MRSCICS Matters

Winter 2018

Shirley Ryan AbilityLab

Welcome to the Winter 2018 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS). In this issue you will read about our move to our new hospital, a new project looking at using exoskeletons, driving, and our new GED program.

Enjoy!

Inside

We Have Moved Into Our New Home

It is official! We have settled into our brand new "translational" research hospital located at 355 East Erie Street. Our groundbreaking 1.2 million square foot facility is home to 5 Innovation Centers and 5 state-of-the-art Ability Labs. The 5 Innovation Centers (Brain, Nerve, Muscle & Bone, Cancer, Spinal Cord, and Pediatric) bring together the best medical and research experts in real time. These experts work together to innovate creative, expedited, efficient rehabilitation methods for our patients.

Shirley Ryan AbilityLab

The 5 Ability Labs (Arms & Hands Lab, Legs & Walking Lab, Strength & Endurance Lab, Think & Speak Lab, and Pediatric Lab) focus on specific functional outcomes. In these dynamic, open and collaborative workspaces, teams of rehabilitation professionals from multiple fields (physical therapy, occupational therapy, recreational therapy, speech and language therapy, nursing, psychology, engineering, and more) provide a full range of therapeutic services and develop new research-based insights to help patients gain function, achieve better outcomes and enjoy greater independence.

The Shirley Ryan AbilityLab (formerly Rehabilatation Institute of Chicago) celebrates 27 years as the number one rehabilitation hospital in the country, according to U.S. News & World Reports. This achievement highlights our dedication to advancing the field of rehabilitation science and providing extraordinary care to each patient who enters our doors. With this new facility, we plan to continue revolutionizing rehabilitation with scientists, clinical staff, physicians, and patients all working together with the goal of

Are You Due For a National SCI Database Follow-Up Interview?

Are you approaching your 1, 5, 10, 15, 20, 25, 30, 35, 40, or 45-year anniversary of injury? If so, you may be due for your next follow-up interview. Please contact **Kayla Jones** at 312-238-1624 or **kjones05@sralab.org** to schedule your interview. Your interview can be completed by phone, mail, or in-person.

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is a national leader in sponsoring research. NIDILRR is located in Washington, D.C., and is part of the Administration for Community Living at the U.S. Department of Health and Human Services.

Education Does Not Stop After SCI

In a workforce that is ever changing, receiving an education continues to be highly important. Living with a Spinal Cord Injury (SCI) can be a limiting factor in the pursuit of employment, especially for those whose injuries have interrupted their education. Many individuals with SCI hope to find educational development opportunities. However, returning to conventional educational settings while completing therapy is not always a workable option.

Shirley Ryan AbilityLab (SRALab) addresses this issue and supports patients' educational and professional development through the Shirley Ryan GED program. This program currently holds courses every Wednesday 10am -1pm at 541 N. Fairbanks Ct., Chicago, IL 60611. Classes are free, and English and Spanish options are available, making this program the ideal launch pad to higher education and potential careers. Pamela Capraro, SRALab vocational manager states, "There have been seven graduates so far. Two of these graduates went on to further their education and are now accepted into four-year universities." Graduation ceremonies are held for graduating classes of two or more to commend students' hard work and commitment to self-improvement. Two graduates, Leomar Leyva and Charles Winters, have been a beacon of hope for many individuals with SCI, and were recently featured on Chicago's WGN News for their accomplishments.

GED graduate Leomar Leyva tosses his graduation cap, while fellow graduate Charles Winters looks on.

We caught up with Leomar to hear about his life after recieving his GED and any advice he has for people with SCI who are seeking to continue their education.

How did you learn about the GED Program at Shirley Ryan Abilitylab?

- "I was working out at the fitness center when Pamela approached me and asked was I planning to get my GED. I told her yes, I was in classes paying what seemed like a fortune. Then two months later the program for the classes closed. That is when I reached out to Pamela to inquire about the GED program at Shirley Ryan AbilityLab."

How did it feel to receive your graduation certificate at the ceremony?

- "It was overwhelming, but good. There was so many flashing lights there taking pictures for media coverage. I originally expected it to be short and small. However, I did enjoy myself and felt very proud."

What did getting your GED mean to you?

