# **Summer Connections**





## August 2020

## SCIMS

Spinal Cord Injury Model System

Since 1970

# What's New

Blood alcohol level and motor function after traumatic spinal cord injury

Osteoporosis In SCI

Resource Spotlight from the Model Systems Knowledge Translation Center

## United Spinal Association

Northeast Ohio Chapter

Physician Spotlight Member Spotlight

#### MetroHealth's Annual SCI Forum

09|25|2020 VIRTUALLY - Via Zoom Link

### Blood alcohol level and motor function after traumatic spinal cord injury Mary Jo Roach, PhD



As part of the SCI Model System grant, MetroHealth led a research project looking at blood alcohol levels at the time of a traumatic spinal cord injury and functional outcomes. The project was a collaboration with four Spinal Cord Injury Model Systems; Harvard University, University of Pittsburg, The Ohio State University and University of Houston. Each center obtained information from their hospital trauma departments, which included percent of alcohol in patients' blood when admitted to the hospital emergency department.

A total of 210 traumatic spinal cord injury patients were identified. The average age of the patient was 47 years old and 73% were male. The study found that higher levels of alcohol in the blood at the time of injury was associated with an increase in motor gain during acute rehabilitation. The study results suggest that alcohol may have some protective properties at the time of injury; however, more studies are needed to confirm what this small study found and to understand what it is about alcohol that may be protective.



Linking Employment, Abilities, and Potential (LEAP) is providing emergency preparedness training for persons with disabilities so that they are ready to advocate for themselves in times of crisis.

In many ways, the year 2020 is the beginning of a new way of life. Throughout the past several months, people have been united in a common goal, surviving a Daily life is spent global pandemic. absorbing news from personally trusted sources, adhering to social distancing and detailed hygiene protocols, and accumulating food, water, and household and personal supplies. For many people, performing these tasks has been difficult. For people with increased functional needs, the sense of urgency to be selfsustained at home has been particularly overwhelming.

LEAP, an independent living center in Cleveland, Ohio, is offering a three-part preparation webinar called Survive and Thrive, Emergency Preparedness for People with Disabilities, beginning September 2, 2020.

#### **SURVIVE AND THRIVE**

**EMERGENCY PREPAREDNESS & RESPONSE** for People with Disabilities

**3-PART WEBINAR SERIES** 



**JOIN US!** SEPTEMBER 2, 9, AND 16 2:00 - 3:30 pm EST

Register: bit.ly/EMPRegisterSept2020 www.leapinfo.or

Primarily, the webinar assists people with functional needs, their family, and caregivers, as well as professionals who serve people with functional needs to actively plan for the unexpected. This webinar series discusses current and potential emergencies, provides tools to identify the particular needs of people with disabilities, and suggests advocacy methods to fulfill these needs before, during, and after catastrophes.

In addition, it outlines physical preparation techniques like formal evacuation plans and disaster kits, addresses emotional and psychological preparedness, and reinforces the civil rights of people with disabilities.

Each session is full of helpful information and resources to implement today and ensure an easier tomorrow. The goal is to survive and thrive, not stress and struggle, during this continuing crisis and future emergencies.

The sessions will be held on Wednesday, September 2nd, 9th, and 16th, beginning at 2:00 P.M. EDT. Each session will be about 90 minutes, with LEAP personnel and other emergency management professionals presenting preparedness strategies, listening to concerns, and answering questions.

Please complete the required registration by clicking on this link: <u>https://bit.ly/EMPrpRspsRegister</u>. Don't let another day go by wondering if you're ready for what may come. Instead, join us and gain the knowledge and resources you need to be prepared.

# Member Spotlight: Kewin King

I'm Kewin King. 43 years of age. Born and raised in Cleveland, Ohio. I suffered a T-12 Spinal Cord Injury 10 years ago. My life has been different but I will say somewhat interesting. In the beginning, I was wondering to myself "How am I going to live with this?" I wanted to give up and feel bad for myself.

