

Winter Edition 2019



Shirley Ryan AbilityLab

Welcome to the Winter 2019 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at the Shirley Ryan AbilityLab. In this issue you will read about adaptive sports, employment and disability, Shriner Hospital's Caregiver Project, pressure injury aids and treatment, and our new Beyond the Research video spotlight.

Enjoy!

Beyond the Research: Video Series

Midwest Regional SCI Model System staff have launched a new video series that provides insights and inspiration to living life after SCI. Sam Schroth shares her touching story on perseverance, mentorship, and the value of research in improving quality of life after SCI.



Sam Schroth

Check out the full video here: <https://www.youtube.com/watch?v=AWUeAueVNpU&t=15s>

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

Are you approaching 1, 5, 10, 15, 20, 25, 30, 35, 40, or 45-year(s) since your 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.

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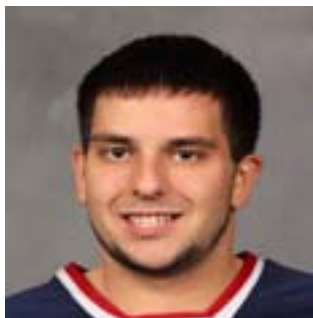
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Adaptive Sports: Anyone Can Try

A spinal cord injury (SCI) does not have to keep you from being active. Adaptive sports and recreation are good for your health and well-being. Recovering and discovering abilities that mean the most to you includes returning to those activities that are important to your happiness. Many options are available: Outdoor recreation activities (for example, adaptive kayaking, fishing, or snow skiing) performing arts (for example, adaptive dance group), individual sports (for example, wheelchair racing or hand cycling), team or competitive sports (for example, wheelchair basketball, wheelchair tennis, quad rugby, or sled hockey)



Kevin McKee, Forward

We caught up with Kevin McKee, to learn about his experience playing sled hockey and his advice for people with SCI who are seeking athletic opportunities. Kevin is an American USA paralympic sledge hockey player as well as on the Shirley Ryan AbilityLab Blackhawks team. He has also won a gold medal with the American team at the 2014 Winter Paralympics.

How did you first find out about sled hockey?

I grew up in Iowa and they started a program here about 18 years ago. My sister was a figure skater at the time so we were at the rink. My mom saw a flyer for it and we just went to it and I fell in love right away. My uncles got me into hockey because one was from Minnesota and one was from San Jose and I got into it because of them and regular hockey. So once the program started here I went for it. Our program here in Iowa was more of a recreational program so once I got better I went to RIC which is now Shirley Ryan AbilityLab.

Growing up in Iowa; would you say being on a team gave you the opportunity to form more relationships or have a sense of community?

Oh for sure, especially being a young disabled athlete. It gave me a huge boost of confidence being around those guys and being around other people that had disabilities. I think that is key for younger people like myself who were born injured or people who have an injury later on that is a huge reason that helps them be successful. That has been huge for me.



McKee and JPaul

Do you have a favorite song you listen to before games or anything that pumps you up?

Not really any songs I did that stuff in the beginning but what I like to do now is be loose and joking around. When I do that kind of stuff I don't think about the game and I can just go out and I don't get nervous or over-analyze stuff. At least I have noticed with our team we play our best games that way. I am also the guy on the team that likes to play pranks and that kind of stuff. I find that doing that before games I do better and the team does better.

What would you say is the best prank you have pulled?

I did one to Brody who is also on the Blackhawks team too. On a US trip he got me on one and then I disassembled his wheelchair. He was playing poker so I convinced him that one of the other guys needed to borrow his chair to go to the pool and I borrowed some tools from the equipment guy and took his wheelchair apart.

Adaptive Sports: Anyone Can Try

What is some advice you would give to someone who wants to get involved?

I would give someone the advice to not give up right away and try everything. Hopefully-I mean there are so many options in the Chicagoland area-different sports and different programs. You have to give something a try and you will find something you are interested in. With sled hockey I tell people not to give up right away because it is harder in the beginning with balancing, and skating, and puck handling, it is a lot. It is different because you aren't in a wheelchair and a lot of people are used to being in their chairs in sports so it is different. My advice is to try everything and not give up.

