

# An interdisciplinary clinic for children with arthrogryposis: Impact on clinicians and families

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# Background

## Arthrogryposis multiplex congenita (AMC):

- 1 in 3000 live births
- Joint contractures  $\geq 2$  body areas
- Impairments in other systems
- Surgeries and rehabilitation

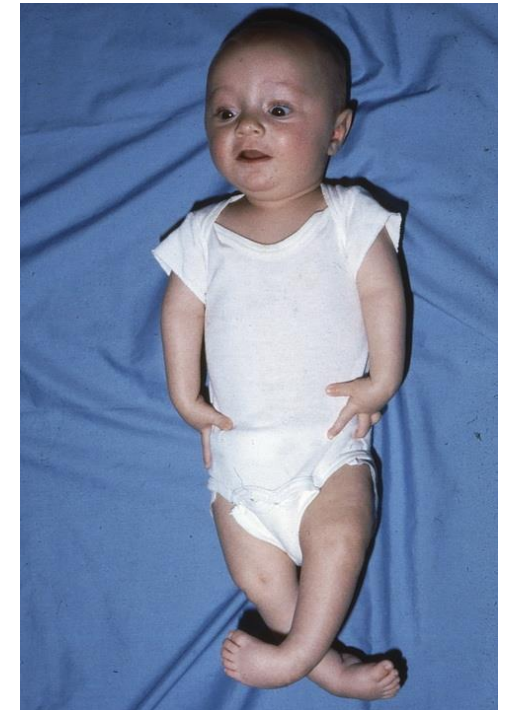
1980-2017 (n= 116/120)

481 procedures:

- bony surgery
- soft tissue



mean F/U 10y5m  
(2 mo-21 years)

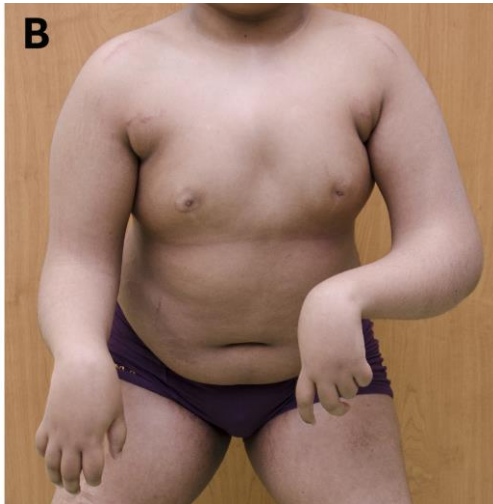
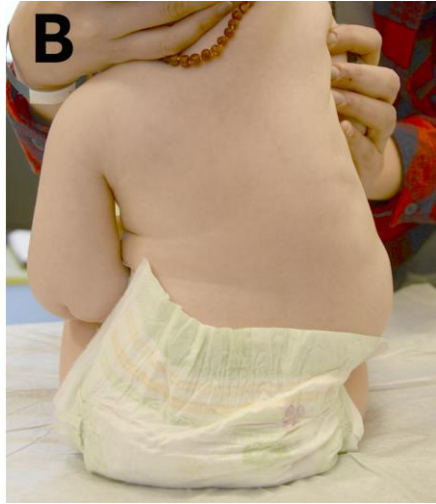


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# Background



# Rationale

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- Children with AMC have multiple needs requiring an interdisciplinary approach
- Seen by various health care professionals (HCP) at different visits
  - Fragmented care
- An interdisciplinary clinic was created in 2016
  - Comprehensive care
  - Engaging families & youth in the treatment plan





# Objective

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- Implement a family-centered interdisciplinary clinic for children with AMC
  - Evaluate the family-centeredness of the clinic



# Methods

- The Canadian Occupational Performance Measure (COPM) is completed with the families 2 weeks prior to the clinic
  - A tracking sheet is used to document the COPM scores,
  - A copy is given to each family when they arrive for their clinic visit,
  - This copy was referred to by the HCPs involved to ensure the intervention plan is linked to goals





Nom / Name \_\_\_\_\_

MRN \_\_\_\_\_

Date \_\_\_\_\_

### Mes buts / My Goals

Buts identifiés pour mon enfant Goals identified for my child	Importance (1-10)	Performance (1-10)	Satisfaction (1-10)
1			
2			
3			

### Mes recommandations / My Recommendations

Bras Arms		Génétique Genetics	
Jambes Legs		Equipment	
Dos Spine		Autre Other	

### Mon plan / My Plan

Prochain rendez-vous avec: Next appointment with:	Clinique AMC / AMC clinic	Clinique spécialisée / Specialty clinic
Dr. Hamdy		
Dr. Janelle		
Dr. Ouellet		
Dr. Campeau		
Autre / Other:		



