AXIS

A NEWSLETTER OF SHEPHERD CENTER

PROVIDER OF MEDICAL TREATMENT, RESEARCH AND REHABILITATION

SUMMER 2018

Walk or Wheel –

Resources to Help Move You Along

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

Despite significant and meaningful advances in spinal cord injury (SCI) rehabilitation in recent years, there are still a large number of questions about how best to improve function after SCI. Although clinicians, researchers, caregivers and persons with SCI may approach these questions from different perspectives, the overall theme is often the same: What is the best way to improve function in the shortest amount of time, that will produce the best outcomes while being conscientious about resources?

For people with SCI who have a goal of walking, there are many rehabilitation approaches that seem to have value; however, these approaches often require access to specialized facilities and advanced technology. These approaches may also require a significant investment of time and financial resources. In addition, many approaches target the spinal circuits that contribute to walking function, while ignoring the important role that the brain has in producing and controlling walking function. To contribute to the development of best approaches to improving walking function, Shepherd Center's Hulse Spinal Cord Injury Lab is conducting the following three studies.

Brain Stimulation and Locomotor Training

The first study is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Spinal Cord Injury Model Systems (SCIMS) grant. The aims of the study are:

- to determine if a brief, but intense training program can improve walking function in persons with SCI, and
- to determine if the addition of non-invasive brain stimulation leads to greater improvements compared to training alone.

With the above questions in mind, Shepherd Center researchers developed a training program that targets components of walking, such as balance, coordination, muscle strength power and the ability to turn muscles on and off quickly. Importantly, the training program is designed in a way that it can be performed as part of home exercise program.

To answer the second question – how increasing brain activity might contribute to improved walking function – researchers are using a non-invasive brain stimulation technology known as transcranial direct current stimulation (tDCS). The stimulation targets brain areas that control muscles of the leg. The idea is that that by combining tDCS with training, communication between the brain, spinal cord and muscles involved in walking could be enhanced to optimize restoration of walking function in persons with SCI. Participants enrolled in the study complete four sets of six standing motor skill exercises. Some of the participants enrolled also receive tDCS along with the motor skill training program to determine if there is an additive therapeutic benefit from this combined approach.

Anyone interested in learning more about this exciting new study is encouraged to contact the study coordinator, Nick Evans, MHS, CEP, at 404-350-7742 or nicholas.evans@shepherd.org.

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Shepherd Center Launches Online Training for Clinicians Across the Country

BY DAVID TERRASO

The hospital's NeuroRehabilitation Learning Institute offers interdisciplinary professional education to support treatment of complex neurological conditions such as brain and spinal cord injury.

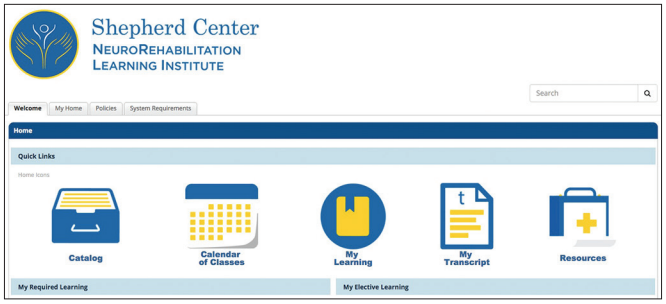
Few things are as complex as providing excellent care for brain and spinal cord injury. Advancements move quickly, and healthcare providers must stay up to date on the latest breakthroughs and new therapies to ensure they are providing the best medical care. For patients, the quality of care often depends on where they live and where they can – or will – travel for treatment.

To improve access to clinicians with expert knowledge in treating these injuries, Shepherd Center's NeuroRehabilitation Learning Institute will launch online training programs in January 2018 to provide ongoing continuing education at reasonable costs. Interdisciplinary teams of experts from Shepherd Center – one of the country's top spinal cord and brain rehabilitation hospitals – will teach courses via a web-based learning management system (LMS) to clinicians who enroll.

