

Winter 2020 Newsletter

Welcome to the Winter 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, you will read about adaptive sports and fitness, adaptive transportation in Chicago, urinary tract

infections (or UTI's), new research findings, and ongoing research opportunities. If you have any questions, comments, or suggestions, please see the back cover for contact information. 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 completely anonymous, and it goes into a big database online that researchers use to collect information about what happens to people after a spinal cord injury. The findings are used to develop treatment plans, community outreach programs, and policies.

Are you due for a follow-up interview?

If your spinal cord injury happened 1, 5, 10, 15, 20, 25, 30, 35, 40 or 45 years ago, it may be time for your next 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**

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Getting Around in Chicago After SCI

Big cities around the country are working to improve transportation options for people with physical disabilities. Many MRSCICS participants live in Chicago, so we wanted to take a closer look at local transportation options. We talked to Karen Tamley, Commissioner of the Mayor's Office for People with Disabilities (MOPD) about transportation and accessibility in Chicago for people with SCI.

Commissioner Tamley outlined four of the most popular transportation options for people with disabilities in Chicago:



1) Chicago Transit Authority (CTA) fixed-route buses and trains (AKA the "L")

In Chicago, all CTA buses, bus stops, and train cars are fully accessible. Although most CTA train stations are accessible, 42 still need updates. The CTA is fully committed to making 100% of all rail stations accessible to people with disabilities, and they released a detailed plan last year called the All Stations Accessibility Program (ASAP) to address this problem. You can read the entire plan, and see a rough timeline, on their website: <https://www.transitchicago.com/accessibility/asap/>

2) Pace ADA Paratransit Services

Pace provides paratransit transportation in Chicago for people who live within six blocks of a public transportation route but cannot use the public bus or train due to disability. To apply for paratransit services, call the Regional Transit Authority (RTA) ADA Paratransit Certification program at 312-663-HELP. Once approved, you can schedule a ride to take you from your home to your destination—just call by 6pm on the day before you need it. Pace paratransit complete about 9,000 rides per day, making it one of the most popular transportation options in Chicago for people with physical disabilities. At \$3.25 per ride, Pace paratransit rides are an affordable option that provides door-to-door service for people who can't ride public trains and buses. You can read more on their website: <https://www.pacebus.com/sub/paratransit/>

3) Accessible taxis and the Taxi Access Program (TAP)

There are over 400 wheelchair-accessible taxis in the city, and Chicago switched to a centralized dispatch service called OpenTaxi to make it easier to request one. Commissioner Tamley explained that OpenTaxi "eliminates the hassle that people with disabilities previously had around trying to call all these different cab companies to request an accessible cab." People with SCI can also apply for the Taxi Access Program (TAP), which provides taxi fare subsidies to people who qualify. TAP cardholders need to buy at least five TAP rides for \$15, or \$3 per ride. Each \$3 ride covers the first \$30 of a cab fare. After the meter reaches \$30, the rider must pay the remaining fare. To learn more about the Taxi Access Program, visit their website: <https://www.pacebus.com/sub/paratransit/TAP.asp>

4) Accessible Rideshares

Uber, Lyft, and Via have accessible vehicles operating in Chicago. Commissioner Tamley wishes more people would try Accessible Rideshares: "I would like people to know...that they can take a rideshare. We want more people testing those apps out and, frankly, giving the city feedback on the levels of service. Because we want to make sure there are enough vehicles out there to meet the demand."

UberWav offers wheelchair-accessible vehicles. Learn more on their website: <https://www.uber.com/us/en/ride/uberwav/>

UberAssist takes folding wheelchairs, folding scooters, and walkers. They don't take power wheelchairs or manual wheelchairs that do not fold.

To request a wheelchair-accessible Lyft, enable "Access Mode" on your Lyft app.

To request a wheelchair-accessible Via, turn on the "Wheelchair Accessible" option in your account profile in the Via app.