- "It meant I was going forward in life with a big step. I was making a statement that my physical appearance of being in a wheelchair does not define my intellect or ability in life."

What are some features about the program that you liked?

- "I have known Pamela for six years; she gave me hope that I can be more successful in life."

What features of the program could be improved to serve people with spinal cord injuries better?

- "It can be difficult for people with spinal cord injuries to commute to the vocational rehabilitation center building every Wednesday downtown to study with the volunteers. Pam understands the issue of accessibility for communities farther into the city. That's why she [is] trying to expand the program by opening another class to focus particularly on Social Studies and Language Arts at Schwab Hospital in Humboldt Park."

Would you recommend this program to others who qualify?

- "Most definitely, I would recommend this program to others. I was able to recruit six other people to join the program after getting my GED. It was easy because I am involved with the sports program at Shirley Ryan AbilityLab and I meet many people. I introduce myself to new friends and pass along the information."

What do you plan on doing now that you have your GED?

- "I have big dreams. One of the volunteers at Shirley Ryan AbilityLab inspired me to pursue a professional career in healthcare after hearing his journey of being a school teacher, to principal to now working as a chiropractor. I want to be in the healthcare field like him and [serve] people as a pharmacy technician."

The opportunities for self-improvement do not stop after SCI. Education is available and resources such as Shirley Ryan AbilityLab GED program help to ensure that each individuals' goals are achieved.

GED Graduate Leomar Leyva comes down the aisle to recieve his diploma.

For more information about SRALAB GED program, contact Vocational Manager, **Pamela Capraro at (312)238-6819 pcapraro@sralab.org**

Visit **https://www.sralab.org/services/vocational-rehabilitation** to learn more about the vocational rehabilitation services we provide.

Driving After Spinal Cord Injury

What you need to know

- You may be able to continue driving safely again, depending on how serious your injury is and how much function you have regained.
- If you can drive, you may need to buy a vehicle that suits your unique needs after the injury.
- Vehicles can be altered with special equipment called "assistive technology" to help you drive safely after your injury.
- Equipment can be expensive based on your function and the type of equipment necessary.
- You should take specific steps before you return to driving; there are resources to help you.

How do I know if I can drive a vehicle again?

The amount of time after your injury is a major factor in deciding whether and how you can return to driving. You may see many improvements in your abilities several weeks or months after your injury. With time, you may regain functions that could make driving possible. With time, the amount and cost of any needed special equipment may be reduced. You should look for these important signs that you are ready to drive again:

- You do not need narcotics to control your pain while you drive.
- You have good vision, or your vision can be corrected.
- You can control the muscle spasms and muscle tightening caused by the injury.

Your doctor can refer you to a driving rehabilitation specialist for a full evaluation to decide if you are ready and able to drive.

A full driving assessment will evaluate:

- Medical data/driving history/driving goals
- Vision
- Strength and range of motion
- Cognitive ability (if indicated)
- Ability to transfer
- Wheelchair or other mobility device loading
- Behind-the-wheel driving to try out equipment options

How can I find out what kind of assistive technology I need?

Your doctor can refer you to a Certified Driver Rehabilitation Specialist (CDRS) near you who can do a driving evaluation for you. You can find a list of specialists and their locations at **http://www.aded.net/** or by calling ADED at 866.672.9466.

The CDRS can help you decide what special equipment you might need to drive a vehicle, and what type of vehicle would be best suited to your needs. The CDRS may also know about special funding to help you get the equipment you need. To be evaluated by a CDRS, you will most often need a referral from a doctor. If you live in an area where there is not a CDRS close by then we recommend you visit **http://www.nmeda.com/**, and use the dealer locator tool to find automotive mobility dealers closest to you. These dealers are specially trained to help with your driving equipment needs. They will know of professionals in your area that can best meet your needs. NMEDA's phone number is (866) 948-8341.

What kind of assistive technology is available?

There is assistive technology for many activities associated with driving; your choice will depend on what you need.

Getting in and out of a vehicle: Two of the main factors to consider in the return to driving after an SCI are vehicle entry and exit, and loading and unloading a mobility device if you use one.