"In the United States alone, there are more than 4.5 million people with some form of disability from brain injury and 450,000 with spinal cord injury, but only a relatively small number of these individuals have medical providers with substantial knowledge to provide the quality of care that allows them to live life to the fullest," says Diane Johnston, MSPT, director of professional education at Shepherd Center in Atlanta. "We want to improve the quality of life, not just for Shepherd Center's patients, but for anyone with a complex neurological condition. That's why we launched the NeuroRehabilitation Learning Institute."

Shepherd Center's LMS hosts an online interdisciplinary professional education program providing continuing education credits to healthcare professionals. The LMS will feature a host of courses spanning brain and spinal cord injury and learning plans. These include a review course of 21 learning modules to support nurses who seek certification in rehabilitation and a Provider's Guide to Spinal Cord Injury geared to home health providers. In the spring 2018, a Provider's Guide to Brain Injury will also be available.

The LMS features both live webinars and webcasts, and it will soon add resources, such as problem-solving tools, to help providers apply their lessons when they are working with a patient. The LMS is available at education.shepherd.org.



"There's a high specificity of care needed for patients with brain and spinal cord injury," Johnston notes. "And they return to the healthcare system at different points throughout their lives. It's incumbent upon healthcare providers to have the most up-to-date level of education possible, and historically, finding these educational resources has been very challenging."

It can be especially difficult for patients of Shepherd Center when they return to their hometown after discharge from rehabilitation in Atlanta.

"We've heard from families, and we've seen firsthand, that many of our patients often need healthcare providers with more education in serving patients with these types of injuries and the related complications that may occur when they return home," Johnston says.

A patient at Shepherd Center may have 10 to 12 healthcare providers with different areas of expertise involved in their rehabilitation care. That means hometown providers need to understand a vast amount of material from an array of disciplines to effectively treat that patient. That is why the interdisciplinary nature of Shepherd's LMS programming is essential. Providers who access the courses will be learning from physicians, occupational therapists, physical therapists, speech therapists, recreational therapists, dietitians, nurses and nurse practitioners.

The goal of the LMS programming is to help hospitals and other healthcare organizations by improving the knowledge and skills of their staff, which can reduce patients' medical complications, result in shorter hospital stays and lower rates of hospital readmission. In addition, by offering courses in specialized skills, the LMS can improve the quality of care for patients at their home trauma center before they're transferred to a facility like Shepherd Center to begin rehabilitation.

"Many people who sustain a brain or spinal cord injury are people in the prime of their lives," Johnston says. "If we can affect the quality of care they receive to help them improve so they can return home after rehabilitation and possibly get back to work, have a family and do all the things we all like to do, then we've achieved a huge accomplishment."

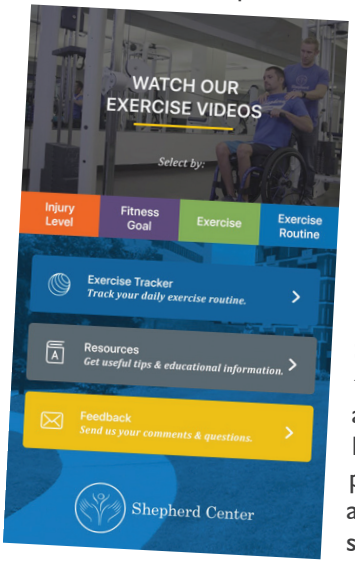
Learn more and enroll in continuing education classes at **education.shepherd.org**

Mobile App Update Includes Home-Based Exercise Program

SCI-Ex promotes fitness for people with spinal cord injury.

BY DAVID TERRASO

Shepherd Center, in collaboration with MobileSmith, has added a home-based exercise program to its free mobile app SCI-Ex, which promotes fitness for people with spinal cord injury (SCI). The update includes video demonstrations of adaptive exercise techniques designed to be used at home, as well as the gym.