Next, we asked Commissioner Tamley how Chicago compares with other cities regarding transportation options for people with disabilities. She explained that Chicago does well compared to other older cities, but falls behind newer cities. Updating structures like L stations involves much more work than simply putting in an elevator. Because some parts of the rail system were built over 100 years ago, making stations accessible can affect nearby buildings, pipes, gas lines, train platforms and other infrastructure. Some stations may need to be completely rebuilt. However, Commissioner Tamley told us that making every L station accessible is one of Chicago's highest-priority projects. "The Mayor's goal, and my goal, is to make Chicago the most accessible city in the nation."

In wrapping up our interview with Commissioner Tamley, we asked her about upcoming projects that might interest Chicagoans with SCI. She told us about a Divvy pilot program that is set to start around Spring 2020. This new new Divvy adaptive bike share program will allow people with physical disabilities to rent public adaptive bikes. If you have suggestions, questions or comments about this program or any of the other programs mentioned in this article, the City of Chicago wants to hear from you. Whether you're a Chicago native, or just visiting, you can provide feedback through one of the sources listed below:



"The Mayor's goal, and my goal, is to make Chicago the most accessible city in the nation."

How to give feedback to the City of Chicago:

CHI 311 to request a service, report an issue, or track a request

Call 311

Visit their website: 311.chicago.gov

Download the CHI 311 free mobile app

Business Affairs and Consumer Protection regulates taxis and ride shares

Call 312-744-6060

Visit their website: [Chicago.gov/city/en/depts/bacp.html](https://chicago.gov/city/en/depts/bacp.html)

Mayor's Office for People with Disabilities

Call 312-744-7050

Visit their website: [Chicago.gov/city/en/depts/mopd.html](https://chicago.gov/city/en/depts/mopd.html)

Urinary Tract Infections (UTIs): Causes, Risks and Prevention



What is a urinary tract infection?

A urinary tract infection (UTI) is a bacterial infection in your urinary system. This system includes your kidneys, ureters, bladder and urethra — the parts of your body that make, store and get rid of “pee.”

What causes UTI?

UTIs most commonly start when bacteria enter the bladder through the urethra. The urethra is the opening in your body where pee comes out. Once bacteria get in, they move up to your bladder and keep growing. When there are a lot of bad bacteria in your body, this is an infection.

Are UTI's common after spinal cord injury (SCI)?

Yes. Here are three common reasons why people with SCI get UTIs:

1. Bladder management program:

Most people lose control of their bladder after SCI, so they need a bladder management program to help get pee out of their body. Most bladder management options involve putting something inside the urethra to get pee out, usually a catheter. This can cause problems by making it easier for bacteria to get inside.

2. Bowel management program:

Most people lose control of their bowels after SCI and keeping clean can be difficult. Stool has bacteria that can cause UTIs when bacteria from stool gets into the bladder as the bladder is being emptied.

3. Bladder stays full:

Bacteria are hard to get rid of once they are inside the bladder. Normally, people can get rid of the bacteria by fully emptying their bladder when they pee. Many people with SCI cannot fully empty their bladder even with a good bladder management program. This means that bacteria stay in the bladder for a long time, so it is more likely that they will grow into a UTI.

What is my risk for UTI?

Anyone can get a UTI, but women and people with SCI have a higher risk. Some things might make you even

more likely to get a UTI, like having a catheter that stays in all the time (like a Foley or suprapubic catheter).

Can I prevent UTIs?

Most people with SCI get UTIs. Even if you can't completely prevent them, there are some things to reduce your risks:

- Stick to your bladder management program so that your bladder doesn't get too full.
- Drink water. You can tell whether you're getting enough water by the color of your pee.
- Eat healthy food and exercise. This boosts your immune system, so your body is able to fight off the bacteria before it turns into a UTI.
- Stay clean. To prevent the spread of bacteria, wash yourself before and after bladder and bowel management, and after accidents.
- Talk to your doctor about cranberry pills. Research is mixed on the benefits of cranberries, but some people think cranberries help prevent UTIs. Cranberry juice has a lot of sugar, but if you think it helps, talk to your doctor about trying a cranberry pill.
- Watch for early signs of infection: Pee that smells bad; Pee that looks cloudy or dark; Pee that has sediment or mucus (this can look like sand, flakes or chunks floating around).

