

## WINTER 2021

Welcome to the Winter 2021 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at Shirley Ryan AbilityLab, formerly the Rehabilitation Institute of Chicago (RIC). The MRSCICS research study started at RIC in the early 1970's to help researchers and doctors understand

what happens to people with a traumatic spinal cord injury (SCI) after they leave the hospital. The MRSCICS team contacts participants for interviews, or surveys, 1 year after SCI, 5 years after SCI, and then every 5 years after that. Researchers use this information about health and daily life to improve therapy, community pro-

grams, and educational resources for people living with SCI. You enrolled in this study while you were a patient at SRAlab (or RIC), and you are receiving this newsletter as a 'thank you' for participating! In this edition, we share exciting new research projects and highlight educational info to help you stay informed. Enjoy!

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Shirley Ryan AbilityLab flagship hospital at 355 E. Erie St in Chicago

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.



# Expanding the Rehabilitation Measures Database

## What is the Rehabilitation Measures Database?

The Rehabilitation Measures Database (RMD) is a collection of over 500 tests to measure rehabilitation outcomes. These tests are standardized, so everyone is given the same questions or tasks to complete and it is always scored the same way. When you take a test for the first time, you will get a baseline score. Later, you can repeat the test and your new scores can be compared to your baseline to measure your progress.

Every test in the RMD has a summary that includes a short description, instructions for using and scoring the test, and a link to the test if it can be found for free. These summaries are written by students as part of their training to become physical therapists, occupational therapists, counselors, and other types of rehabilitation workers. Then, staff at Shirley Ryan AbilityLab check the summaries for accuracy and completeness. This helps to keep the RMD up to date and teaches students how they can use it after they finish school and begin working.

We have seen huge growth in RMD use over the years. When the RMD was released in 2011, it had an average of 1,300 views per day. In 2020, the RMD averaged 12,750 views per day. Our viewers are therapists, doctors, nurses, researchers, and patients from more than 150 countries. They use the RMD to build rehabilitation plans, check the patient progress, and learn more about the tests that they use.

## How is it expanding?

We received funding for a new grant from the National Institute on Disability, Independent Living, and Rehabilitation Research, which is the same organization that funds MRSCICS. We will use this funding to make information about tests available and understandable to people who need it, including patients, rehabilitation workers, and students. The goal of the project is to help people living with physical disabilities--and their family and friends--understand the tests and measurements used during rehabilitation so they can participate more in their own care and recovery. We plan to give patients, doctors, researchers, and educators one website to find information about standardized tests.



## The new project has 4 aims:

1. Improve patients' and care partners' understanding of the standardized tests in the RMD
2. Help students easily add standardized tests in clinical practice
3. Promote the regular use of standardized tests in clinical practice
4. Share information on standardized tests to patients, care partners, students, and doctors

## What is the connection to MRSCICS?

Summaries of tests on the RMD are grouped into categories based on which conditions they are designed to measure. One of the categories is made up of tests specifically related to spinal cord injury (SCI). The funding for the MRSCICS project also helped pay to add SCI-related tests to the RMD. Today, the RMD has 134 SCI-related tests. Our goal is to improve these resources for people living with SCI and other physical disabilities by making them easier to understand for everyone. We hope this will help patients communicate with their rehabilitation team and improve overall care.

You can check out the RMD at <https://www.sralab.org/rehabilitation-measures>. It is easy to use and there are simple tests you can do for free at home. Over the next few years, we will be adding more information for individuals living with a disability. You can contact us at [rehabmeasures@sralab.org](mailto:rehabmeasures@sralab.org) if you have any suggestions, questions, or concerns. We are also planning online focus groups for people to share their opinions about how to make the RMD more user-friendly, but availability is limited! If you are interested in participating, please send us an email.

# COVID Corner

## Is Covid-19 more dangerous for people with SCI?

Having an SCI weakens the immune system overall, making it harder for your body to fight off infections. Complications related to SCI, such as respiratory weakness, urinary tract infections (UTIs), and pressure sores, also make Covid-19 more dangerous for people with SCI. Everybody is different--your overall health and lifestyle can make a big difference--but we recommend that people with SCI take extra care to protect themselves against any illness, including Covid-19.

## What can I do to stay safe?

Wash your hands. Wear a mask. Keep your distance from other people. These are the easiest and best ways to protect yourself and your loved ones.