MobileSmith, the Raleigh, N.C.-based company that developed SCI-Ex in early 2017 in collaboration with Shepherd Center, says the app is the first of its kind in terms of targeting the fitness needs of people with SCI. Users can access information and videos in a suitable, goal-oriented manner.

The latest updates were developed based on user feedback from the initial version of the app. More than 20 new exercise videos have been added, targeting a variety of muscle groups. Users can access videos either by injury level, fitness goals or the body part they wish to target.

"We have created what we believe to be a more intuitive decision tree to guide users through the exercise selection process," says Nick Evans, a lead exercise specialist at Shepherd Center. "Selecting any of these categories will automatically direct individuals to a series of appropriate exercise videos."

The SCI-Ex app is available as a free download in the Apple iTunes and Google Play stores (search "Shepherd Center"). It was developed with funding from the Craig H. Neilsen Foundation and Shepherd Center Foundation with videos produced by Brothers Young Productions.

Shepherd Center is recruiting individuals with SCI to participate in a research study evaluating the effectiveness of the SCI-Ex app. Participants are expected to download and use the free SCI-Ex app for 90 days. They will be asked to complete a survey at the beginning of the study and again 30, 60 and 90 days later. At the end of the study, participants will receive a $10 Amazon gift card for each completed survey.

Those interested in participating should send an email to **SCI.EX@shepherd.org** and provide their contact information.

WALK OR WHEEL
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Activating Spinal Circuits Related to Walking Function and Spasticity

The second walking-related study in the Hulse Spinal Cord Injury Lab is supported by a grant from the National Institutes of Health (NIH) and focuses on spinal circuits related to walking function. This study is designed to evaluate how whole-body vibration (WBV) affects walking function and leg muscle spasticity. My earlier published studies have shown that vibration seems to activate circuits in the spinal cord that contribute to stepping movements, while also reducing some forms of spasticity. Based on that information, the laboratory team has developed a study to determine how the frequency and timing of WBV influence walking speed and spasticity. Together, timing and frequency are part of the dose of WBV. Like many other forms of rehabilitation interventions, we know relatively little about how the dose of therapy affects outcomes. To learn more about this study, contact study coordinator Elizabeth Sasso, at 404-350-7551or elizabeth.sasso@shepherd.org.

Spinal Cord Stimulation and Locomotor Training

The third and final walking-related study in the Hulse Spinal Cord Injury Lab is supported by a grant from the Wings for Life Foundation. Spinal cord simulation has received a great deal of media attention; however, many of the studies use expensive devices that are out of reach for many clinics, as well as most individuals with SCI. Everything we know about rehabilitation is that the people must continue to practice the skills they achieve in therapy in order to retain them. To meet this need, we are conducting a study to evaluate the benefits of a commonly used stimulator for improving walking function when combined with locomotor training. To participate in this study, the individual must be enrolled in one of Shepherd Center's locomotor training programs because this study adds stimulation to supplement the training. For more information about this study please contact the study coordinator, Stephen Estes, Ph.D., at 404-603-4967 or stephen.estes@shepherd.org.

For many people, when they think of a person who has sustained a SCI, they think of the wheelchair first; however, for individuals with SCI and for those who know and care for them, we understand that walking is just one aspect of function. We also know that walking may not be a goal for particular individuals depending on the individual's function and/or priorities. For wheelchair users, having a wheelchair in proper working order is essential. As part of the SCIMS program, there are some excellent resources available at the Model Systems Knowledge Translation Center (MSKTC) website. A three-part series of fact sheets is available on Getting the Right, look for a new fact sheet soon titled Maintenance Guide for Users of Manual and Power Wheelchairs. Find these and other valuable fact sheets at **MSKTC.org/SCI/FactSheets**.

Study Finds that Stiffness, Ineffectiveness of Medication are Challenges for People with Spinal Cord Injury Who Experience Spasticity

Shepherd Center spearheads comprehensive survey of people with spinal cord injury, a majority of whom face daily episodes of spasticity.