- You may be able to transfer from a wheelchair into the vehicle and then load the manual wheelchair on your own.
- If you cannot load your wheelchair, there are adaptive wheelchair loading devices like the one shown on the left.
- If you cannot safely and independently transfer from the wheelchair to the driver's seat, you may need a wheelchair accessible vehicle that lets you drive or push your wheelchair into the vehicle.
- Some modified vehicles let you drive while sitting in the wheelchair.

Whichever device you choose, the wheelchair must be secured while the vehicle is moving.

Operating the gas and brake controls: There are many different types of gas and brake controls; the most common are hand controls. Hand controls are available with many types of motion—push-pull, push-twist, push-rock, and push right angle—so that drivers can use the one that suits them best. A CDRS can help you choose the best type for your injury or disability.

Steering: Often a driver using hand controls will use only one hand for the steering wheel because the other hand is controlling the gas. A steering device like the one pictured here can help a driver steer efficiently with only one hand. The device can be placed on either side of the steering wheel, depending on which arm is strongest. The steering system can also be adapted so the driver can turn the wheel with less force using a smaller steering wheel, a separate electronic steering wheel, or even a foot-operated steering device.

Electronic Gas/Brake Lever used with left arm and Electronic Wheel used with right arm for steering.

A tri-pin steering device allows someone without finger function to turn the steering wheel.

Electronic Gas/Brake Lever used with left arm and Electronic Wheel used with right arm for steering.

Photos Courtesy of Shepherd Center

Driving After Spinal Cord Injury Cont.

How will I pay for this equipment?

Assistive equipment can be expensive. An accessible vehicle can cost a few hundred more than a basic vehicle all the way to over $100K based on your situation. Costs include equipment, installation, training, insurance, and upkeep. You might be able to get help to pay for these costs. Some options include:

- Your State's vocational rehabilitation (VR) programmight help you buy, equip, and learn to use a vehicle. VR programs usually are for people who plan to return to school or work and who need costly high-tech equipment and/or a wheelchair-accessible vehicle.
- Most vehicle companies offer a rebate (about $1,000) to qualified people who buy a new vehicle. These rebates usually limit what equipment can be purchased.
- The Crime Victims' Compensation Program might help if you are a victim of a crime (such as gunshot, drunk driver, violence). For more information, go to **http://victimsofcrime.org** , or call (202) 467-8700.
- Your State might have a trust fund that could help you. (For example, The Georgia Brain and Spinal Injury Trust Fund Commission helps Georgia residents with uninsured costs related to disability, including buying or modifying a vehicle. For more information, go to **http://www.ciclt.net/bsitf**.
- HelpHOPELive helps organize community-based fund raising efforts to help cover the costs of uninsured medical expenses for people with tragic injuries. For more information, go to **http://www.helphopelive.org/about/**.
- The U.S. Department of Veterans Affairs, or VA, offers grants to veterans who become disabled due to disease or injury associated with their military service, or who become disabled as a result of therapy, rehabilitation, or medical treatments provided by the VA. For more information, go to **http://www.va.gov/**.

When is the best time for me to get started?

Timing is everything. Take your time and get all the facts. Your body might need time to adjust to the effects of your SCI. For example, your motor functions might be different 1 month after your SCI than even a few to several months later. We urge you to take the time you may need after your SCI to be evaluated by a CDRS. The CDRS will evaluate your skills and help you decide what vehicle and equipment you will need. If you use a wheelchair, it will be important to coordinate your new chair with any plans for driving and also to have your own chair available before you purchase a vehicle so that the vehicle choice supports you and your chair.

An adapted vehicle can be expensive. It is important to truly understand your needs before buying anything. Do not feel pressured to make quick decisions. Rushing into a purchase will almost always make an appropriate vehicle more expensive than when a full evaluation is made at the proper time. When a purchased vehicle cannot be adapted to meet your needs, money and time are wasted in selling it and then buying a well-matched vehicle.

Authorship
Driving after Spinal Cord Injury was developed by John Anschutz in collaboration with the Model Systems Knowledge Translation Center.

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Mobility After Spinal Cord Injury

Stephanie Kanter: Consumer Advisor for the Project Entitled Using a Health Technology Assessment Framework for Evaluating the Utilization and Efficiency of Wearable Exoskeletons for SCI Rehabilitation.