## Should I get the vaccine?

Talk to your doctor about your specific situation. If a health care provider gives you the 'okay,' we recommend getting the vaccine as soon as possible. Because people with SCI are more likely to get sick, the vaccine may be especially important for you.

## Where can I learn more?

[The Christopher & Dana Reeve Foundation: Coronavirus and SCI](#)

[Memorial Hermann: Covid-19 and the Spinal Cord Injury Patient](#)

[Center for Disease Control and Prevention: Covid-19 Vaccines](#)



## Research Highlight: Turning Thoughts into Movement

Using mind control to move robots may sound like something out of a movie, but this exciting study is very real! Researchers at the Universities of Chicago and Pittsburgh are working toward a future where we can control computers and robots using just our thoughts.

As a first step, they are developing technology that helps people with disabilities, including people with SCI, control a robotic limb in place of their own paralyzed one.

### How does it work?

First, there is a surgery to put sensors into the brain. The sensors are very small (Figure 1). They are used to communicate between the brain and the robot, so the robot 'knows' what the brain is thinking. Then, when someone tries to move their own limb, the sensors use those brain signals to move the robotic limb. This method is called Brain-Computer Interface (BCI).

Right now, this study is focused on controlling robotic arms, but BCI can actually be used with anything that connects to a computer. This means it is possible to use

our thoughts to control a phone, a computer cursor, and other types of robots. There are many possibilities to explore.

Not only can these sensors turn thoughts into movements, but they can also activate parts of the brain to produce very realistic touch sensations on the paralyzed hand. The user can pick up an object with the robotic arm and actually feel the object through it, almost as if it were their own hand!

In 2012 in Pittsburgh, Jan Scheuermann, who is completely paralyzed below the neck, was the first to use this technology to control a robotic arm. She was able to move objects, shake hands, and even feed herself chocolate (Figure 2).

A few years later, Nathan Copeland was the first person to experience artificial touch. "I can feel just about every finger" he said a month after receiving the electrodes. "Sometimes it feels electrical and sometimes its pressure, but for the most part, I can tell most of the fingers with definite precision. It feels like my fingers are getting touched or pushed."

Nathan had not been able to feel anything in his hands for over 10 years due to a high-level SCI. Being able to feel touch again allowed him to move the robotic limb more confidently, quickly, and skillfully.

Both Nathan and Jan were motivated by a desire to help others. In 2012 Jan told Scott Pelly of 60 Minutes, "I've

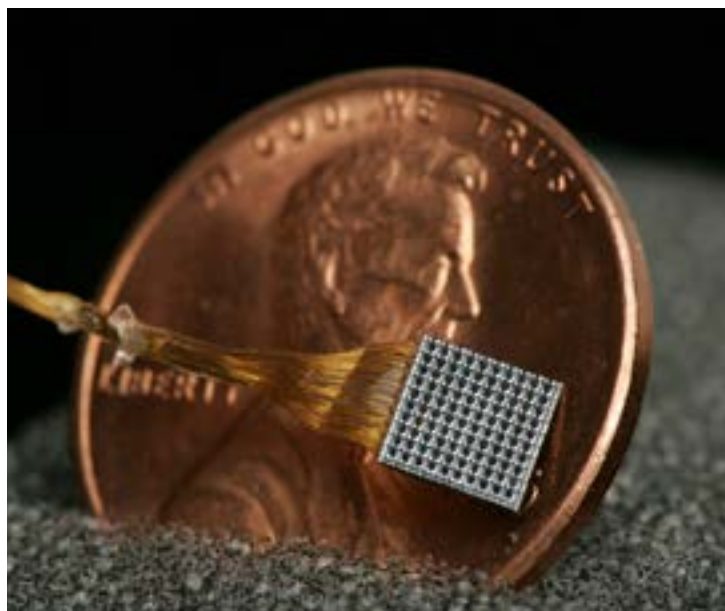


Figure 1. Size of electrode (photo credit: Blackrock Microsystems)

always believed there's a purpose to my illness. I didn't think I would ever find out what it was in my lifetime. And here came this study where they needed me. You know, they couldn't just pick any Tom, Dick or Harry off the street. And in a few years, the quadriplegics and the amputees this is just going to help."

Nathan agreed, saying "I wanted to help build a future where people in similar situations won't have to go through the hardships I did after my accident."

The Chicago team has been working with the Pittsburgh team for over a decade to create this study. To support the work in Pittsburgh and speed up the development of this technology, human testing will also be happening in Chicago.

