



Thank you for joining us in welcoming the summer! While we may be halfway through 2023, this year has been an exciting time for AMC Research.

In January, we brought back the AMC newsletter in hopes of sharing new developments in the field of AMC, and hearing about what you like to see from us.

Since then, the COVID sub-study has been completed, thank you so much for your participation. We are excited to look at the results and share our findings with you, so please stay tuned!

We also held our first webinar in May on a topic that many of you expressed that you wanted to learn more about: being active living with AMC. We had over 50 attendees join us from all around the world. While sport and exercise can look different for different people, this webinar demonstrated that there is a form of activity for anyone, and that it is never too late to start. With an amazing panel of speakers, ranging from adults with AMC sharing their lived experiences to experts in the field of physical activity and rehabilitation, it is clear that some activity is better than none at all, there are boundless ways to pursue physical activity, and that staying active can be fun!

You can watch the [recorded webinar here](#), or see the archived webinar and other [archived AMC content on our website](#).

After watching the webinar, we would greatly appreciate if you could fill out a short feedback survey to help inform future webinars and AMC related content. Please find the survey [here](#). Keep reading to see what other exciting developments have unfolded in AMC research!.

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## What the AMC Webinar Meant to Me



The AMC in Sport and Exercise Webinar was a fantastic example of the tenacity and drive so many of my fellow peers with AMC have. I have AMC in all limbs, and I grew up in a rural area and had no access to adaptive sports and no exposure to fitness beyond the realm of post-surgery physical therapy. I associate fitness with physical therapy and for me, PT was always just another medical professional pointing out what I couldn't do.

I love that the webinar showcased that sports and fitness can be adapted and that any movement, even if it looks different, is good for the body and mind. It's so important that this message is heard by all people with disabilities and that exposure to adaptive activities starts early. I've always had this mindset that exercise, or sports wasn't really for me because I couldn't do things as vigorously as an abled body person.

This webinar totally blew that mindset to pieces, Brian leg pressing 300 pounds, and David riding 100 miles a month, that's just astonishing! I didn't know before watching this webinar that sit skis can have joysticks and be totally controlled by the person in the seat. This almost makes me want to fly down a mountain too, even though I'm not usually into adrenaline-spiking activities. It was so great that all the presenters emphasized the psychosocial benefits of exercise including increased self-esteem and an increased social circle.

I hope this webinar encourages other adults with AMC to find adaptive sports within their own communities and encourages parents of kids with AMC to find programs or camps for their kids to try. I hope that medical professionals who treat kids with AMC start teaching life-long fitness skills as part of their rehabilitation plans.

- Tracey Schalk



# Adult AMC and Mental Health

## [Mental health in adults living with arthrogryposis multiplex congenita](#)

Shirromi Sarveswaran, William Ben Mortenson, Bonita Sawatzky

[Please find the link to read the full article here.](#)

Although the physical challenges of AMC and treatments such as rehabilitation and surgical intervention are well understood, little is known about the mental health of adults living with AMC. Emotional and social wellbeing are equally important determinants of health and in need of more extensive research. In the first study to examine specific predictors of depression in adults with AMC, 60 participants from the International Adult AMC Registry answered questions about mental health.

Using the Hospital Anxiety and Depression Scale (HADS) – a self-report questionnaire – participants were assessed along other criteria such as pain, functional and physical independence, environmental barriers, and self-perceived challenges to complete tasks at work. Although 19% participants showed some signs of depression, the prevalence of depression in this adult AMC sample is similar to the general adult population of the United States.

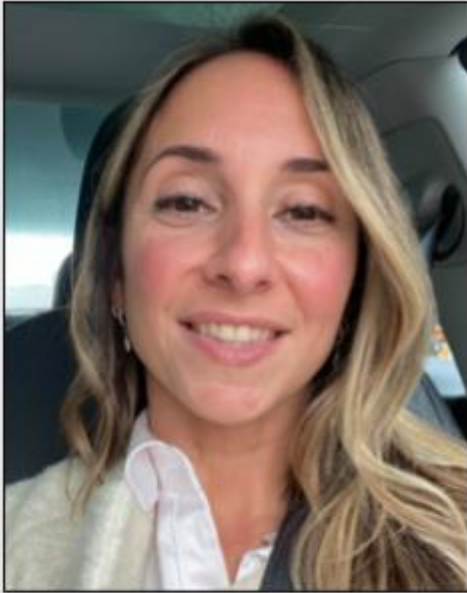
### Key Take Home Messages

1. Fatigue and anxiety correlated the highest with depression
2. Other key emerging factors include occupational status (paid and volunteer), environmental status, as well as age and sex

In summary, clinicians can consider medications, treatments, and rehabilitation that target reducing anxiety, fatigue, and environmental barriers as helpful tools to improve mental health for adults living with AMC.

For more adult AMC Research like this, keep up to date with the most recent research [here.](#)

## AMC Community Spotlight: Meet Noémi!



### **Noémi Dahan-Oliel**

**Current Job Title:**

Clinician scientist, Associate Professor

**Current City:**

Montreal, Canada

**What does your workspace look like today?**

Shriners Hospital for Children  
McGill University



**What is your field of research and expertise?**

I am an occupational therapist by training and completed a PhD at McGill University in 2014. As a therapist, I worked in the fields of neurology, driving evaluation and recommendations, and technical aids. I established my research program in 2016 and it is dedicated to improving the clinical interventions for children with arthrogryposis.

