACTS

- Curran's favorite NBA team is the Los Angeles Lakers – despite the addition of LeBron James. “I don't like LeBron. I always liked the Lakers because of Kobe (Bryant) and Pau Gasol.”
- Her favorite college basketball team: “I'm loyal to my school, Illinois, even though they're not the best in sports.”
- Her role on the Shepherd Stealers wheelchair basketball team: “I don't like to shoot, I like to get others open to shoot. I pick and seal for the big guys – do the dirty work so they can make the shot.”
- Other passions: cooking (“I watch the Cooking Network all the time”) and travelling. Trips so far include 25 states in the U.S., Germany, Paris and the Cayman Islands, where Curran became a certified scuba diver.
- What's next: “Just experiencing the unknown – I want to know what's out there. And I want to go to graduate school to become an occupational therapist.”

After Spinal Cord Injury Rehabilitation, Woman Achieves Long-Time Goal of Becoming an Occupational Therapist

BY DREW JUBERA

Sarah Cutler Benzing of Asheville, North Carolina, finds motivation and perspective through rehabilitation.

Sarah Cutler Benzing, 25, from Asheville, North Carolina, has wanted to be an occupational therapist since the eighth grade. That's when she came down with a rare autoimmune disease that left her, she says, "not being able to get off the floor." Sarah was treated for a week at Duke University Children's Hospital & Health Center, in Durham, North Carolina, and had follow-up appointments for several years afterwards. During this time, she became close with her therapists.

"It was neat to see the relationship you could build with someone and how that impacted my life," Sarah says. "It helped me get stronger and back to the things I enjoyed."

Fast forward to Thanksgiving Day 2014. Sarah was a senior in college majoring in psychology and applying to graduate school to study occupational therapy. She'd gotten engaged to her then-boyfriend, Ben Benzing, three days earlier. But while taking a family photo after dinner with her fiancé and more than two dozen family members, the deck they stood on collapsed. In the 15-foot fall, Sarah sustained an L-1 incomplete spinal cord injury, resulting in paralysis in her legs.

Sarah spent a week at Greenville Memorial Hospital in South Carolina, before transferring to Shepherd Center. At the time, she couldn't even sit up in bed.

"It was scary," she recalls. But soon staff used a lift to get her into a wheelchair and whisked her to therapy. Sarah's response: "Let's do it!"

Sarah left seven weeks later, more determined than ever to pursue occupational therapy. "I was really emotional," she says of leaving Shepherd. "I progressed so much there. They motivated me, they pushed me. I was thankful for that."

Sarah got married in the spring of 2015, finished her undergraduate degree that summer, and then participated in further outpatient therapy. In spring of 2016, she spent a month back at Shepherd Center in the rigorous, activity-based Beyond Therapy® program to build strength and endurance for graduate school.

Two years later, she walked across the stage at Lenoir-Rhyne University, in Hickory, North Carolina, to receive her master's degree in occupational therapy.

Sarah believes her years of rehabilitation – and all the moments of doubt, frustration, exhilaration and reward – give her work a rare perspective.

"I think I really can be used in a greater way," she says. "I've been in their shoes. I know what it feels like. I feel I'll be able to understand them in a way some people can't."

"I've already had great conversations with patients," Sarah adds. "I'm able to say I've been in those dark places, that it sucks right now, but it's going to get better. Look where I am now. Never give up."



PHOTO COURTESY OF SARAH CUTLER BENZING



Shepherd Center Hosts 2019 Recreation Therapy Events and Outings

Recreation therapy events provide physical activity, education, skill development, community reintegration – and fun!

The Shepherd Center Recreation Therapy Program encourages all former patients, their families and community members to participate in its upcoming events in 2019. From sporting events to health and wellness clinics to trips large and small,

the hospital's recreation therapy program has something to satisfy every interest.

The mission of Shepherd Center's Recreation Therapy Department is to help people with a temporary or permanent disability caused by injury or disease to lead healthy and active lifestyles as independently as possible through the use of recreation activities, providing education, skill development and community reintegration opportunities.

For a complete list of events, visit shepherd.org/rec-therapy/events

Spinal Cord Injuries Lead to Shared Dreams

Inspired by their time at Shepherd Center, two former patients are now doctors of physical medicine and rehabilitation.

BY PHILLIP JORDAN



PHOTOS COURTESY OF HAMMAD ASLAM AND WOODY MORGAN

Woody Morgan and Hammad Aslam met in 2009, in Athens, Georgia. Woody was a senior at the University of Georgia. Hammad had just graduated. The pair quickly bonded over a shared dream of becoming physiatrists – doctors specializing in spinal cord injury (SCI) medicine – working to help patients with spinal cord injuries regain their functional ability and quality of life.