BY AMANDA CROWE, MA, MPH

Many people with spinal cord injury (SCI) report that spasticity – specifically stiffness – has a significant negative impact on daily activities and quality of life, according to a recent study by the spinal cord injury research team at Shepherd Center.

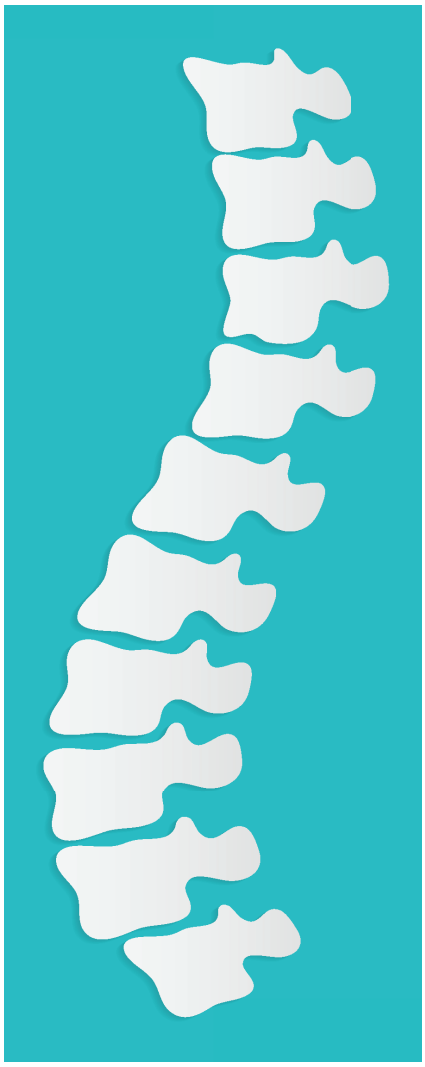
The study, published in the January 2018 issue of Spinal Cord (Nature publications), explores which specific characteristics of spasticity – for example, muscle spasms, jerking muscles (clonus) or stiffness – are most troublesome for people with SCI. Ninety-five percent of respondents reported having at least one spasm each day. Of these, 44 percent had 10 or more spasms a day. While conventional wisdom has pointed to spasms as a main spasticity-related challenge in people with SCI, this study suggests that stiffness may be the more troublesome issue.

"Spasticity is a highly common experience after SCI," says Edelle Field-Fote, PT, PhD, director of spinal cord injury research and the Hulse Spinal Cord Injury Laboratory at Shepherd Center. "What was particularly striking is that stiffness appears to be the most problematic aspect of spasticity – over and above muscle spasms or jerking muscle movements, which are what we typically think of as spasticity."

Stiffness was also found to have the greatest negative impact on daily activities and patients' overall wellbeing.

"It can keep someone from being able to use the remaining muscle power they might have," Dr. Field-Fote explains. "While they may have some muscle function, if on top of being weak they are also stiff, it really limits their ability to function. Even rolling over in bed is very difficult."

To conduct the study, researchers at Shepherd Center developed and fielded a comprehensive survey of people with SCI. The study involved 145 people with SCI – the majority of whom were more than two years post-injury. They completed a 75-item questionnaire, which included questions from a validated tool called the Patient Reported Impact of Spasticity Measure (PRISM). They also answered questions derived from neurophysiological research that were intended to give a more complete picture of when and how spasticity happens, as well as how it interferes with certain activities such as exercise, feeding oneself, hygiene and getting dressed. Researchers say it's the largest survey to date to assess the characteristics of spasticity that most affect daily life.



Another key finding is that among those who take medication for spasticity, more than half – 58 percent – reported they don't get relief from them. Not only does this underscore the need for more non-pharmacologic ways of managing spasticity, it may also suggest that current medications have limited effects on stiffness.

"People experience spasticity in very different ways, so there can't be a one-size-fits-all approach to how it is treated," Dr. Field-Fote says.

Shepherd Center researchers are hopeful that these findings will encourage clinicians to adopt a broader understanding of how spasticity affects people with SCI, including applying a more expansive definition of spasticity proposed by the European SPASM Consortium, which includes both the intermittent muscle activity associated with spasms, as well as the more sustained muscle activity that gives rise to stiffness.

