

Summer 2020 Newsletter

Welcome to the Summer 2020 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at Shirley Ryan AbilityLab, formerly RIC. In this issue, we provide COVID-19 updates, including tips for taking care of your physical and mental health. Keep reading to find out what to expect as you age with a spinal cord injury (SCI) and learn about research

opportunities you can participate in. A lot has happened since our last newsletter in January. We hope that you and your loved ones are safe and healthy. MRSCICS and SRA Lab stand united against all forms of racism. We will continue fighting for equality in healthcare and beyond. Thank you, as always, for participating in spinal cord injury research. Enjoy!



Shirley Ryan AbilityLab Flagship Hospital – Chicago, IL

What is MRSCICS?

MRSCICS is a research study about outcomes after spinal cord injury. When you were an inpatient at Shirley Ryan AbilityLab (formerly RIC), you enrolled in this study and completed your first interview. We contact people one year after their injury for another interview, and then once every five years. The study has been going on since the 1970s, and

there are currently 14 hospitals that participate around the United States. The information we collect from you is entered into a database online for researchers to analyze. The findings are used to develop treatment plans, community outreach programs, and policies to help more people with SCI.

Are you due for a follow-up interview?

We will contact you by phone, mail or email to schedule a time to complete your interview. If you've moved or changed phone numbers in the past 5 years, we may not have your new information.

To update contact information, please call Jennifer Burns at 312-238-2826, or email jburns03@sralab.org

INSIDE:

COVID-19 and MRSCICS
Learn how this study is adapting to COVID-19

Mental Health
Advice on managing mental health during this pandemic

Aging with SCI
Learn about getting older with SCI

COVID-19 and the SCI Model Systems

Almost everyone in the world has been affected by COVID-19 in some way. Shirley Ryan AbilityLab is still running as a fully functional rehabilitation hospital during the outbreak, admitting new patients every day and providing essential therapies, although some outpatient services have paused for everyone's safety. Hospital visitors and staff members are screened for fevers and symptoms before they're allowed to enter the building. Clinical visits, like annual check-ups with doctors, are taking place online through Telehealth as much as possible. Research projects, like the Midwest Regional SCI Model System study, continue remotely as much as possible.



Luckily, the MRSCICS long-term follow-up study can continue while we work from home. This means that we are enrolling new patients to the study via email and phone, and we are conducting the 1- and 5-year follow-up interviews via email, mail, and phone.

That said, there are some small changes to the way we're operating. For example, the study team does not have regular access to mail, so there may be some delays if you completed your follow-up interview on paper or mailed back a contact preferences sheet. We forwarded our office phones to our remote phones, so you can call us and leave voicemails as usual. Our outgoing calls (i.e., when we call you) may come from 312-238-2802, or show up as 'anonymous' or 'private caller' on your caller ID. We understand that you may not answer 'anonymous' calls, so we will always leave a voicemail with a call-back number. We are always available through email, as usual.

Whether you had your spinal cord injury a few months ago, or a few decades ago, it is more important than ever to take care of your health. There is so much information coming out about COVID-19 that it can be

stressful and confusing to keep track of it.

Wash your hands with soap and water. If you have a personal care attendant, nurse, friend or family member who helps you with daily activities, remind them to wash their hands! You should always wash your hands before and after eating, preparing food, caring for someone who is sick, and performing bladder, bowel, or other medical care.

Social distancing lowers your risk of contact with someone who is infected. However, we know that is not possible for some people. Try to stay at least 6 feet away from others. Remember that people without symptoms can still spread the virus, and germs from coughs and sneezes can travel over 20 feet.

Wear a mask if you need to go to public areas. Your mask should cover your mouth and nose. Wash your hands before and after putting on and taking off your mask. REMEMBER that the virus that causes COVID-19 is small enough to pass through many masks, so you should still stay as far away from other people as possible!