I felt like I had lost the game of life. I knew I had to dig deep and pray hard to get over this one. I have overcome those negative thoughts and turned those negatives into positives. I have developed numerous of unknown skills. It took my injury to enlighten me on the power of our brain.



I have made transitions in my life. All for the better. And I would be lying if I said my injury is what I asked for. I just made my mind up that if I'm going to be paralyzed, I'm going to be the best at whatever it is I'm still capable of doing. My goals in life remain the same and I'm going to still be a successful entrepreneur and I would like to help others that have given up and empower those that are going thru the struggle. I believe we can help one another.

Spinal Cord Injury lives Matter!



#### Equity and Quality in Assistive Technology for Individuals with Spinal Cord Injury

This study looks at the characteristics that impact the quality of assistive technology received and the health-related outcomes for individuals with spinal cord injury. If you decide you would like to take part in this research study, you will be asked to complete a series of questionnaires over a phone interview.

#### **Residential Instability in Chronic SCI**

This study explores the effect of moving and changing addresses on the health and wellbeing of persons with SCI.

Specifically, we want to assess: 1. who moves, why they move, and where they move; 2. if movers and non-movers differ in health and community participation outcomes; and 3. if movers and non-movers differ in healthcare access and utilization. You will be asked to complete a short survey which asks about your past and present addresses, neighborhood choice, how you feel about your neighborhood, and what types of resources and services are available where you live.

Participants receive a small compensation for each study completed

If you would like to take part, let us know! We would love to hear from you!!

Megan Hammond 216-957-3562 mhammond1@metrohealth.org

### The role of administering intravenous Zoledronic acid for the prevention of bone loss given in the first 21 days following SCI

#### by Dr. Christina Oleson

The August edition of Spinal Cord, a leading journal in the publication of spinal cord injury research, features an article by Professor of Physical Medicine and Rehabilitation Christina Oleson MD on the role of administering intravenous Zoledronic acid for the prevention of bone loss given in the first 21 days following SCI. Rapid loss of bone begins as early as 10 days following injury in those with complete SCI and the process continues at an aggressive pace for the initial 3 months post-injury.

The subsequent 2-2.5 years show a continued steady decline in bone density, during which individuals can lose large amounts of skeletal structure in hips, upper legs, and lower legs, putting them at risk for fractures even early after SCI. The risk only increases as years from injury progress. The findings, which were published online in February 2020, show that 4 months after the study drug was given, those who received a saline placebo lost an average of 9-13% of bone in 3 hip areas (range of 3-25% loss) whereas those persons receiving the Zoledronic acid had a net gain of 0-1% in the same hip regions (range of 6% loss to 22% gain).

In the distal femur bone located just above the knee, the loss was 6% for control participants receiving saline (range of 1.4-12% loss) and an average of 0-1% loss (range 7% loss to 7% gain) for those receiving Zoledronic acid. Although differences were less pronounced at the knee, they were statistically significant. Findings at one year were even more pronounced at the hip, but less pronounced at the knee.



Zoledronic acid is an FDA approved medication for osteoporosis, but special protocols are needed to deliver this medication safely in those with spinal cord injury. Despite many safety measures, the majority of those receiving Zoledronic acid still experienced side effects of fever and body aches for 24-72 hours. Due to the potential of harming the kidney, the protocol in the outpatient setting would need to be entirely different than what might be given to non-paralyzed individuals with age-related osteoporosis. The intravenous medication would need to extend over several hours, which is not done in most infusion centers.



Dr. Oleson is working to develop a safe and effective protocol to administer this to outpatients. When the 6-year study was begun in 2011 at Dr. Oleson's former institution in Philadelphia (Thomas Jefferson University), few other options existed that had the power to truly impact long term bone health. Currently, other agents have emerged with this potential, but all of the newer agents, as well as Zoledronic acid, require further investigation in a larger number of individuals with SCI to look at gains experienced by the larger population.



The MSKTC works closely with researchers in the 14 Spinal Cord Injury (SCI) Model System Centers to develop resources for people living with spinal cord injury and their supporters. They have several user-friendly resources that are grounded in evidence and available in a variety of formats such as printable PDF documents, videos, and slideshows. We would like to feature a resource from <u>www.msktc.org/sci</u> in each of our newsletters.