Professional pursuits and a common alma mater are not all that has kept these two bonded through nearly 10 years of medical school, residencies and fellowships crisscrossing the nation. Woody and Hammad also each know what it’s like on the other side of the doctor-patient equation.

In 2008, Woody – then a sophomore at UGA – waded into the Gulf of Mexico. He handed his sunglasses to a friend, dove into a cresting wave and didn’t return to consciousness until the next day, in the ICU at Sacred Heart Hospital, in Pensacola, Florida. His dive into what turned out to be very shallow water resulted in a paralyzing incomplete cervical-5 to -6 spinal cord injury. A week after his injury, Woody was at Shepherd Center.

A year later, Hammad and his family were returning home from a visit to his future medical school when they were involved in a car crash. Hammad sustained a traumatic brain injury (TBI) and was paralyzed from the chest down due to a complete thoracic-2 spinal cord injury. He was initially treated at the Augusta University Medical Center, and regained consciousness two weeks later at Shepherd Center.

A mutual friend from UGA introduced the two men not long after Hammad began medical school. For almost a decade now, the duo has stayed in steady contact as they’ve pursued different paths to their mutual calling. Today, Woody Morgan, M.D., is a fourth-year physical medicine and rehabilitation resident at Harvard Medical School’s Spaulding Rehabilitation Hospital in Boston. Hammad Aslam, M.D., is finishing his post-residency fellowship in spinal cord injury medicine at Stanford University in northern California.

“No matter where we’ve been, we’ve texted, emailed, connected on social media, talked on the phone,” Woody

says. “We’ve given some needed pick-me-ups to each other over the years.”

Along the way, they also realized how pivotal their time proved to be at Shepherd Center.

Before his injury, Woody planned to study orthopedics and sports medicine. Hammad was considering pediatrics or neurology. Both changed course after working with their physiatrists at Shepherd Center.

Hammad, who progressed quickly from his TBI, remembers a nurse explaining why his attending physicians — Brock Bowman, M.D., associate medical director at Shepherd Center, and John Lin, M.D., medical director of the Spinal Cord Injury Rehabilitation Program — were called physiatrists.

“I had no idea what physiatry was then,” he says. “But I started observing how they interacted with me, what questions they asked, the comprehensive care they provided. I loved how they formed relationships with their patients. The wheels definitely started turning in my head.”

Dr. Lin, in particular, inspired both young men. He also has paralysis and uses a wheelchair due to an aneurysm-like condition known as epidural arteriovenous malformation. He also was a patient at Shepherd Center nearly two decades ago.

“Just seeing Dr. Lin doing his job was big,” Woody says. “He’s a different injury level than the two of us, but watching how he made things work, you realize you’re not the first; you’re not reinventing the wheel. You saw what was possible.”

Watching Dr. Lin use creative solutions to accommodate his abilities also prepared Woody and Hammad for the two-step dance they’d have to learn in med school. As Woody puts it: “First, we had to learn the textbook way of doing something. Then, we had to figure out how to adapt that approach so that it could work for us.”

Hammad, for example, never regained function in terms of movement or sensation after his injury, and doesn’t have abdominal control or stability in his core to help him stay upright. So, to deliver an ultrasound-guided injection in a

patient's shoulder, for instance, Hammad uses a standing wheelchair with a chest strap to hold him steady.

"I'd fall down without it," he says. "But with it, I can hold the probe in one hand and the needle in the other without worrying about my balance. Everything requires more planning to execute, but you just figure it out. I've learned there's always a way to get things done."

Of course, being in a wheelchair also has its advantages when working with patients who have spinal cord injuries.

"We go into a room and we have street cred right away," Woody says. "It can help you connect quicker, can mean a little something extra with patients sometimes, knowing that you've been where they are."

Woody and Hammad have returned often to Shepherd Center, both as peer supporters and also as students. As he prepared to apply to medical schools, Woody shadowed Anna Choo Elmers, M.D., staff physiatrist at Shepherd Center, to observe her day-to-day routine. Hammad completed one of his psychiatry rotations at Shepherd Center, with Dr. Lin's supervision.

"It was awesome seeing him interact with patients," Hammad says. "They're not just names in a chart; they're friends to him. That's a lesson I've tried to take with me: To see each patient, not as a name on a chart, but as a holistic person with needs, conflicts, and social and psychological issues that all play a part in their health."

Hammad and Woody both label that relational, patient-centric focus as a point of distinction throughout Shepherd Center.

"Shepherd Center is very unique in that it's such an incredibly happy and uplifting place to get such comprehensive team care," Hammad says. "It's just the attitude everyone has, from the directors on to the doctors, nurses, therapists, assistants, facilities staff. Everyone's so positive. They make

you feel like you're going to make it. That, no matter what, there's a next step and we're going to show you how to take it."

