

Summer 2018



Shirley Ryan AbilityLab

Welcome to the Summer 2018 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS). In this issue you will read about Facing Disability's new video series, a new research project investigating clinical use of low oxygen levels, and our very own SRALab wheelchair basketball teams.

Enjoy!

Facing Disability Launches New Video Project

For many individuals with a new spinal cord injury (SCI), the world of SCI is full of uncertainty about the future. Individuals with a new SCI are often preoccupied with questions such as, "Will I ever be able to have a normal life?" or "Will I ever be independent again?" Without family or friends who can relate to their situation, many people feel isolated and struggle to understand their new world. The stellar care SCI patients receive from Shirley Ryan AbilityLab can help to relieve some of their uncertainties; however, there are not many opportunities for patients to hear from other individuals with SCI about the challenges they've faced and how they were able to live their lives with satisfaction.



Co-Project Directors of the Midwest Regional Spinal Cord Injury Care System, Dr. Allen Heinemann and Dr. David Chen, partnered with Facing Disability (facingdisability.com) to create a video series that explores the experiences of people living with SCI. The 10-part video series is titled "Voices of Experience—Living with Spinal Cord Injury." Each video explores a different topic, ranging from people's greatest fears to maintaining relationships. These videos will be used nationwide to provide answers to some of the most common questions from individuals with new injuries. What sets these videos apart from most is that the people speaking have lived and experienced what they are discussing. Thus, they are able to share firsthand knowledge about what to expect after SCI.

Take a look at the first two episodes: "What was your greatest fear at first?" <https://youtu.be/9Tpgwbuf1Q> and, "What was the hardest part of the first days in the hospital?" <https://youtu.be/-YnjgP7c7V4>. Eight more videos will be released through the upcoming year.

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.

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SRALab Adaptive Sports are Flying High

Being involved in the world of sports can be a fulfilling lifestyle. Through dedication and hard work, many athletes learn discipline, the importance of a work ethic, and teamwork. For individuals with spinal cord injury (SCI), it may seem like shooting hoops or hitting home runs is out of reach. This could not be further from the truth!

SRALab's Adaptive Sports Program offers youths and adults with a physical disability a variety of year-round sports and recreation opportunities such as sled hockey, hand cycling, wheelchair rugby, golf, and basketball. One of the more popular sports is wheelchair basketball. In partnership with the Chicago Park District, SRALab has organized several teams that compete nationwide in the National Wheelchair Basketball Association. The wheelchair basketball program is open to all individuals with lower body physical impairments. A common misconception is that you have to be a wheelchair user to participate, but this is not true. Teams travel all over the country to compete against some of the top teams in the nation.



SRALab offers 4 teams:

- **Adult Teams**

- Chicago Skyhawks (NCAA Division 3): meet on Wednesdays & Fridays from 6:00 - 9:00 pm at Jesse White Community Center 410-412 W. Chicago Avenue, Chicago IL 60610.
- SRALab Hornets: meet September – April on Tuesdays from 6:00 - 9:00 pm at S.J. Gregory Auditorium 5649 N. Sheridan Rd., Chicago, IL 60660.

- **Junior Teams**

- Junior prep: Ages 6-13 years old
- 10 foot team: Ages 13-21 years old or enrolled in high school
- Meet to practice on Saturdays from 9:00 am - Noon at Rainbow Beach Park 3111 E. 77th St., Chicago 60649

We caught up with the head coach of the junior prep team and sports coordinator for SRALab, Mark Schultz, to learn about his experience coaching and advice for people with SCI who are seeking athletic opportunities.

How did you get your start coaching SRALab's Wheelchair Basketball Program?

- Through my previous work in special recreation, working with people who have cognitive impairments, I was introduced to adaptive sports. I was looking for a change and really enjoyed working with athletes with physical impairments, so when the opportunity to coach at SRALab came up, I did not hesitate.

What has been your best experience as a coach?

- As a coach, I just like seeing our players enjoying new experiences. We get to travel all around the nation and for some of our players, it is their first time travelling since their injury. I remember one of our junior players came up to me in excitement because we were driving to Fort Wayne, Indiana for a tournament. To me we were just travelling to Fort Wayne, but for him, it was his first time ever leaving Chicago and to provide that opportunity was a great feeling.

Has being a part of the team resulted in any significant benefits for your players?

- I think the biggest benefit for most of our players is the ability to get involved in a community. Living with a spinal cord injury you are constantly thinking "What do I do now?" The family environment and close bonds that you form joining SRALab basketball really helps our players to see that they are not alone. Playing, travelling, and practicing with teammates who share your story is pretty much invaluable as a player and coach.

What improvements would you make to the program?

- There is always room for growth. I know there are so many more athletes out there for us to reach and we are developing ways to expand throughout Chicago. Eventually we would like to have our own SRALab basketball league.