What is your favorite part about playing?

Definitely the speed of the game is the best part about the sport. It is such a fast paced game and just over the time I have played I have noticed how it has gotten better and better over the years especially at the international level. It is just so fast, it is crazy. It is starting to get to a regular hockey speed almost. They are taking it more serious and it is getting bigger in popularity and people are starting to work out more and stuff like that and that is helping the sport.

For information on how to get involved check out: <https://www.sralab.org/services/adaptive-sports-and-fitness-program>

Our Lab News

Rehabilitation Research Training Center on Employment of People with Physical Disabilities

To promote keeping workers working, a Department of Health and Human Services agency recently awarded the Shirley Ryan AbilityLab's Center for Rehabilitation Outcomes Research a five-year, \$4.375 million grant to research and promote positive employment outcomes for people with physical disabilities. This is the first grant of its kind awarded to the AbilityLab.

The five-year grant by the National Institute on Disability, Independent Living, and Rehabilitation Research establishes a Rehabilitation Research Training Center on Employment for People with Physical Disabilities.

“While many people with functional disabilities are in the prime of their careers, they’re at high risk for job loss and unemployment,” said CROR director Allen Heinemann, PhD. “With the RRTC, we will create best practices and new resources, bending the arc to help people maintain steady, fulfilling employment.”

The grant will fund research, forums, consumer and employer education, and will develop a knowledge translation strategy that builds on an established KT infrastructure to disseminate and implement findings.

The Center will investigate how chronic pain affects employment; identify the barriers to and facilitators of job retention; develop strategies that support employment for people with Parkinson’s disease and other progressive neurological disorders; and create evidence-based decision support for requesting reasonable accommodations under the Americans with Disabilities Act.

Employment After Spinal Cord Injury



Being able to work provides people a way to interact with other people, higher self-esteem, and overall life satisfaction. People working after a spinal cord injury tend to live longer, have better health, and higher life satisfaction. Vocational Rehabilitations services are a great resource for people interested in employment.

What is vocational rehabilitation?

Vocational rehabilitation programs offer a wide range of services to help people with disabilities find jobs. Rehabilitation Counselors are trained to provide these services. These services help people with their interests and skills; training or education; finding and applying for jobs; and getting accommodations for their job.

How does it work?

Assessment

Your rehabilitation counselor will begin by helping you to find your interests, skills, limitations, health needs, work history, education history, and even personality style.

The job market

Your rehabilitation counselor can help you look at job opportunities in your area, wages, tasks, education needed, and other information.

Landing a job

If extra help is needed, a rehabilitation counselor can help determine whether a potential job would be a good match for you.

Getting support at work

You might need ongoing support and accommodations at work and counselors can provide you with resources.

Authorship:

Employment after Spinal Cord Injury was developed by Kurt Johnson, PhD and Jim Krause, PhD, in collaboration with the Model Systems Knowledge Translation Center.

For more information check out: <https://msktc.org/>

Work vs. Benefits: finding a balance

People can be hesitant to work because they do not want to lose their medical benefits under Social Security Disability Insurance, Supplementary Security Income, or private or state long-term disability insurance. Federal work incentive programs under SSDI or SSI allow people with disabilities to receive benefits and federal health care (Medicare and/or Medicaid) while still keeping some of their earnings from work. Some LTD policies include work rehabilitation benefits or incentives to return to work. You might want to consult with a vocational rehabilitation counselor, a resource specialist, or a social worker familiar with benefits systems because they can be confusing.

The law protects you

The Americans with Disabilities Act stops employers from discriminating against people with disabilities who fit the job and are able to work with or without accommodations. Employers must make “reasonable accommodations” to your disability. An employer cannot ask you about the existence, nature, or severity of your disability during a job interview. An employer can ask about your ability to perform certain job tasks.