Woody remembers public outings as a patient – such as going to an Atlanta Braves game – that helped him learn to navigate the outside world again, and also to bond with his patients and staff members.

"It's a sense of community they build," he says. "They understand that patients still have their same dreams and wants out of life. As a physician, you don't want to discourage. You want to help patients adapt and facilitate ways for patients to make their goals possible. You want to facilitate hope."

In January 2019, Hammad and his wife Zainab Alwan welcomed their first child to the world, a baby boy named Laith. Hammad is also interviewing for full-time psychiatry positions, while Woody will soon begin his fellowship in SCI medicine at Craig Hospital in Denver.

"Seeing where we each are now compared to where we were when we first met," Hammad begins, and then exhales, letting the thought drift, unfinished.

"It's been special," Woody says. "We've seen each other at conferences through the years, as med students and residents, even shared accessible hotel rooms together."

"Now, the next time we see each other at a conference, we'll be colleagues."

Hammad Aslam's route to his current Stanford University fellowship was preceded by medical school at the Augusta University | University

of Georgia Medical Partnership and a residency at the University of Alabama at Birmingham. Woody Morgan graduated from Tulane University's School of Medicine, completed a year of internal medicine at Ochsner Medical Center in Louisiana, and then began his current residency at Harvard Medical School's Spaulding Rehabilitation Hospital.



Hammad Aslam, M.D.



Woody Morgan, M.D.

Advanced Wheelchair Skills Clinic Set for October 12 at Shepherd Center

Shepherd Center's Advanced Wheelchair Skills Clinic aims to provide persons who are currently using manual wheelchairs with continued education to learn, review and practice wheelchair skills under the guidance of Shepherd Center therapists. Practicing these skills may translate into increased confidence, safety and independence when performing manual wheelchair skills during daily activities and in the community. Skills covered in this clinic may include propulsion technique, wheelies, curbs, falling safely, uprighting the wheelchair, and negotiating elements such as grass, stones, sand and stairs.

TARGET AUDIENCE: This clinic is appropriate for:

- Persons who use a manual wheelchair as their primary means of independent mobility.
- Persons independent in personal care or who will have a caregiver present.
- Persons with a working wheelchair that does not currently require maintenance.

DATE & TIME: October 12, 2019 from 9 a.m. to 1 p.m.

COST: Free

LOCATION: Shepherd Center - Mike Utley Terrain Training Course (outside the plaza level of Woodruff Family Residence Center)

TO REGISTER: To register, go to shepherd.org/wheelchairskillsclinic. For more information, please contact Kallie Phillips at kallie.phillips@shepherd.org or 404-603-4664.



Returning to Work After Injury

BY DREW JUBERA

PHOTO BY LOUIE FAVORITE



Fewer than three weeks after Ryan Gibson sustained a complete C-7 spinal cord injury from diving into a lake in 2015, Debbie Page, MS, LPC, CCM, vocational rehabilitation case manager at Shepherd Center, visited him to talk about going back to work.

“I was still thinking about the injury and the recovery process – I hadn’t thought about employment much,” says Ryan, then a 25-year-old auto technician in suburban Atlanta. “But sometimes it takes an outside eye to shake you and say, ‘By the way, you’ve still got to do this.’”

Ryan’s employer visited him at Shepherd, where Ryan completed both inpatient and outpatient rehabilitation over five months. Along with Page, Ryan communicated with his boss throughout, keeping him posted on the timeline of his recovery, as well as updating him on duties of the job that might need to be modified or delegated completely.

Six months after the accident, Ryan returned to work. Ryan, who uses a wheelchair for mobility, transitioned from the service department to sales in the parts department. He is able to complete his job with a few accommodations.

“You have to reach out and talk, tell your employer what you’re thinking,” Ryan says. “I realized that no employer knows what shape you’re in or what you’re thinking unless you tell them.”

While Ryan’s return to work was fairly seamless, not everyone has that experience.

While the employment-to-population ratio – the ratio of people working compared to the total population – for people with disabilities has risen to about 30 percent, that’s still

well below the 73.6 percent of all Americans who are employed.

Shepherd Center’s vocational rehabilitation program, which is available to patients because of the generous support of donors, aims to change that. Of the 468 patients Shepherd Center’s vocational rehabilitation program served during the last fiscal year, 90 returned to work or school, and 33 were volunteering, which many patients do to build physical and cognitive endurance to work again. A total of 289 were referred to state vocational rehabilitation programs, which assist with job training, adaptive technology and other benefits.

“Everyone who’s able to go back to their jobs, if the position remains available, does return to work,” Page says. “Sometimes the recovery takes too long and the employer is forced to fill the position.”