The first feature is about adjusting to life after a spinal cord injury. Adjustment is how you adapt to or become used to those new situations. A few examples of exciting changes in life are starting a new job, getting married, and having children. Losing a job, getting divorced, and losing a loved one are examples of changes that can be challenging.

Having a spinal cord injury (SCI) is, without doubt, a new and challenging situation. SCI affects almost every aspect of your life when it happens, and it can be hard to put your life back in order and adjust to living with SCI. This initial adjustment period may be hard, but most people adjust well in time. Then, they continue to adjust to ongoing changes in life similar to those that everyone experiences.

To learn more about this, visit <u>www.msktc.org/sci</u>to download this factsheet as well as any others you may be interested in.





There have been some exciting things happening for The United Spinal Association Northeast Ohio Chapter. This summer we held our first Annual Fundraiser and we are continuously looking to grow the chapter! Read more about everything we're doing here!

On, Saturday, July 25th, the Chapter had a Night of Trivia, the first annual fundraiser in the chapter's history! We had a lot of fun testing our knowledge of history, sports, disability, movies, and so much more. We hope you all can join us for next year's event!

The chapter is continuously looking to grow- have something you want to see? Have a skillset you want to share? Looking to get more involved? Have an idea for a speaker? Have a topic you want to see/ hear? We would love to have you as we grow our board and membership base. Please reach out (information below) if you are interested in finding out more ways to engage with the chapter!

SUPPLIES AVAILABLE!!! The chapter received a COVID-19 grant where we are able to provide \$50 grocery store gift cards and KN95 mask to our members, while supplies last. Please fill out this form (<u>https://forms.gle/sVstWLfamebeg6e59</u>) if you are interested in receiving those resources.

The chapter is Linkedin official, if you engage with the platform, consider going to follow the page here: <u>https://www.linkedin.com/company/united-spinal-association-of-northeast-ohio/</u>.

Beyond officially implementing our official fundraiser and developing Board leadership, there are a lot of exciting things happening and we cannot wait to share this journey with our members.

Just a reminder- all meetings have been moved to a virtual platform until further notice in the wake of the Coronavirus (COVID- 19). The meetings still occur on the 3rd Monday of each month, starting at 7:00 PM. Meeting announcements will be posted on the Facebook page (<u>https://www.facebook.com/unitedspinalneo/</u>) and through our email distribution. If you would like to sign up for our email list, please visit unitedspinal.org and select the Cleveland/Northeast Ohio chapter to be affiliated with.

If you are interested in becoming more involved in the chapter, or would like more information, please reach out to the chapter email (<u>unitedspinalneo@gmail.com</u>) and a board member will get back to you!

# Connect-In

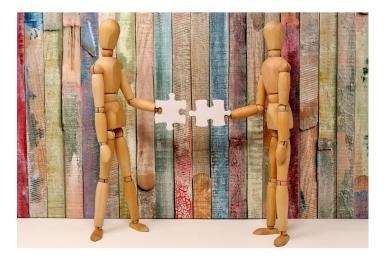
## SCI Program Initiative supported by our SCI Model System Grant.

All persons with a new traumatic SCI in the MetroHealth acute care hospital will have the opportunity to connect with a Peer Navigator.

Peer Navigators are persons living in the community with a SCI. The Navigators will be an important link to SCI information, community resources, information about SCI health care and health insurance.

It is our hope that this program will provide the links, information and skills patients with new injuries need to successfully adapt and connect with their communities so that they can lead a fulfilling life.

If you or someone you know would like to be a Peer Navigator, please contact:



Megan Hammond 216-957-3562 mhammond1@metrohealth.org

## Dr. Oleson steps up as COVID spikes

Information and quotes from original article by Troy Schmidt. You can read the original article here: <u>https://www.usfigureskating.org/news/article/member-lends-expertise-crowded-covid-ward</u>

When MetroHealth Medical Center needed more of its physicians to help in a crowded COVID-19 rehabilitation unit this spring, Dr. Christina Oleson stepped up to the challenge. Dr. Oleson is one of the doctors in the Physical Medicine and Rehabilitation Department that specializes in spinal cord injuries. She also serves as a professor of physical medicine and rehabilitation at Case Western University. Dr. Oleson spent four weeks in May caring for many of the illest patients in the hospital's COVID-19 ward.