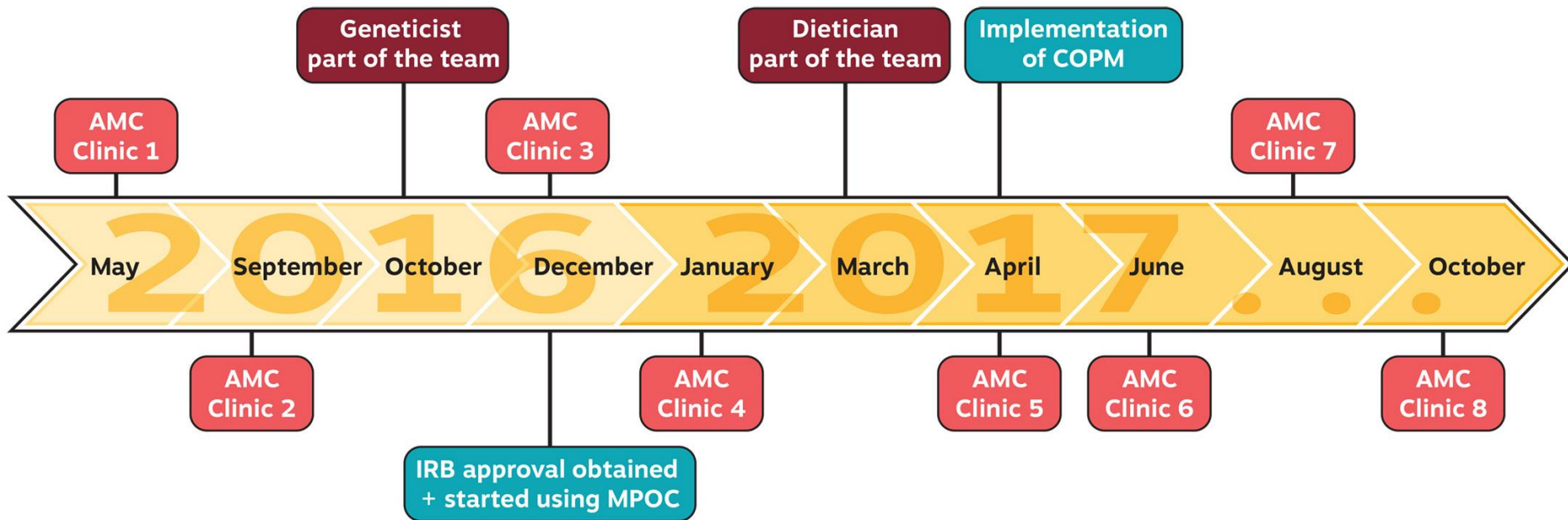
# Methods

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- The Measure of Process of Care (MPOC) questionnaire was completed by family members and HCPs to evaluate the family-centeredness of the clinic



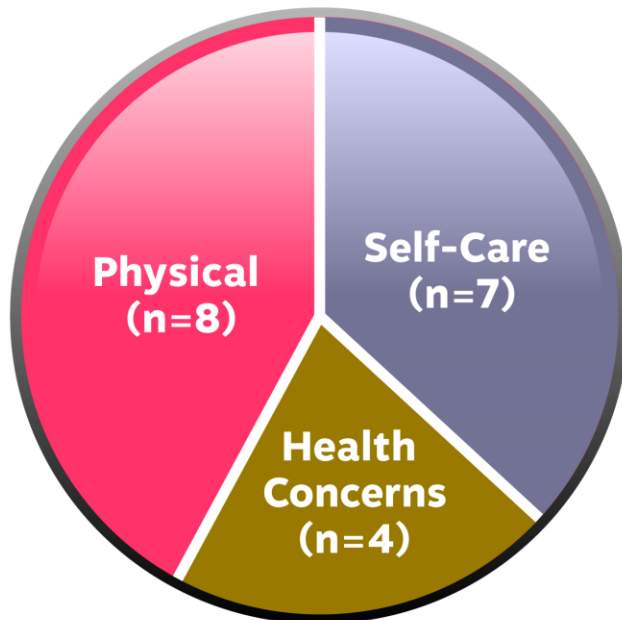
# Results



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# Results



## Physical

- Maintain/Increase mobility
- Increase functional use of hands
- Improve seated position
- Rise-to-stand without support
- Equipment adaptation

## Self-Care

- Self-feed
- Brush teeth independently
- Dress independently

## Health Concerns

- Understand proposed surgery
- Identify cause of pain/falls
- Gain strategies to increase food repertoire





# Results

Scale	Item	N	Mean
<b><i>Enabling and Partnership</i></b>	In the past year, to what extent do the people who work with your child... <b>provide a caring atmosphere rather than just information</b>	14	6.2
<b><i>Respectful and Supportive</i></b>	In the past year, to what extent do the people who work with your child... <b>provide enough time to talk so you don't feel rushed</b>	14	6.1
<b><i>Coordinated and comprehensive</i></b>	In the past year, to what extent do the people who work with your child... <b>plan together so they are all working in the same direction</b>	14	6