For more information about Junior SRALab Wheelchair Basketball, contact Junior Head Coach, **Mark Schultz** at mschultz@sralab.org or **(312)-238-5011**.

For more information about Adult SRALab Wheelchair Basketball, contact Manager of Sports and Recreation, **Derek Daniels** at **(312)238-5001**.

Visit <https://www.sralab.org/services/adaptive-sports> to learn more about all of the adaptive sport programs that SRALab has to offer.

Depression & Spinal Cord Injury



Depression is common and can affect anyone. About 1 in 20 Americans (over 11 million people) become depressed every year. Depression is even more common in the spinal cord injury (SCI) population—about one in five people. Estimated rates of depression among people with SCI range from 11% to 37%.

What is depression?

Depression is not just “feeling blue” or “down in the dumps.” It is a serious medical disorder (just like diabetes, in which both biology and behavior can help or hurt). Depression is closely linked to your thoughts, feelings, physical health and daily activities. Depression affects both men and women. Depression can cause some or all of the following physical and psychological symptoms:

- Changes in sleep (too much or too little)
- Feeling down or hopeless
- Loss of interest or pleasure in activities
- Changes in appetite
- Diminished energy or activity
- Difficulty concentrating or making decisions
- Feelings of worthlessness or self-blame
- Thoughts of death or suicide

Causes of depression

Although we don't know for sure what causes depression, we do know that life stresses and medical problems can cause a change in certain brain chemicals, called neurotransmitters. This chemical imbalance is linked to changes in mood, enjoyment, sleep, energy, appetite and ability to concentrate.

Depression can and should be treated

The good news is that the symptoms of depression can almost always be treated with specific types of counseling or antidepressant medications. However, a combination of both counseling and antidepressant medication has been shown to have the best results. Regular exercise or physical activity can also improve mood, especially when used together with counseling.

It is important to treat depression because it can have such a harmful effect on a person's ability to function in day-to-day life.

Depression can make pain worse, make sleep difficult, sap your energy, take away your enjoyment and make it difficult for you to take good care of your health. Untreated depression can last 6 to 12 months or more. Thoughts of death are a symptom of depression. The risk of suicide is higher while someone is depressed. Due to both brain chemistry and thought patterns, often people who have severe depression and suicidal thoughts have difficulty seeing a way out of their problems. Suicidal thinking goes away once depression is treated.

What counseling really is

Counseling or psychotherapy is often misunderstood. There are many different kinds of therapy, but one type that has been proven to help depression is called “cognitive-behavioral therapy.” Cognitive-behavioral therapy is based on the idea that depression improves when people are more engaged in meaningful activities and when they regain their positive beliefs and attitudes about themselves, their world and their future. The therapist helps you find or resume activities that are meaningful or enjoyable to you. There will be barriers to overcome, so the therapist supports you like a coach to help resolve the problems you face. The therapist also helps you recognize how your thinking becomes more negative in depression and how, through experimentation and logic, you can improve your outlook and rebuild confidence.

How do antidepressants work?

Antidepressant medications seem to work by restoring a normal balance of important brain chemicals such as norepinephrine and serotonin. Rebalancing these chemicals leads to feeling better both emotionally and physically. Treating depression can also help you function better at home and at work. Antidepressants are not addictive. Some people experience side effects, but they tend to lessen over time.

Depression & Spinal Cord Injury, Cont.

Depression Self-Test

For each of the nine items listed below, circle the number (0-3) that corresponds to how often you have been bothered by that problem over the past two weeks.

Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or no pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite: being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3

What you can do

1. Take a “depression self-test” like the one above.
2. Answer all the questions honestly, add up your score and see where your score falls.
3. If your score is 10 or higher and you have been feeling this way for more than a week or two, contact your health care provider or a psychologist, psychiatrist or counselor who has experience treating depression.
4. If you are having thoughts of death or suicide, contact your health care provider or a mental health specialist immediately. Also, inform those around you about how badly you are feeling so that they can support you and help keep you safe while you go through this difficult period.

If you are in danger of harming yourself now, please call 911, the 24-hour National Crisis Hotline at 800-273-8255, or your local Crisis Clinic right away.

Remember, depression is not a necessary or inevitable part of living with SCI. In fact, most people with SCI are not depressed. If you are struggling with depression or feeling low for more than two weeks, talk to your doctor. Depression is treatable and beatable.