To learn more and stay updated, we recommend these reliable sources:

National Institutes of Health (NIH): <https://www.nih.gov/health-information/coronavirus>

World Health Organization (WHO): <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

Food and Drug Administration (FDA): <https://www.fda.gov/emergency-preparedness-and-response/counterterrorism-and-emerging-threats/coronavirus-disease-2019-covid-19>

Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/coronavirus/2019-nCoV/index.html>

Find your State Health Department website here: <https://www.cdc.gov/publichealthgateway/healthdirectories/healthdepartments.html>

Find your local health department website and contact information in this directory put together by the National Association of County and City Health Officials: <https://www.naccho.org/membership/lhd-directory>

Taking Care of Your Mental Health During the COVID-19 Pandemic

Even if you and your loved ones are not sick from COVID-19, this is an emotional and stressful time for many people. If you are feeling lonely, sad, down, or anxious, know that you are not alone. Stressful situations, such as the COVID-19 pandemic, affect different people in different ways. Anyone can experience depression or anxiety at any time. However, outside stressors can trigger mental health problems when they might not have happened otherwise. Anxiety, depression, and other mental health disorders are real medical problems with biological causes and environmental triggers—it is not a choice, and it does not make a person ‘weak.’

Whether you’re concerned about yourself or someone else, knowing the symptoms of depression can help identify the problem before it gets worse.

Depression is more than just feeling “sad.” Whether you’re concerned about yourself or someone else, knowing the symptoms of depression can help identify the problem before it gets worse. For example, physical symptoms, like changes in sleep, appetite, concentration, and energy, may be signs that you are experiencing depression, even if you don’t feel “sad.” Many people say that the classic symptom of depression is not “sadness,” but really “loss



of interest or pleasure” in usual activities. This means that things you normally used to enjoy, like talking to friends or watching movies, are not as fun as they used to be. You may feel withdrawn, irritable, or angry at yourself.

Taking care of your mental health can be very empowering. Getting professional help early is one of the best ways to feel better faster. Many mental health providers are offering remote services by phone and online video. There are also some online-only services — Talkspace, Betterhelp, Amwell, 7 Cups of Tea, Doctor on Demand, and more — that offer phone, video, email, or instant chat. Check with your insurance provider to make sure these options are covered under your plan.

If you ever have thoughts that you’d be better off dead, or thoughts of hurting yourself, you should call 9-1-1 promptly. You can also call the National Suicide Prevention Lifeline at 1-800-273-8255, where someone is available 24/7.

If you’d rather not speak on the phone, there are also options for text and online chat:

Lifeline Chat: <https://suicidepreventionlifeline.org/chat/>

I’m Alive Chat: <https://www.imalive.org/>

Crisis Text Line: Text the word “HOME” or “Hello” to 741741 on your cell phone

<https://www.crisistextline.org/>

To learn more about depression after spinal cord injury, read this factsheet: <https://msktc.org/sci/factsheets/depression>

Stay Home! Stay Active!

People with SCI are more likely to get serious infections than other adults. Serious infections can happen any time, whether they are caused by the flu, urinary tract infection (UTI), or something new like COVID-19. Whether or not there is an official “stay at home” order in your area, it is important for people with SCI to be extra safe.

This means washing your hands often, avoiding public areas, and staying away from other people. Physical activity makes your immune system stronger so that your body can fight off sicknesses like COVID-19. If you normally exercise outside your home, it may be difficult to think of ways to stay active at home. If you normally spend most of your time at home anyway, it’s more important than ever to take care of your body. But, it can be hard to motivate yourself to exercise at home. The good news is that there are ways to work on your physical fitness without leaving your bed or wheelchair. Here are a few simple ideas to get started!

Breathing exercises

You may not think of breathing as a physical exercise, but this is one of the best ways to quickly lower heart rate and blood pressure. Breathing exercises may also help with sleep, pain, spasticity, and relaxation. Start by taking a slow, deep breath in through your nose for 8 seconds, and let it out through your mouth for another 8 seconds. Repeat as many times as needed. You can find different guided breathing videos, podcasts, and soundtracks online for free.

Head rolls, shoulder shrugs, stretching and range of motion exercises

Simple motions like head rolls and shoulder shrugs can build endurance and strengthen important muscles. “Range of motion” exercises are all about increasing movement and flexibility around the joints by gentle movement.