Researchers stress that larger studies are needed to more fully understand the dynamic nature of spasticity in people with SCI so that clinicians can help patients manage their condition more effectively.

For more information about research at Shepherd Center, visit **shepherd.org/research**.

Former Shepherd Center Patient Shines in Adaptive Sports After Sustaining a Spinal Cord Injury

Mackenzie "Mack" Johnson, 20, learns importance of moving forward at Shepherd Center.

BY PHILLIP JORDAN

Mackenzie "Mack" Johnson, 20, laughs now when he remembers it. When he first transferred from University of Tennessee Medical Center to Shepherd Center – a few weeks after sustaining an incomplete T-12 spinal cord injury in a 35-foot fall from a cabin balcony on November 5, 2016 – the first task physical therapists gave him was to put on his own shorts.

"They didn't give me much assistance, either," Mack says. "They'd just come by every few minutes and say, 'Hey, your shorts still aren't on.' I remember thinking, 'This is the place that's supposed to be so great? Don't they know I'm paralyzed?'"

"But they knew what they were doing and they knew what I was capable of," he adds. "That's what I grew to love about Shepherd Center. They prepare you. They challenge you. They support you, but they don't pity you."

Another challenge he received at Shepherd Center was to try some new sports. A former high school football player, Mack had never played basketball competitively. But during his six-month stay at Shepherd Center, he started falling for the game, enamored with its competitiveness, physicality and camaraderie. He began practicing with the Shepherd Stealers basketball team, and when he left, the coaches gave him information on a summer hoops camp at Auburn University.

Today, Mack, an accounting major, is a member of Auburn's wheelchair basketball team, where he attends thanks to a scholarship from the Swim With Mike Foundation. Mack has also struck up an unlikely friendship with NBA legend Bill Walton. A chance encounter at a Dateland sandwich shop in Arizona turned into an ongoing bond between the two athletes. Thanks to Walton's encouragement, Mack has spread his sporting focus to cycling and swimming, too, and has become active with the Challenged Athletes Foundation. At Walton's invitation, Mack even participated in the Million Dollar Challenge – handcycling with Walton's team down portions of the 620-mile route along the California coastline.

Mack still visits patients and staff at Shepherd Center whenever he passes through Atlanta, too.

"This is where I learned the importance of going forward and staying active," Mack says. "Now, I'm the one telling new patients to try doing more than they think they're ready to!"

Advanced Wheelchair Skills Clinic Set for October 13 at Shepherd Center

Shepherd Center's Advanced Wheelchair Skills Clinic aims to provide persons who are 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.

DATE & TIME: October 13, 2018 from 9 a.m. to 1 p.m.
COST: Free
LOCATION: Mike Utley Terrain Training Course (outside the plaza level of Woodruff Family Residence Center adjacent to Shepherd Center)
TO REGISTER: To register, go to **shepherd.org/wheelchairskillsclinic** or contact Brian Maloney, PT, DPT, NCS, at brian.maloney@shepherd.org or 404-603-4634.

Shepherd Center and Microsoft Team to Help Ensure Accessible Technology for All

BY DAVID TERRASO

Partners create Accessibility User Research Collective to connect people with disabilities to technology developers.

Shepherd Center is collaborating with Microsoft to collect user feedback on the accessibility and usability of its products and services from people with disabilities. The Accessibility User Research Collective (AURC) now connects Shepherd Center's nationwide database of 1,300-plus volunteer users with various types of disabilities to Microsoft employees.

Shepherd Center, ranked by *U.S. News & World Report* as one of the country's top 10 rehabilitation hospitals, has been working with companies to address the technology needs of people with disabilities since 2001. By teaming with Shepherd Center, Microsoft will be able to gain feedback from people with many types of disabilities not just in its hometown of Redmond, Washington, but from people all over the country.