What should I do if I notice these early signs of UTI?

- Cut back on alcohol, caffeine, and sugar
- Drink more water
- Change your catheter
- Do your ICP cathing program more often

Contact your doctors right away if you think you have a UTI. They may take a urine sample, prescribe antibiotics, change your bladder management program, or suggest something else. A UTI can be very dangerous when left untreated, so better safe than sorry!

Source: <https://msktc.org/sci/factsheets/urinary-tract-infection>

MRSCICS Research Alert

For almost 50 years, the National Spinal Cord Injury Database has tracked the health and well-being of people after spinal cord injury (SCI). The more we learn what puts people at risk for complications—and what helps people stay healthy—the more we learn how to help. This year, SCI Database researchers published a paper in Archives of Physical Medicine and Rehabilitation that studied a health problem affecting many people with SCI: obesity.

Obesity (too much body fat) can lead to diabetes and heart problems. People with SCI who are obese have more problems getting around in their daily lives and spend more time hospitalized.

People who live in disadvantaged neighborhoods or are members of certain races are more likely to become obese. A disadvantaged neighborhood is an area where people live that has less money, more single-mom families, more kids and more people without jobs than advantaged neighborhoods. We know little about whether this is also true for people with SCI. Midwest Regional Spinal Cord Injury Model Systems co-director, Dr. Allen Heinemann, worked with researchers from across the country to learn if people with SCI are at greater risk for obesity depending on their race and where they live.

The researchers learned that participants who live in disadvantaged neighborhoods are more likely to be obese than participants who live in more advantaged neighborhoods. Hispanic participants are at greater risk for obesity than Caucasian and African American participants. Hispanic people with SCI who live in disadvantaged neighborhoods are at greatest risk for obesity.

Health care workers and policy makers can use these findings to focus resources on people with SCI who live in disadvantaged neighborhoods. Programs exist across the nation that improve health in disadvantaged neighborhoods. Making it easier to eat healthy food, go to the doctor, and exercise can help reduce obesity.



Follow the links below for more information:

Read the full paper here: <https://doi.org/10.1016/j.apmr.2019.02.008>

See the full list of SCI Database research findings here: <https://www.nscisc.uab.edu/Public/DatabasePublications.pdf>

Wen H, Botticello AL, Bae S, et al. Racial and Ethnic Differences in Obesity in People with Spinal Cord Injury: The Effects of Disadvantaged Neighborhood. Arch Phys Med Rehabil. 2019.

Getting Involved in Adaptive Exercise

It can be difficult knowing how to start an adaptive sport or exercise program. Whether it's your first time ever or you want to try something new, there can be many obstacles. When you have SCI, it is important to exercise because there are many health benefits from staying active.

For SRAlab athlete Nicki Sweezer, getting started took some time. She first learned about the adaptive sports programs in 2013 but didn't join until 2015. "I was very nervous about starting adaptive sports because I didn't know anyone," said Nicki. "That is why it took me a few years to actually show up and give it a chance."



Nicki Sweezer playing basketball

Now, Nicki handcycles and mountain bikes through SRAlab. She also plays football, basketball, softball, and CrossFit by making adaptations. Adaptations are changes made to a sport that allow a person with a disability to participate. Adaptive sports have improved a lot in recent years. Today, there are few sports and activities that cannot be adapted.

If you would like to start an exercise program but you're not sure of where to begin, try searching the internet for adaptive programs in your area. Even if you don't see something that's exactly what you're looking for, call one of the organizations you find. The people who work at these programs are happy to answer your questions. They can connect you to other programs in your area. Nicki found out about many of the programs she participates in by browsing the internet.

Nicki's advice: "I would encourage everyone to just get out there and try it. We are capable of so much more than what we think we are."

When you're looking, it is important to know that the ADA requires all fitness centers to be accessible. So, if you don't see any adaptive sports programs in your area, you can still get involved through your local fitness center. For example, if your fitness center has a tennis

court, you only need a sports chair and a few rule changes to play wheelchair tennis.