April Ross was a Fulton County, Georgia, assistant district attorney when she sustained a spinal cord injury in 2014 after being shot by her estranged husband. Paralyzed from the chest down, she returned to the district attorney’s office about a year and a half later.

“I was concerned with how soon I’d get back to work for reasons more than money,” Ross says. “I’m used to a life where I’m doing something.”

With the help of Shepherd’s vocational rehabilitation services, Ross navigated the insurance and government agencies she needed to help her return. While at Shepherd, Ross also became fluent with adaptive technologies, such as dictation software, that she now uses in her office.

For many people with disabilities, focusing on what you can do is more important than what you can’t do.

Ryan and April had engaged, proactive employers who educated themselves on their employees’ disabilities – a crucial next step in getting more people with disabilities employed.

John Smith, director of government relations and advocacy at Shepherd, ticks off medical, technological and legislative advances over the past few decades for people with disabilities. But he says there is more progress to be made with employment.

“Financial stressors can have a significant impact on well-being – often times not working translates into poverty,” Smith says. “The heavy lift now is bridging the gap between employers and a willing and capable workforce.”



PHOTO COURTESY OF RYAN GIBSON

Shepherd Center Releases Video Series for Women with Spinal Cord Injury

Videos funded by grant from Craig H. Neilsen Foundation address life after SCI for women.

BY KERRY LUDLAM

Shepherd Center recently released “Empowering Women After SCI: Safe Health Care Goes Beyond Accessibility,” a video series that aims to empower women who have sustained spinal cord injuries (SCI) to advocate for their own health and wellness. The videos also serve to better equip healthcare providers to treat women with SCI.

“Research shows that while both men and women with disabilities are at a greater risk for health challenges and health care disparities, women in particular are more likely to delay or avoid routine primary and preventative healthcare appointments, such as mammograms, pelvic exams and screenings for cervical cancer than their counterparts who do not have disabilities,” said Teresa Foy, OT, Comprehensive Rehabilitation Unit program manager at Shepherd Center.



“Without these routine screenings and preventative care, women with disabilities are at an even higher risk for serious health complications. Through this video series, we hope to create opportunities for women with SCI to seek out the medical expertise they need and deserve to pursue lifelong health and wellness.”

The video series was funded by a generous grant from the Craig H. Neilsen Foundation and donations from grateful Shepherd Center patients and families. The series covers topics ranging from doctor’s office visits, diet and exercise, medical care, pregnancy, childbirth, parenting, fashion, dating and intimacy. The final content was determined based on the feedback from focus groups comprised of local consultants, consumers, peer supporters, Shepherd Center’s women’s SCI support group and expert SCI clinicians. The videos feature open and honest commentary with female patients who have sustained spinal cord injuries, as well as interviews with medical experts.

You can view all nine videos at myshepherdconnection.org/sci/women

ALL THE IMPORTANT INFORMATION YOU MAY HAVE FORGOTTEN

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based tool to search and view research articles published by SCI Model System centers) and Systematic Reviews (formal, organized articles compiling, evaluating and summarizing published research evidence related to a specific medical or health topic).

In addition to the above resources, the MSKTC website offers a directory of the 14 SCI Model System centers and access to information produced by the National Spinal Cord Injury Statistical Center. Finally, by clicking on the “Get Involved” button, individuals with SCI and their supporters can find out about ways that they can become involved in consumer testing, as well as enroll in research studies.

The MSKTC website provides a great way to get a refresher on the important information you may have forgotten from the hectic, activity-filled days that are part of the early period after SCI. Additionally, the website offers up-to-date information about ways to improve physical and mental health and wellness. Last but certainly not least, the MSKTC website offers opportunities to share your insights and experiences in ways that can benefit others with SCI. I encourage you to visit the MSKTC website to refresh your knowledge and skills, discover all that the SCI Model System centers are accomplishing and learn about opportunities to get involved.

AXIS

AXIS covers news and information about research, medical treatments, healthy living and events for people who have experienced spinal cord injury, brain injury or a related neurological condition.

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If you would like to make a gift to support the work you have read about, please contact the Shepherd Center Foundation at 404-350-7305 or visit shepherd.org.



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The contents of this newsletter were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90SI5016). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this newsletter do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

We Want You!



The Spinal Cord Injury Research Lab at Shepherd Center has a number of open studies that are recruiting research volunteers. Our research focuses on a variety of subjects, including finding ways to reduce spasticity for individuals who experience spasms or stiffness in their legs, targeting the development of treatments to improve walking function for individuals who have some walking ability and studying how brain stimulation might be useful for improving hand function in people with tetraplegia. There is no charge for participating in our research studies.

Our research volunteers are important members of our research efforts, and we welcome your participation. Please visit shepherd.org/SCIResearch to learn about current studies. You may also contact us by email at sciresearch@shepherd.org.