**What interests you about arthrogryposis?**

What interests me about arthrogryposis is working together with youth and adults with arthrogryposis, their families and clinicians to develop studies that are meaningful and impactful to them. There is currently very little guidance as to what interventions work, which assessments to use in arthrogryposis, and this motivates me to work with the arthrogryposis community and experts worldwide to advance these important needs.

**What arthrogryposis research are you working on?**

I am currently working on 4 projects related to arthrogryposis.

1. A registry for children with arthrogryposis to describe patient outcomes such as mobility, quality of life, pain, using standardized questionnaires, and identifying genetic causes using whole genome sequencing across 8 Shriners hospitals.
2. A new measure to evaluate the upper extremity of children with arthrogryposis that looks at task completion in everyday activities as well as which joints were used and how. We expect this measure called the SHAPE-UP to guide individualized treatments and evaluate the effectiveness of treatments.
3. Evaluating the costs of caring for a child with arthrogryposis. this includes the direct, indirect, and psychosocial costs of the caregivers and identifying supports and recommendations that can help alleviate these costs.
4. Identifying the common data elements for arthrogryposis in order to work and collaborate at the international level, so that different experts worldwide working in arthrogryposis can exchange and learn together using the same data.

**Do you have any specific plans for your research?**

My dream for my research is to have an international registry for arthrogryposis, where we can all learn more about individual types, discover new genetic causes and find new ways to treat arthrogryposis to improve the functional outcomes in this condition.

**What advice would you give those aspiring to pursue a similar career as you?**

To exchange with those who have expertise in arthrogryposis, whether it be people with arthrogryposis, their family members, clinicians and researchers to identify what matters most, to have an open mind and not be afraid to innovate and try something new when we believe it can help the arthrogryposis community, to have open communication and share our research back to the community.

**Is there anyone whose work has inspired you in your journey?**

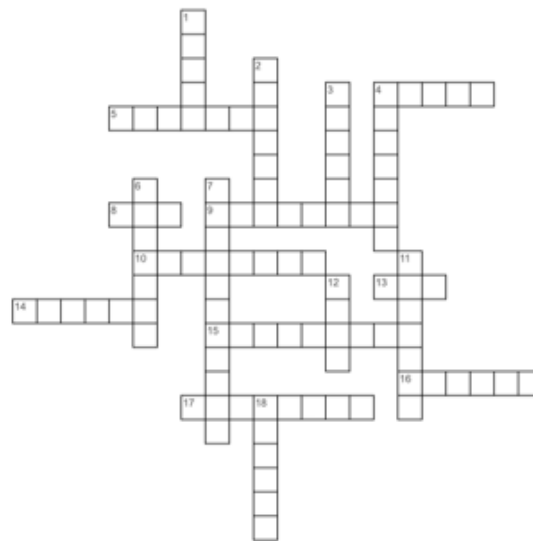
The work Dr. Judith Hall has done and continues to do inspires me, as well as her openness to what is new, important and relevant to the arthrogryposis community, the work Dr. Bonita Sawatzky is doing on the outcomes of adults with arthrogryposis, as children grow into adults and it is important to position ourselves as to how we can support this transition and promote the best outcomes possible.

## Where can we find you when you are not doing research?

Haha, you can find me home with my five children, doing yoga and pilates, teaching and exchanging with my students, enjoying the pool when it is not cold and snowing in Montreal, traveling, and cooking and baking for my family and friends 😊

# AMC Crossword: July Edition

AMC Crossword puzzle



### Across

- 4 is the maximum (max) rate (V) of oxygen (O<sub>2</sub>) your body is able to use during exercise (abrev.)
- 5 a session of vigorous physical exercise or training
- 8 shortened word for gymnasium
- 9 activity requiring physical effort, carried out to sustain or improve health and fitness
- 10 compound weight training exercise in which the individual pushes a weight or resistance away from them using their legs (2 words)
- 13 a triangular staysail set forward of the forward-most mast
- 14 the life-supporting component of the air
- 15 a hormone secreted, especially in conditions of stress, increasing rates of blood circulation, breathing, and carbohydrate metabolism and preparing muscles for exertion
- 16 is an adaptation of ice hockey for disabled player
- 17 an act of changing physical location or position or of having this change

### Down

- 1 a canoe of a type used originally by the Inuit, made of a light frame with a watertight covering having a small opening in the top to sit in.
- 2 extreme tiredness resulting from mental or physical exertion or illness
- 3 A ski/sled variant adapted for wheelchair-bound skiers, with a seat, and ski or skies mounted underneath (2-words)
- 4 a band or bundle of fibrous tissue in a human or animal body that has the ability to contract, producing movement in or maintaining the position of parts of the body
- 6 the sport or activity of riding a bicycle
- 7 the process of taking air into and expelling it from the lungs
- 11 the condition of being physically fit and healthy.
- 12 a group of players forming one side in a competitive game or sport
- 18 the strength and vitality required for sustained physical or mental activity

If you would like to complete your own crossword, [you can click here.](#)

[Answer Key to July Crossword](#)

## Contact Us & Get Involved

We want these newsletters to be meaningful to you! What would you like to learn more about related to living with AMC? What do you think AMC research priorities should be? Please send your ideas to us at [bonita.sawatzky@ubc.ca](mailto:bonita.sawatzky@ubc.ca) and we will see how we can explore these further in our next newsletter, or better yet, in a webinar event.

## Acknowledgments | Declaration of Interest

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