So far, the focus has been on picking up and moving objects, but that's just the beginning. Our hands can do a wide range of things, and next generation brain-con-

trolled bionic hands will be more versatile, allowing users the ability to control the fingers individually and experience more natural touch sensations. While Jan was ecstatic to be able to feed herself a chocolate bar, new participants may be able to open one and snap off the individual pieces.

Most of us will have to wait to control robots with our minds, but the researchers and participants at the Universities of Chicago and Pittsburgh are working hard to make it a reality for those who will benefit the most.

**If you are interested in participating in this research project, contact John Downey and his team at the University of Chicago:**

**[bcistudy@uchicago.edu](mailto:bcistudy@uchicago.edu)  
773-834-5204**

*"Sometimes it feels electrical and sometimes its pressure, but for the most part, I can tell most of the fingers with definite precision. It feels like my fingers are getting touched or pushed."*



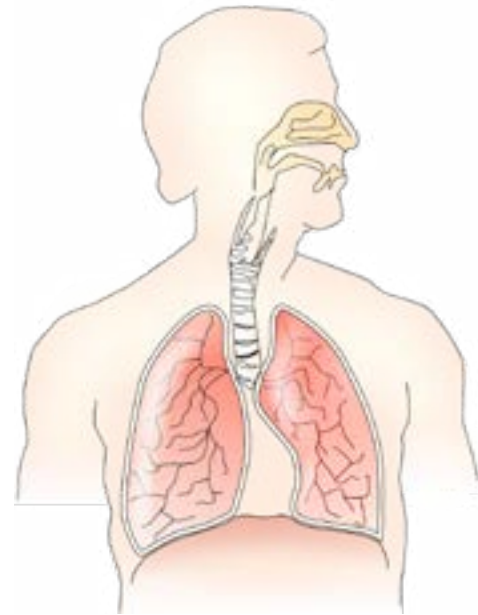
Figure 2. Jan controls a robotic arm by thinking about bringing the chocolate to her mouth. (photo credit: UPMC)

## Respiratory Health and SCI



The respiratory system is responsible for breathing. Our bodies need oxygen to survive. Our bodies also produce carbon dioxide, which needs to be removed to prevent acid from building up. The respiratory system puts oxygen into your blood when you inhale (breathe in), and takes carbon dioxide out of your body when you exhale (breathe out).

Breathing happens automatically, which means you don't have to think about it. But it is actually a complicated process that requires your brain to control every breath. Your brain does this by sending signals down your spinal cord to the nerves in your neck area, which causes your diaphragm to contract. Your diaphragm is a muscle under each lung. When your diaphragm contracts, or tightens, it moves down to create more space for fresh air with oxygen to flow in. This is what happens when you inhale, or breathe in. When you exhale, or breathe out, the diaphragm relaxes and moves back up. This pushes air with carbon dioxide out of your chest. Your lungs take fresh oxygen and transfer it to your blood so it can move around your body.



Your body needs to use more muscles when you cough or exercise. The brain sends signals down to nerves at the middle part of your spine that cause the muscles in your stomach and ribs to tighten. This forces air out faster than normal breathing. Coughing is important to clear mucus and other particles out of your lungs so that they don't build up and block air flow.

### How does SCI impact the respiratory system?

The impact of SCI on your breathing depends a lot on the level of your injury. The brain can't send messages below the level of injury. If your injury is at a high level, in your cervical (neck) area, your brain may not be able to tell your diaphragm when to contract or relax. This is why people with very high-level injuries (C3, C4, C5) may need a tracheostomy (trach) and/or mechanical ventilator (vent) to help them breathe.

People with thoracic (middle back) injuries will probably not have issues with their diaphragm muscles, but the brain may not be able to send signals far enough to reach the abdominal or rib muscles. This can cause problems with breathing harder than normal, coughing, or sneezing. People with low level injuries (lumbar or sacral) usually do not experience any problems with breathing.

### How does this affect my health?

If your SCI affects the muscles you use to breathe, your body will have to try harder. You may not be able to breathe hard or cough with enough force to clear your lungs. When you cannot clear your lungs, mucus can build up. All of these things can increase your risk of respiratory infections and make it harder for you to breathe.

### What health problems are common?

#### Infections

Infections can cause extra mucus buildup in the lungs. Coughing can help clear mucus, but some people with SCI have trouble coughing. If too much mucus builds up, the lung may collapse--this is called **atelectasis**.