If employment is not possible

Sometimes it is not possible for a person to work after SCI. Volunteering can provide a sense of accomplishment, skills, confidence, and contacts.



Source: MSKTC

The Caregiver Project: A Mixed-Methods Study

For the last four years, a team of researchers has been studying how family caregivers of adults with SCI adjust to their role, what their daily lives are like, and what supports they may need to provide care for their loved one. The study is funded by the U.S. Department of Defense and includes former Shriners Hospitals for Children patients and patients from Shirley Ryan AbilityLab, Schwab Rehabilitation Hospital, and Edward Hines Jr. Veterans Administration hospital. Marquette University also is a study partner. In all, the study enrolled 52 pairs of caregivers and their family members with SCI.

One aspect that sets the study apart from others is that the participants are racially diverse. It's important to understand the needs of all caregivers in order to develop programs that will benefit the diverse group of people with SCI.



Family Caregiver

A number of caregivers we talked to exhibited strengths that helped them succeed in their role. Strengths included staying physically healthy and strong, believing that they could learn the new tasks needed to care for their loved one, and keeping control of their own life. We also found strengths demonstrated by the family as a whole, including bringing “all hands on deck” to care for their loved one, finding humor in everyday situations, and having more than one generation involved in care.

A sister who cares for her brother said: “See, throughout the whole thing, we’ve pretty much been happy. There’s been ups and downs, of course, but there’s never been any moments where we’ve been just like really unhappy or felt too overwhelmed that we didn’t think we could do it.”

A husband who cares for his wife said: “This life has just handed us thing after thing after thing, and it is what is. We hold tight to our faith and our God.”



Kerry O'Rourke, MPH, Research Specialist

We found that the caregivers who reported less depression and anxiety and a higher quality of life were those who had strong emotional support from family and friends and whose family and friends provided practical help with daily tasks. These caregivers also took time to care for their own emotional and physical health.

A wife who cares for her husband said: “Gratefully, we had a lot of support from family and friends and several fundraisers that they did for him, so that kind of buffered our financial responsibilities there. Yeah, it gave me time to focus on myself a little bit when I took the year off. It gave me an opportunity to breathe and still assist him but be able to not be stressed out over working and running a house.”

Caregivers who had smaller support networks, chronic health concerns, and felt lonely or isolated reported more depression and anxiety and considered caregiving to be a burden.

A mother who cares for her son said: “I’m the only one here. My husband passed away a year before [my son]’s accident, so all of the household everything is up to me, inside and out. So there’s a lot to do there. I wake up tired because for 5 years I haven’t gotten to sleep the whole night through. And it’s lonely because my friends have kind of left me.”

One goal of the study is to propose programs that could help caregivers better adjust to their role of caring for a loved one. While all caregivers need support, some may need additional assistance in dealing with depression or anxiety, for example.

Authorship: Scinformer, A publication of Shriners Hospital for Children, Kerry O’Rourke

Wheelchair Lets Users Move While Standing or Sitting

As much as we love covering cool tech that has the ability to make life more fun, there are few things more awesome than technology that can be used to alter people's lives for the better. That is what engineers at Chicago's Center for Bionic Medicine in the Shirley Ryan AbilityLab may have achieved with the creation of a manual standing wheelchair that does not limit its users to sitting down the whole time.



Dr. Todd Kuiken

“It’s an incredibly exciting innovation that expands users’ workspace and, most importantly, enables them to look their peers straight in the eye during interaction. It offers a number of physical benefits as well.”



Participant using the arms of the standing wheelchair on sidewalk

“This is the first manual wheelchair that allows users to move while in both standing and seated positions,” Dr. Todd Kuiken, who led the research, told Digital Trends. The wheelchair’s unique hand drive mechanism lets users manually drive the wheels while sitting or standing, along with any position in between.

While they do so, they are secured safely in place using a lap belt and knee restraint to protect against falls. “This wheelchair will be transformative for people who haven’t stood in many years and have only looked up at the world,” Kuiken continued. “It will give them the opportunity to converse, directly and at eye-level, with their peers.”