Over the years, she's also managed those with heart, lung or bone marrow transplants, brain tumors, and advanced Parkinson's disease. "This expanded background, in addition to my experience in managing patients on ventilators, made me better prepared to treat the tremendous variety of pulmonary, neurological, and musculoskeletal conditions experienced by those with COVID-19," Dr. Oleson said.

Initially assigned to work two weeks in the ward, Dr. Oleson committed to spending the entire month there to help fill the need. This measure facilitated the continuity of care on other services by not shifting physicians to the COVID unit and not putting her colleagues at risk of taking the virus home to their families.

"I don't have children, a dog or a spouse," Dr. Oleson said. "I was living alone so I didn't have anyone that I would be worried about infecting. For me, the risk of exposure to another family member or loved one was potentially nonexistent."

"I was also learning a lot from the experience. I felt prepared based on my background, working with spinal cord injury patients and ALS patients and those with cancer; these are groups of people with similar cardiopulmonary deconditioning, critical illness polyneuropathy (muscle and nerve damage) and hypercoagulability problems (blood clotting) that are prevalent in COVID-19."

We want to thank Dr. Oleson and the other healthcare workers that risked their lives to serve our community. Without these people, our community would have suffered an even greater loss.

## MetroHealth's Annual SCI Forum

The 24th Annual MetroHealth SCI Forum is scheduled for Friday, September 25, 2020. We are happy to announce it will still be taking place; however, like many things this year, we will be shifting to a virtual format. Our "Roaring Twenties" forum will include sessions with topics such as a tribute to the 30th Anniversary of the ADA, Healthy Living, and Dating, Relationships, and Sexuality.

We are looking forward to "seeing" you all! Mark your calendars now and register with the link below:

Register in advance for this meeting: <u>https://cwru.zoom.us/meeting/register/tJYpdeqvqz0jG9L1ApvfpWeDHNoOkMBPt3qL</u>

After registering, you will receive a confirmation email containing information about joining the meeting.

9:00 – 9:15 Welcome / Introduction 9:15 - 10:00 Session I: Past, Present & Future: 30th Anniversary of ADA 15-minute break (vendor presentations) 10:15 – 10:45 Keynote: Hanane Hmada 15-minute break (vendor presentations) 11:00-11:50 Session II: Fitness & Nutrition 70 min break for Lunch (vendor presentations) 12:15-12:45 Bonus Session: Caregiver Corner Session III: "Ask the Medical Panel" 1:00 - 1:30 15-minute break (vendor presentations) Session IV: Dating/Sexuality/Relationships/Drive of Social Media 1:45-2:30 2:30 - 2:45 Wrap Up Remarks

## Check out some of these events hosted by local groups



## Visit <u>ohiowheelchair.com</u> for upcoming activities and events

Adaptive Sports Connection 6000 Harriott Drive Powell, Ohio 43065 <u>info@adaptivesportsconnection.org</u> 614.389.3921

For more information, visit their website:https://adaptivesportsconnection.o rg/sports-programs/



#### Mercy Health & Recreation Adaptive Sports & Recreation Program

Jennifer L. Pospisil Mercy Adaptive Sports & Recreation Program Leader 3700 Kolbe Rd. Lorain, OH 44053 440.960.3423 or Jennifer.pospisil@mercy.com

Various adaptive events each day of the month - contact Jennifer Pospisil to find out more!



LoCo 'Yaks In Lorain has adaptive equipment and, when the season arrives, are ready to take you out on the water!

Check them out on their Facebook page: <u>https://www.facebook.com/locoyaks</u>



Did you enjoy reading the Spring Newsletter? If so, please share with anyone you feel would be interested!