



# Adult AMC Registry Newsletter

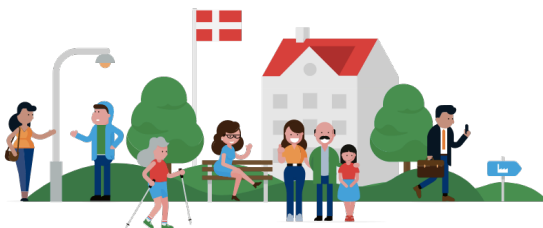
## Adult AMC Registry is Here!

Canadian and American researchers as well as those living with AMC have developed an online registry for adults with AMC to provide their own data towards an adult registry for those with AMC.

In a focus group of adults with AMC, they showed concerns about what will happen to them when they age? What challenges such as pain, fatigue, physical, and financial challenges will people face when they grow older? What treatment works best for long term functioning outcome? The purpose of this registry is to address some of these questions.

The registry asks about quality of life, work, living situations, education, mobility, experiences with surgery, pain, etc

The registry is up and running. **We have 70 people** who have already signed up to participate.



Our goal is to have up to 400 people to participate from around the world. The more data we have the better we can answer the questions. We need you if you have been diagnosed with AMC and are over the age of 18yrs old.



The first year of the questionnaire takes about 30-40 min to complete. We will collect annual information so the subsequent years require less time (<15 min). All data is collected online through a secured portal specifically set up for each person. All data is secure.

For more information, please email Dr Bonnie Sawatzky at [bonita.sawatzky@ubc.ca](mailto:bonita.sawatzky@ubc.ca)

### Registry team:

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## Recent and upcoming AMC research publications

SAWATZKY B, DAHAN-OLIEL N, DAVISON AM, HALL J, VAN BOSSE H, MORTENSON WB. DEVELOPMENT OF AN ONLINE REGISTRY FOR ADULTS WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA: A PROTOCOL PAPER. [AMERICAN JOURNAL OF MEDICAL GENETICS PART C: SEMINARS IN MEDICAL GENETICS. MAY 2019. DOI/10.1002/AJMG.C.31706](#)

This paper describes the process by which an international online adult registry for people with AMC was originated. It provides the process by which researchers and those with AMC discerned what were the key elements that were needed in the survey. It provides insight to the lay audience just how much time and effort goes into creating a registry such as this one.

ELFASSY C, DARSAKALI VB, SNIDER L, GAGNON C, HAMDY R, DAHAN-OLIEL N. **REHABILITATION NEEDS OF YOUTH WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA: PERSPECTIVES FROM KEY STAKE HOLDERS.** [DISABILITY AND REHABILITATION.](#) FEB 2019. [DOI.ORG/10.1080/09638288.2018.1559364](#)

Twenty-seven participants completed the interviews and demographic information was collected where early-active rehabilitation began at birth in most cases and became less frequent through adolescence. Three overarching themes were determined for each stakeholder group.

HALL J, DAHAN-OLIEL N, SAWATZKY B, SAMARGIAN A, VAN BOSSE H. **SUMMARY OF THE 3RD INTERNATIONAL SYMPOSIUM ON ARTHROGRYPOSIS.** [AMERICAN JOURNAL OF MEDICAL GENETICS PART C: SEMINARS IN MEDICAL GENETICS.](#) MAY, 2019. [DOI.ORG/10.1002/AJMG.C.31705](#)

This is a summary of the 3rd international meeting on Arthrogryposis held in Philadelphia Sept 2018. Key issues from the meeting are described in this introductory paper to the special issue on AMC.

SAWATZKY B, JONES T, MILLER R, NOURAEI H. **THE RELATIONSHIP BETWEEN JOINT SURGERY AND QUALITY OF LIFE IN ADULTS WITH ARTHROGRYPOSIS: AN INTERNATIONAL STUDY.** [AMERICAN JOURNAL OF MEDICAL GENETICS PART C: SEMINARS IN MEDICAL GENETICS.](#) ACCEPTED JUNE, 2019).

Many people with AMC require many surgeries, especially during childhood. This study looks at the relationship between those surgeries and the adult quality of life.

CIRILLO A, COLLINS J, SAWATZKY B, HAMDY R, DAHAN-OLIEL N. **PAIN AMONG CHILDREN AND ADULTS LIVING WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA: A SCOPING REVIEW.** [AMERICAN JOURNAL OF MEDICAL GENETICS PART C: SEMINARS IN MEDICAL GENETICS.](#) (SUBMITTED MAR 2019).

Pain is a significant challenge for both adults and children with AMC. This paper reviews the literature on tools to measure pain as well as what has been reported on the problem of pain for these individuals.

JONES T, MILLER R, STREET J, SAWATZKY B. **USING THE OSWESTRY DISABILITY INDEX FOR PAIN AND DISABILITY IN ARTHROGRYPOSIS MULTIPLEX CONGENITA.** [ANNALS OF PHYSICAL AND REHABILITATION MEDICINE.](#) 62,2, MARCH 2019, PAGES 92-97 [/DOI.ORG/10.1016/J.REHAB.2018.05.1319](#)

Prior to this study, no clinical or research outcome was validated for people with AMC who experience pain. Fifty adults with AMC were included to validate the Oswestry Disability Index to measure the impact of pain on activities of daily living.

MILLER R, SAWATZKY B. **OUTCOMES AT 2-YEAR MINIMUM FOLLOW UP OF SHOULDER, ELBOW AND WRIST SURGERY IN INDIVIDUALS WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA.** [JOURNAL OF CLINICAL EXPERIMENTS IN ORTHOPEDICS](#) 3:28, 2017. DOI:10.4172/2471-8416.100028

Hand, elbow and shoulder surgery are less common in AMC than in the lower extremity. Using a systematic approach to the research, this paper explores what surgeries have shown to be the most successful with a 2 yr follow up minimum.

KOMOLKIN I, ULRICH E, AGRANOVICH O, VAN BOSSE H. **TREATMENT OF SCOLIOSIS ASSOCIATED WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA.** [JOURNAL OF PEDIATRIC ORTHOPEDICS.](#) 37, S24-26. 2017. DOI: 10.1097/BPO.0000000000000993

Scoliosis in children with arthrogryposis occurs in the minority of patients, but appears early, often present at birth. Curves can progress quickly. Treatment options include spine casting, bracing, expandable implant surgery, and spinal fusion. The goal is to allow as much chest growth and development as possible, along with a resulting well-balanced spine.