If programs exist but you're not sure whether they'll work for your functional level, call them! At SRAlab, staff will ask about your interests and guide you to a sport that works for your ability level. Nicki's advice: "I would encourage everyone to just get out there and try it. We are capable of so much more than what we think we are."

If fitness is your goal but you're not sure what exercises will work for you, you have many resources available online that demonstrate adaptive exercises for all levels. Some fitness centers have personal trainers who are certified to teach individuals with SCI. The American College of Sports Medicine offers certification for inclusive training. Call gyms in your area to learn if one of the trainers has a certification like this.

Once you find a program you are interested in, it can be difficult to figure out how to pay for it. SRAlab does not charge for its adaptive fitness programs, but that's rare. Specialized equipment – like a sports chair – can cost \$1,500-3,500, but grants exist to help people purchase them. The Kelly Brush Foundation provides payment for expensive equipment and programs. The Challenged Athletes Foundation is another organization that gave out 3,260 grants last year, totaling \$4.8 million! Their website also has lists of programs in each state, so you

can learn which to contact. Nicki received grants from the Challenged Athletes Foundation for a handcycle and another training grant to do CrossFit in 2015.

No matter what your reason is for hesitating, just start. Search for programs, call and talk to their staff, ask questions, and remember that there are ways to help with the costs. When asked to offer advice to help people get started in adaptive sports and fitness, Nicki said, "I would let them know that it will be the best decision they have ever made. I have made so many friends, grown as a person, and have also gotten to visit many places across the country because of adaptive sports. You literally have nothing to lose."

For more information: www.sralab.org/services/adaptive-sports

A special thank you to Stephanie Kanter for many of the ideas and resources mentioned in this article.



Nicki Sweezer riding a mountain bike

"I have made so many friends, grown as a person, and have also gotten to visit many places across the country because of adaptive sports. You literally have nothing to lose."

Check out these resources to learn more about the adaptive sport community, financial aid opportunities, and recreational events happening near you:

***Challenged Athletes Foundation (CAF) – challengedathletes.org**

***Kelly Brush Foundation – kellybrushfoundation.org**

***Triumph Foundation – triumph-foundation.org**

National Sport Center for the Disabled (NSCD) – nscd.org

National Center on Health, Physical Activity and Disability (NCHPAD) – nchpad.org

Disabled Sports USA (DSUSA) – disabledsportsusa.org

***US Paralympics – teamusa.org/us-paralympics**

Paralympic Sports Clubs (PSC) – teamusa.org/us-paralympics/find-a-club

*These organizations offer grant programs to help with the cost of equipment and training

Residential Instability in Chronic SCI: An Investigation of Patterns and Consequences

Researchers at Kessler Foundation are studying housing stability and the effects of moving on the health and well-being of people with spinal cord injury (SCI). We want to understand who moves after SCI, where and why they move, and what people think about their neighborhood and community participation.

What's involved?

The study involves a one hour telephone survey. Participants may receive up to \$50 for their time.

Even if you haven't moved since your injury, you may be eligible if you:

are at least 18 years old

have a traumatic SCI (such as from an accident, fall, or sports injury)

have ongoing limitations using your legs, arms, or hands

have lived in the community for at least one year after completing an inpatient rehabilitation program

For more information or to see if you qualify, please contact:

Ms. Rachel Byrne: 973-324-3567 or rbyrne@kesslerfoundation.org

Ms. Lauren Murphy: 973-324-3580 or lmurphy@kesslerfoundation.org

This project is under the direction of Dr. Amanda Botticello of Kessler Foundation
1199 Pleasant Valley Way, West Orange, NJ 07052



What do you need to know about living with a Spinal Cord Injury? Tell MSKTC what you think in this brief survey!

https://www.surveymonkey.com/r/sci_consumers

If you have questions about this survey or the MSKTC, please contact Cindy Cai, Ph.D. (mstkc@air.org, 202-403-6929).



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 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 312.238.2826 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 an institute 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.