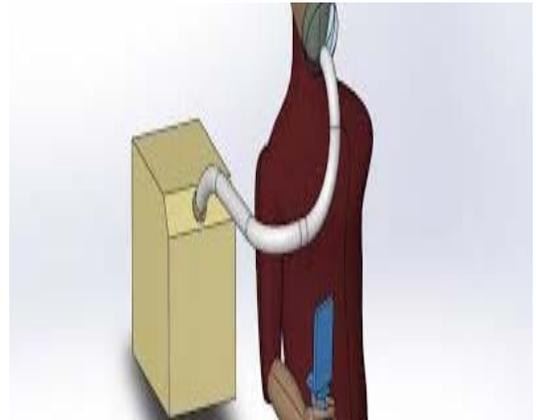
How to find help

Many mental health professionals are qualified to treat depression. For example, psychiatrists have specialized training in medication management for depression and psychologists are trained to provide counseling for depression. Other physicians, such as primary care physicians, neurologists and physiatrists, and nurse practitioners with experience in treating depression can often get treatment started and refer you to mental health professionals when needed. When available, seek treatment from a comprehensive spinal cord injury rehabilitation program that can address all aspects of SCI recovery.

Authorship: Depression and Spinal Cord Injury was developed by Charles H. Bombardier, PhD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

Using Acute Intermittent Hypoxia as a Therapeutic Intervention for Individuals With Spinal Cord Injury

A new and relatively simple approach to improve function in people with some types of tetraplegia is being evaluated at the Shirley Ryan AbilityLab. During this therapy, a person breathes air with of low oxygen through a face mask, similar to being on the top of a high mountain – for about a minute, alternating with normal air. As a result of this treatment, proteins are released within the spinal cord that strengthen the connections between the brain and spinal cord. This treatment temporarily strengthens neural connections, and when combined with rehabilitation, may enhance function.



Known as acute intermittent hypoxia, this approach may increase strength in ankle muscles within a few minutes. Coupling daily intermittent hypoxia with walking training for one week enhanced walking recovery in a recent study, compared to walking training alone. Importantly, no one has been harmed during this study. Although studies have looked at walking, we know little about acute intermittent hypoxia effects on arm and hand function. Dr. Sandhu's team seeks to learn if – and how – this treatment, either alone or in combination with training, might improve strength and function in the arm and hand. He is conducting a clinical trial which focuses on daily intermittent hypoxia along with various forms of training.

If Dr. Sandhu's team is able to demonstrate the effectiveness and safety of intermittent hypoxia combined with intense upper limb training, the next step will be to learn how to use this procedure in clinical settings. The information from his studies will help us understand the effectiveness of intermittent hypoxia and which patients could benefit.

We spoke with Dr. Milap Sandhu, the Principal Investigator for this study, and got his take on how he believes this study can benefit people with SCI.

Tell me about your experience with Intermittent Hypoxia thus far.

- Intermittent hypoxia is a unique therapy that is being investigated for improving recovery after spinal cord injury. During this therapy, patients breathe low oxygen air from a face mask for about 60 seconds. This level of low oxygen is similar to being on a tall mountain.
- Low oxygen air helps patients form new proteins that can strengthen the connections between the brain and spinal cord. This process is called “plasticity,” and plays a big part in the success of most rehabilitation therapy. I take great joy in helping to support rehabilitative training with intermittent hypoxia.

Using Acute Intermittent Hypoxia as a Therapeutic Intervention For Individuals With Spinal Cord Injury, Cont.

How could intermittent hypoxia be used in the future?

- Intermittent hypoxia therapy is at an early stage of development, but compared with other restorative therapies it is relatively inexpensive and induces rapid spinal cord strengthening. While intermittent hypoxia could eventually be a stand-alone therapy, we believe its ultimate use will involve pairing with rehabilitative training.
- This therapy seems to open up a temporary window when individuals are able to generate more strength. Intermittent hypoxia before rehabilitation could improve the benefits of training.

How do you believe that people with SCI can benefit from intermittent hypoxia?

- In the short term, we will be able to determine the effectiveness of this therapy in a diverse group of patients with SCI. We will gain critical insights into dosage, timing, and other aspects of hypoxia therapy. If we are successful in using hypoxia therapy to boost the benefits of rehabilitation, the next issue will be how to best use this approach in clinical settings.
- I hope that this strategy may be used outside of a medical rehabilitation facility, such as in a physical therapy clinic. In the long term, this treatment could help people with SCI get back into their everyday life, as well as improve their sense of autonomy, confidence, and self-esteem.

While intermittent hypoxia is still in development, the use of this therapy with conventional rehabilitation therapy may improve the independence of people with SCI.

With Dr Sandhu's insight and the contributions of people who participate in this study, we hope to create a way to improve therapy that will increase function and overall quality of life.

For more information on Intermittent Hypoxia, contact:
Sofia Anastasopoulos (sanastasop@srilab.org) 312-238-1173 or
Milap Sandhu (m-sandhu@northwestern.edu)



Milap Sandhu, Research Assistant Professor of Physical Medicine and Rehabilitation

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** or apeipert@sralab.org

We want to hear from you!

Interested in other SCI topics? Want more information? Need to update your contact information? Want to receive this newsletter by email?

Let us know. Contact **Ontonio Jackson-Lucas** at **312-238-4442** or ojacksonlu@sralab.org

Want to get involved in research at SRALab?

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.