- **Bronchitis:** An infection in the tubes that leads to the air sacs in the lungs
- **Pneumonia:** An infection in the air sacs in the lungs

Signs & Symptoms: Fever, chills, cough with thick mucus, chest tightness, shortness of breath

#### Obstructive sleep apnea

Sleep apnea occurs when muscles in the tongue and throat relax too much and block the airway. When air cannot get into the lungs, your oxygen levels drop, and your body forces you to wake up very suddenly to breathe. This keeps happening throughout the night, which stops you from sleeping normally.

Signs & Symptoms: Loud snoring, restless sleep, gasping for air, sore or dry throat, headache, feeling tired or sleepy during the day even though you think you are sleeping long enough

Sleep apnea is more common in men, people who are overweight or obese, people who snore, drink alcohol, take muscle relaxers, and people with a small jaw/large tonsils/difficulty breathing through nose.

### Who is most at risk for respiratory problems?

- High level SCI (injuries in the neck region)
- Complete SCI (no feeling or movement below the level of injury)
- Smokers
- Breathing through a tracheostomy (trach) or mechanical ventilator (vent)

### How do I keep my respiratory system as healthy as possible?

- Do not smoke! Stay away from secondhand smoke
- Keep your lungs clear
- Healthy lifestyle—control your weight, stay hydrated, exercise, and eat healthy
- Prevent infectious diseases
- Stay away from people who are sick
- Get a flu shot every year
- Get a pneumonia shot
- Early detection--the sooner you notice you might have a respiratory problem, the better.



This article was summarized from the "Respiratory Health and Spinal Cord Injury" fact sheet created by the Model Systems Knowledge Translation Center (MSKTC). Access the full fact sheet here:

<https://msktc.org/sci/factsheets/respiratory>

MSKTC offers many educational resources that cover topics related to living with SCI. Discover more fact sheets, slideshows, videos, quick reviews, and SCI hot topics on their website:

[msktc.org/sci](https://msktc.org/sci)

# Get involved in more research!

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## EMPLOYMENT-RELATED TELEPHONE INTERVENTION FOR PAIN (E-TIPS) STUDY

Chronic pain is one of the most prevalent and persistent symptoms associated with physical disabilities. Pain self-management, based on cognitive behavioral therapy (CBT), is a valuable treatment for chronic pain. The purpose of this study is to evaluate CBT delivered via telephone and adapted for employed individuals with physical disabilities.

### What does the study involve?

- Eight treatment sessions via telephone over 8-10 weeks
- Four online surveys over the course of 8-9 months.
- No in-person visits are required.
- Compensation (up to \$125) will be provided.

### You may be eligible to participate if you:

1. Are an English-speaking adult (18+)
2. Have a self-reported physical disability
3. Experience chronic pain
4. Have access to a phone and the internet

Interested? Contact Angelika Kudla:  
312-238-8167 or [akudla@sralab.org](mailto:akudla@sralab.org)

## SURVEY ABOUT EMPLOYMENT FOR PEOPLE WITH PHYSICAL DISABILITIES

The Rehabilitation Research Training Center on Employment for People with Physical Disabilities is recruiting to study job retention for people with disabilities. We are looking for people with disabilities to share their experiences with employment and job accommodations. Survey results will help guide services to improve employment outcomes for people with physical disabilities. The survey takes about 45 minutes. Survey results will be anonymous, so your name will not be saved or shared with your answers. Participation will qualify entry to a raffle for a \$50 gift card.

### You are eligible to take the survey if you:

1. Are an English-speaking adult (18+)
2. Have a physical disability that affected your ability to work

### [CLICK HERE TO TAKE SURVEY](#)



Questions? Contact Angelika Kudla: 312-238-8167 or [akudla@sralab.org](mailto:akudla@sralab.org)

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## WHEELCHAIR KEEP MVN APP

The SCI Model System researchers at University of Pittsburgh Medical Center are conducting a study about wheelchair repairs and everyday mobility. If you use a wheelchair as your main way to get around, you might be eligible to participate!

In the KeepMvn study, you'll be asked to download a smartphone app to track wheelchair repairs.

Find out more:

<http://www.upmc-sci.pitt.edu/KeepMvn/>

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## Want to get involved in our research?

Contact Jennifer Burns at 312.238.2826 or [jburns03@sralab.org](mailto:jburns03@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](http://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 Jennifer Burns at 312.238.2826 or [jburns03@sralab.org](mailto:jburns03@sralab.org).