Users can participate by filling out a brief survey, estimated to take only five to 10 minutes to complete. Participants can fill out the questionnaire either online, via email or by phone. Once in the collective, Microsoft researchers will be able to connect with users from the disability community. Then, Shepherd Center's research coordinator will contact potential participants to check their availability, determine their level of interest and help get them connected to designers, developers and researchers at Microsoft.

"If a study involves working with participants who have dyslexia, Shepherd Center will screen people to confirm they have dyslexia and then make contact for the researchers," explains Ben Lippincott, research coordinator at Shepherd Center's Crawford Research Institute and co-director of the AURC.

All studies will need to be approved by Shepherd Center's Research Review Committee, which ensures that safety and privacy protocols are in place. The contact information for participants will be confidential, and participants will be compensated for their time for each study in which they take part.

"At Microsoft, getting feedback from people with disabilities is such an important piece of the way we can create great products and services," says Megan Lawrence, Ph.D., accessibility technical evangelist for Microsoft. "We have a deep respect for their needs and opinions and we want to incorporate that in everything we do. In partnering with Shepherd Center, we are building a deeper relationship with the community to provide more ways for the voices of people with disabilities to be heard."

Microsoft is interested in both increasing the quantity and quality of feedback from people with disabilities and ensuring they can both identify and address the needs of people with disabilities of all ages. Microsoft works hard to make products and services accessible to people of all abilities.

One potential study will focus on individuals with visual impairment using Microsoft Word or a screen reader. A different study may examine the experiences of people with hearing difficulties while playing gaming consoles like the Xbox One.

"When we put accessibility at the heart of our design, we are providing great technology that meets people's needs across devices," Dr. Lawrence says. "I often find that the features we add, which are originally for people with disabilities, can become a universal tool providing the kind of usability that everybody wants."

As people age, their abilities and technology needs change, Dr. Lawrence notes.

"What they don't need today, they may need tomorrow," she adds. "By investing in accessibility, Microsoft is also investing in innovation and natural user-interface design. By working together with people in the disability community, we can ensure they have a role in shaping who Microsoft is."

Participants will be able to take part in usability studies, focus groups, interviews and feedback sessions, among others. They'll be conducted remotely with technologies like Skype, remote desktop/laptop monitoring, surveys and the telephone.

"Working with Microsoft in the Accessibility User Research Collective allows Shepherd Center to continue to promote social participation for people with disabilities across the country," says John Morris, Ph.D., clinical research scientist at Shepherd Center's Crawford Research Institute. "That is a vital part of our mission to rebuild lives and restore hope."

Join the Accessibility User Research Collective by taking the survey: **https://is.gd/AURCmemberform**

or by phone or email:
1-800-582-6360
AURC@shepherd.org

Patient Pledges Game On While in Rehabilitation for a Spinal Cord Injury

Will Condon approaches rehabilitation like preseason football practice – with grit and humor while cheering on his fellow patients.

BY DREW JUBERA

He doesn't remember any of it – the dive into his apartment complex pool, hitting the water at a freakish angle, drowning. All Will Condon remembers is waking up 36 hours later in the intensive care unit at Carolinas Medical Center in Charlotte, North Carolina, surrounded by family and being told he was paralyzed from the chest down.

Intubated and unable to talk, Will's face registered an urgent expression. His girlfriend improvised a system that let him spell words by blinking when she pointed to the right letter of the alphabet. He batted out a painstaking but blunt response to his predicament: NOT FOR LONG.

After surgery for an incomplete C-5 spinal cord injury, the youthful teacher and coach was airlifted to Shepherd Center in Atlanta. Determined to recover, but told in North Carolina that his chances of walking again were slim, Will arrived on June 6, 2016, both hopeful and terrified. A fourth-floor night nurse recognized the fear on Will's face and assured him: "You're going to be fine. We do this all the time."