As patient-centered technology continues to make strides, the use of robotic exoskeletons are becoming more of a mainstream option in the healthcare arena. Over the last few years, people with SCI purchased exoskeletons with the hope of walking independently. However, not much is known about the benefits and limitations of these devices, nor is there much research surrounding the topic. The lack of robotic education prompted Drs. Allen Heinemann and Arun Jayaraman to propose an innovative research study entitled "Using a Health Technology Assessment Framework for Evaluating the Utilization and Efficiency of Wearable Exoskeletons for SCI Rehabilitation." The study aims to describe the physical, psychological, and socioeconomic benefits and barriers of exoskeleton use, as well as the effects of exoskeleton-centered therapy. One major component of the study is an Advisory Board, a group of stakeholders including executives at leading robotic manufacturing companies, professional associations, major insurance companies, and consumers. Persons with SCI are significant members of this board. Individuals who have a SCI and experience in robotic exoskeleton therapy can provide real world knowledge and insight on these products. Stephanie Kanter serves on the advisory board and has been an important source of knowledge for this study. We interviewed Stephanie about her robotic exoskeleton experience. We asked her what benefits or limitations she encountered, and what advice she has for people seeking new therapy options after SCI.

Tell me about your experience with robotic exoskeletons.

- "I took part in a study led by Arun Jayaramun at RIC in 2014. It was with the exoskeleton from Ekso Bionics. As a wheelchair user since 1994, I'd used braces early on after my accident but it had been years since I stood upright. More than anything, it was exciting to be able to use my body in a different way. I also enjoyed the challenge of learning a new skill.

- I had the chance to also try the ReWalk exoskeleton, which was great because it gave me the opportunity to see how similar devices work differently. And, like anything, I found that one size/style does not fit all. In my case, I found the Ekso to be a more comfortable device to wear and work. Essentially, it was a better fit. What's great is that there are options for people – more opportunity that something will work."

Do you feel robotic exoskeleton have the potential to improve mobility of individuals with SCI?

- "I feel that robotic exoskeletons have the potential to be a mobility resource for people with SCI. I don't think it will replace a wheelchair, which is about as reliable a device there is for getting around quickly and safely, but I do think in its current form, robotic exoskeletons can be another tool in the tool chest. And, certainly, the physical benefits of being upright can be part of the routine people with SCI use to stay healthy and live healthy lives."

Continue on Page 8

Mobility After Spinal Cord Injury Cont.

In your opinion, non-physical benefits do people experience after using an exoskeleton?

- "I know being at "eye level" with people who are standing is a motivating factor behind using an exoskeleton and that in itself brings great psychological improvement. In my case, the emotional payoff had more to do with the satisfaction of using my body in a new way and the satisfaction of successfully learning a new skill.

- There is a lot to be gained from exerting control in how we interact with our environments – something that is challenged daily when you use a wheelchair. I think robotic exoskeletons can give us a sense of that control even in a controlled setting such as therapy or a study. There is also something to the impact of physical improvement one can experience as the result of using these devices that can be psychologically beneficial – in my case it was the improved flexibility I gained."

Do you believe that the SCI community can benefit from robotic exoskeletons?

- "Braces used for walking have essentially remained unchanged over the years which is why robotic exoskeletons are so exciting to me. It's a major advancement in how technology is being used to bring increased opportunities and options to the SCI community. And, this is only a starting point. It will be exciting to see the technology evolve."

Many exoskeleton devices are relatively unknown to individuals with SCI, while individuals with SCI who are aware of their existence have minimal information to justify purchasing the machine. With Stephanie's insight, and the insight of future study participants, Drs. Heinemann and Jayaraman hope to create a comprehensive reference point for patients interested in using exoskeletons in therapy and potentially as a daily mobility device.

We want to hear from you!

Interested in other SCI topics? Want more info? Need to update your contact information?
Want to receive this newsletter by email?
Let us know, contact **Jamal Spraggins** at **312-238-4856** or **jspraggins@sralab.org**

Want to get involved in more research at RIC?

Contact **Dian'Ella Ramsey** at **312-238-1624** or **dramsey@sralab.org** to learn about the Center for Rehabilitation Outcomes Research's (CROR) registry. After you enroll in this registry, we will contact you about CROR's upcoming studies.
Visit **https://www.sralab.org/search?content_type=clinical_trial** for a list of Shirley Ryan AbilityLab's research studies and clinical trials.

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