Check out this link for the full video:

https://youtu.be/4I_OTUS9heQ



Participant using standing function to reach for library books

While most of us take for granted simple acts like looking a coworker in the eye when we speak to them, or reaching overhead cabinets and grocery store shelves, for the 1.7 million Americans who rely on wheelchairs or scooters for mobility, things aren’t so straightforward. As a result, a wheelchair like this one could prove to be a life-changer.

“The wheelchair is ready to be commercialized and we are currently in talks with potential commercial partners,” Kuiken said. “In the meantime, we’re working to continually refine the design.”

Authorship: Digital Trends, Luke Dormehl

Research Aids Prevention and Treatment of Pressure Injuries

Registered nurse Samantha Zoellick, who works in Shirley Ryan AbilityLab's Spinal Cord Innovation Center, had a question.

She noticed that many patients with paralysis were arriving at Shirley Ryan AbilityLab with their own positioning devices — everything from standard pillows to specialized foam wedges — to position themselves comfortably. Yet, despite frequent turning by nurses and the use of these devices intended to relieve pressure, some patients were experiencing discomfort nonetheless.

“We're turning patients regularly and closely following clinical protocol, but some still are getting sores,” Samantha said. “We wanted to find the root cause and to address it.”

Samantha wondered if the answer could be found in which devices were being used. Did some work better at helping position patients and relieving pressure on their bodies? Samantha asked her supervisor, Katie Earnest, RN, nurse manager of the Spinal Cord Innovation Center, if she knew of any evidence supporting certain positioning products over others.

“It turns out there really isn't a lot of research on this topic,” Katie said. “So we decided to spearhead some of our own.”

After some discussion in their nursing group, Katie and Samantha brought the idea of studying positioning device effectiveness to the clinical nurse educator.

“I'm eager to put our findings into practice and am hopeful this research will really make a difference for a lot of people,” Samantha said.

“It is essentially an overlay that will be placed on top of patient beds,” Katie said. “We can put individuals — study subjects, patients — on top of that overlay. It will show us where the pressure is, and how much pressure exists, on different pressure points on their bodies. Using this, we can determine how effective we are at repositioning and how effective a certain repositioning device is at relieving pressure.”

The study will collect data for several variables, including different positioning devices, for individuals with and without paralysis.

Katie said. “Nurses are the ones on the frontlines repositioning patients every two hours, 24 hours a day, so it's only natural that we lead this exploration.” The research itself will hinge on a technology called pressure mapping.



Pressure Mapping software



Bed Transfer Lift

Research Opportunity: Clinical Adaptation of Spinal Cord Injury Quality of Life Psychosocial Measures

We are conducting a study to evaluate the Spinal Cord Injury Quality of Life (SCI-QOL) instruments.

Participants in this study will be asked to:

- 1) Answer questions about your age, gender, education, income, description of your injury, your capabilities, your emotions, and your health;
- 2) Meet with a study investigator in person or by phone interview who will ask you questions about your emotions.

Participants must meet the following criteria:

- Sustained a traumatic spinal cord injury at least 1 month ago
- At least 18 years of age
- Able to read, understand, and respond to statements about quality of life
- Read and comprehend English

Participants will be compensated for their time.

For additional information and to see if you qualify for the study, please contact:

Allison Peipert at [312-238-2813](tel:312-238-2813) or apeipert@sralab.org

We want to hear from you!

Interested in other SCI topics? Want to be the next “Beyond the Research:Video Series” guest? Want more information? Need to update your contact information? Want to receive this newsletter by email?

Let us know. Contact [Kayleigh Mann](mailto:kmann@sralab.org) at [312-238-8256](tel:312-238-8256) or kmann@sralab.org

Want to get involved in research at SRALab?

Contact [Emily Anderson](mailto:eanderson@sralab.org) at [312-238-1226](tel:312-238-1226) or eanderson@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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