"Everything was positive," recalls Will, 31, in reflecting on his Shepherd Center experience. "It's frustrating, humbling and depressing to go from being the most athletic person in my family to being completely helpless. But in that atmosphere, surrounded by people in the same boat, you have the sense you are not alone. That atmosphere is so important for the recovery process."

A high school football and baseball player, Will adopted what he called an "athletic frame of mind." Rehabilitation was slow and tough going. Because of damage to his lungs from the near-drowning, breathing remained a problem. It was two weeks before he clenched a fist. Two days later, he lifted a leg.

Meanwhile, he cheered on his fellow patients' breakthroughs and consoled them during setbacks.

"I've always been a team player," he says. "I don't want to be the only person succeeding. I want the team to get better, and the people at Shepherd with me were my team."

During Will's rehabilitation, his parents moved from their home in Painted Post, New York, to live in Shepherd Center's on-campus Woodruff Family Residence Center. They got to know the therapy team. They recorded Will's first fist clench. His father read Will a book every morning about an NFL player's recovery from a similar injury.

They also met other parents who lived on campus, bonding over their shared hopes and fears while performing mundane tasks.

"Being in the laundry room was as therapeutic as anything else," says Barbara Condon, Will's mother. "You really got to know people. It was a wonderful situation."

Lou Condon, Will's father adds: "It was our indoctrination to the 'Shepherd Way.' They don't see anything as a handicap. They see what they need to do and start working at it. It's why I never had the feeling this was awful. It was awful, but from that point on, we were only going to go up."

A benchmark moment came on the Fourth of July. Seated in a power wheelchair on the sidewalk outside the Center, still largely immobilized as he watched 60,000 runners rush by in Atlanta's annual 10K AJC Peachtree Road Race, Will silently fumed.

"I was so angry, all those fully healthy people running by," he says. "All I wanted to say was: 'Don't pity me. Don't patronize me.' For two hours out there, I slowly released all my anger. It was something I had to go through."

Then, after he released it: "I started enjoying myself. I was high-fiving people as they ran by. I told myself, 'I'm going to run this next year.'"

Will graduated from inpatient rehabilitation six weeks later, an event made memorable by a poem he read to about 30 staffers, patients and parents. Filled with bracing insights and inside jokes, it touched on everything he went through and everyone who helped him. It ended: "Then I'll go home to be with my pup/ For life knocked us down but now we get… back up."

There wasn't a dry eye in the house.

Next, Will moved into Shepherd Center's Spinal Cord Injury Day Program for continued rehabilitation. He finished each session dripping wet.

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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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Kerry M. Ludlam

NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

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GAME ON
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"That athletic mentality and competitiveness came through. I was able to push him to do more than even he knew he could do," says Jennifer Wile, a physical therapist who worked with Will on the treadmill. "His willingness to trust us that the harder we pushed the better he gets was tied to his overall success."

Two months after he'd arrived, he finally stood up. When he left Shepherd Center that October, he used one forearm crutch to walk out on his own.

Will now lives back in New York, teaching biology and coaching baseball. He tires easily, but walks his dog, hikes and even went skiing with his girlfriend.

He returned to Shepherd Center last July 4th – for the AJC Peachtree Road Race. He and his girlfriend walked the whole route. When he passed Shepherd Center near the halfway point, virtually dead last, memories rushed back – tubes choking his throat, pushing himself with his therapists, standing up.

A couple nurses still stood outside. Will yelled, "I was there a year ago!" They clapped, but he didn't stop.

"I just kept walking," he says. "That's a statement right there."

Shepherd Center Hulse Spinal Cord Injury Lab

STUDY ALERT

Enhancing Corticospinal Activation for Improved Walking Function

TIME COMMITMENT: 5 consecutive sessions (2-3 hours/session)

PARTICIPANT CRITERIA: Persons with AIS C or D at least 12 months since injury

COMPENSATION: $200

PRINCIPAL INVESTIGATOR: Edelle Field-Fote, PT, Ph.D.

STUDY CONTACT: Nick Evans MHS, ACSM CEP
(404) 350-7742, nicholas.evans@shepherd.org