Sources:

<https://www.christopherreeve.org/living-with-paralysis/health/staying-active/how-to-get-and-stay-fit-no-matter-what-your-injury>
<http://sci.washington.edu/info/forums/reports/SCI%20Home%20Exercise%20Packet.pdf>



If you have a friend, family member, or assistant available, ask them to help out with range of motion exercises. A helper can also provide gentle resistance to your movements for more of a challenge.

Chair yoga

Yoga combines a lot of the great benefits of breathing exercises with stretching and strength training. Depending on how hard you push yourself, yoga can also be a way to get cardio exercise. You can do yoga anywhere, and there are a lot of different adaptations available for different ability levels.

Weights and bands

If you don’t have weights or bands at home, you can still do exercises with everyday items around your house. Use a rolled-up towel as a resistance band. Canned foods and bottled drinks make great light weights—load up a backpack for something heavier. A hardcover novel weighs about 1-3 pounds, a gallon of milk weighs 8-9 pounds, and a small bag of flour or uncooked rice weighs about 5 pounds.

Research Opportunities

Two At-Home Wheelchair Studies through the University of Pittsburgh Medical Center

The SCI Model System at University of Pittsburgh Medical Center is conducting two studies for wheelchair users. If you use a wheelchair as your main way to get around, you might be eligible to participate!



KeepMvn

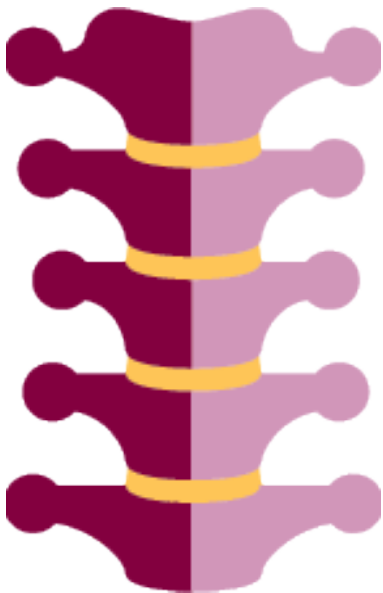
In the KeepMvn study, you'll be asked to download a smartphone app to track wheelchair repairs. Read more about the Wheelchair Maintenance Mobile App (KeepMvn) study here:

Wheelchair Maintenance Mobile App (KeepMvn) Study:
<http://www.upmc-sci.pitt.edu/KeepMvn/>

Wheelchair Maintenance Training

In the Wheelchair Maintenance Training Study, you'll be asked to answer questions about yourself, your wheelchair, and your knowledge of wheelchair maintenance. Researchers will use this information to see if an online training program can be helpful for people trying to improve their wheelchair maintenance skills. Read more here:

Wheelchair Maintenance Training Study Link:
<http://www.upmc-sci.pitt.edu/maintenance/>



To view other remote research opportunities, you can visit the UPCM-SCI website and Facebook page:

UPMC-SCI website Remote Research Opportunities: <http://www.upmc-sci.pitt.edu/research>

UPMC-SCI Facebook: <https://www.facebook.com/upmcsci/photos/a.314439012253345/1120524898311415/?type=3&theater>

Aging with SCI

Why is aging an important issue for people with SCI?

Our body slows down as we get older. Many things that used to be easy become harder. This is true for everyone, including people with SCI. The good news is that people with SCI are living longer because of better health care. The bad news is that people with SCI show signs of aging earlier than other people. As you get older, you may have health problems that you never had when you were younger.

Through research, we've learned a lot about how people with SCI age. People with SCI are more likely to experience chronic pain, bone loss, pressure sores, kidney stones and bladder stones. Certain parts of the body are more likely to age earlier with SCI, such as musculoskeletal (muscles and bones), endocrine (glands and hormones), and cardiovascular (heart and blood) systems.

The way that you age with SCI can also depend on your situation. Things like family health history, level and severity of SCI, and lifestyle behaviors, such as smoking, alcohol, exercise, and diet can all affect your health.

If you notice something change in your body, it may be hard to tell whether it is a sign of 'normal' aging, or a sign of a problem. Talking to your doctor about these changes can help you figure out what to do.

The choices you make about your health now are just as important as the choices you made in the first months after your SCI.

Keys to Successful Aging

Aging is a part of life for everyone. With or without SCI, most adults adjust to physical changes and live happy lives without major emotional problems. Older adults report better relationships with loved ones, more appreciation for life, and changes in priorities. As you age with SCI, it is important to get regular check-ups with your doctor. The choices you make about your health now are just as important as the choices you made in the first months after your SCI, such as working hard in rehabilitation. Talk to your doctor about your emotions and independence, especially if you feel stressed, anxious, or depressed.

Aging well with SCI means staying physically healthy and independent as much as possible. It also means adapting to new limitations, taking care of your emotional health, and participating in activities that are important and meaningful to you.



Aging with SCI continued...

Medical Care Guidelines for Aging with SCI

Things to do every day:

- Check skin, stay active, eat healthy

Things to do every month:

- Breast or testicular self-exam

Things to do every 1-2 years:

- Physical check-up with your doctor: Check weight and blood pressure, fecal occult blood test
- Annual flu shot (especially for people with injuries T8 and higher)
- Mammography (Women 40 years and older)
- Comprehensive eye exam (55 years and older)
- Digital rectal exam and PSA (prostate specific antigen) test (Men 75 years and older)

Things to do every year during first 3-5 years after injury:

- Full history and physical check-up with doctor
- Assess adaptive equipment and posture
- Assess motion, contractures, and function
- Full skin check
- Bladder and urethra exam

Things to do every 2-3 years:

- Complete blood count with biochemistry
- Women: Breast cancer exam, gynecological exam and Pap test

Things to do every 5 years:

- CT scan or X-ray of colon
- Screening sigmoidoscopy (doctor looks inside large intestine with a flexible scope) (50 years and older)
- Full lipid panel (35 years and older for men, 45 years and older for women)
- Motor and sensory testing with SCI team
- Assess lung function, lung capacity test

Here are a few tips:

- Don't be afraid to adapt the way you do certain activities if you need to.
- Use the right equipment—wheelchairs, special beds, cushions, braces, etc.—to help you with everyday tasks.
- Get help from others as needed, but keep your independence. Even if you need physical help with your daily activities, you can still make decisions about your health and daily life. This includes hiring, training, and firing helpers.
- If possible, find more accessible housing.
- Participate in social activities that you enjoy to connect with others.
- Stay active.
- Learn something new.
- Get regular check-ups and follow a health plan.
- Volunteer or get support from organizations in your community, such as independent living centers, aging and disability centers, and faith-based organizations.



Model Systems
Knowledge Translational
Center

Coronavirus / COVID-19

STAY HEALTHY

This article summarizes a factsheet developed by MSKTC titled, "Things to Know About Aging and Spinal Cord Injury." To read the full factsheet and find more resources about living with a spinal cord injury, visit their website at www.msktc.org

VOLUNTEERS NEEDED for a Study for Women with Spinal Cord Injury



The research study will test “ZEST,” a group program for women with SCI to be held in Second Life[®], an online virtual world.

Welcome to



You may be eligible if you:

- Are a woman at least 18 years of age
- Have had a traumatic spinal cord injury (SCI)
- Have had your injury for at least 1 year
- Have access to a computer with high speed Internet
- Are able to use a computer and communicate in online group conversations in English

Eligible women will be randomized (like flipping a coin) to either the intervention group or a control group. Those in the intervention group will participate in a 10-session weekly program. Both groups will complete questionnaires on three occasions. A small payment is offered for participation. Enrolling through August 2020

CONTACT THEM!

by phone: **713-797-7572** by email: **Zest@memorialhermann.org**
Please leave your name and phone number, and they will contact you right away.

This research study is being funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. It is conducted by the Spinal Cord Injury and Disability Research Center at TIRR Memorial Hermann, the University of Texas Health Science Center at Houston, the University of Montana, and Baylor College of Medicine.

Want to get involved in our research?

Contact Nick McCombs at **312.238.4856** or **nmccombs@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 **sralab.org/clinical-trial** for a list of Shirley Ryan AbilityLab's research studies and clinical trials.

We want to hear from you!

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

Contact Jenny Burns at **312.238.8256** or **jburns03@sralab.org**

The contents of this newsletter were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90SI5009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this newsletter do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.