# Results

Scale	Item	N	Mean
<b><i>Coordinated and Comprehensive</i></b>	In the past year, to what extent do the people who work with your child... <b>provide you with written information about your child`s progress</b>	12	4.2
<b><i>Enabling and Partnership</i></b>	In the past year, to what extent does the organization where you receive services... <b>have information available to you in various forms (booklet, kit, video, etc.)</b>	14	4.7
<b><i>Coordinated and Comprehensive</i></b>	In the past year, to what extent does the organization where you receive services... <b>provide advice on how to get information or to contact other parents</b>	13	4.5



# Conclusion

- Some of the issues raised by the MPOC-20 could be addressed by using the COPM
- Families anecdotally expressed their appreciation for the opportunity to discuss goals prior to the clinic







## Multidisciplinary clinic for arthrogryposis multiplex congenita (AMC)



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### What is AMC?

AMC is a term used to describe contractures present at birth in more than two body parts. If your child has AMC, you could come meet our interdisciplinary team at the Shriners Hospitals for Children - Canada. The Shriners Hospitals for Children - Canada is located in Montreal, Quebec and is a specialized orthopedic hospital for children. Our team includes many different health care professionals to meet the needs of your child and family. Our goal is to provide coordinated family-centered care to children with AMC from birth to 21 years of age in one setting.

This pamphlet provides information on the multidisciplinary clinic.

### Referral Process

Once received, your consultation will be evaluated by a doctor to ensure good management of your medical referral. The doctor will determine if your child should be seen urgently or not, and will assign your request to a specialist, according to the expertise required. If your child presents certain signs and symptoms leading to the diagnosis of AMC, the nursing care coordinator will call you to get a better understanding of your child's medical status and needs, and determine admission to our AMC clinic. The Care coordinator will then contact you for an appointment.



### During the AMC clinic

You will meet and receive support from our multidisciplinary team. Depending on your child's needs, your visit may include orthopedic surgeons, a geneticist, nurses, physical therapists, occupational therapists, social workers, and other professionals as needed who will work closely together to provide you with comprehensive care. During the clinic visit, your child may undergo several tests to help us gain a better understanding of his or her condition. These tests could include blood analysis, ultrasound or x-ray, bone density measurements, photographs, videos and research questionnaires.

### The clinic is broken down into two days

#### Day 1

- Assessment by our rehabilitation team (physical and occupational therapy)
- Imaging: ultrasound/x-ray, bone density
- Meeting with our research team
- Photos and videos

#### Day 2

- Upper limb surgeon
- Lower limb surgeon
- Spine surgeon
- Geneticist



**Below, you will find a description of our different teams involved in the multidisciplinary AMC clinic.**

## **Nursing Care Coordination**

The Nursing Care Coordinator coordinates your child's care within the health care team. He/she implements the plan of care in partnership with the patient, the family and the multidisciplinary team in a timely manner and specific to the needs of your child and family.

**The Nursing Care Coordinator is available to provide:**

- support to your child and family,
- information about issues such as growth and development, health and well-being,
- information and education about your child's health condition and treatment plan.

He/she will link care and services between the hospital and the community, share the evaluation results and recommendations from our team with your local service provider to ensure continuity of care for your child at home, school and in the community.

## **Orthopedics**

Your child will be seen by an orthopedic surgeon to evaluate the location and severity of contractures. The surgeon will propose a treatment plan in line with your child's needs. This may include observation, bracing, casting, therapy and/or surgery. Depending on your child's needs, a lower limb, upper limb and spine specialist may be involved with your child's care.

## **Genetics**

In order to gain a better understanding of the type of AMC your child has, a geneticist will meet with you and your child and suggest certain tests. The doctor will then communicate the results of these tests with you at a later time and provide consultation as needed.

## **Physical Therapy**

Our physical therapist will evaluate your child's ability to perform various gross motor movements, such as rolling, crawling, standing, and walking. The physical therapist will recommend stretching exercises, bracing, and technical aids as needed. More intense physiotherapy treatment may be provided depending on your child's intervention plan.

## **Occupational Therapy**

Our occupational therapist will evaluate your child's ability to perform fine motor and bimanual activities to better understand your child's ability to dress, feed, toilet, etc. The occupational therapist will then be able to recommend a home program, splints, and technical aids as needed. More intense occupational therapy treatment may be provided depending on your child's intervention plan.

## **Social Work**

Our social workers will accompany your child and the family, during the adjustment and management of living with a diagnosis of AMC. The social workers will evaluate your family's resources and needs and direct you to appropriate resources to your community. Our social workers aim is to help maintain a balanced life.

## **Clinical Research**

At the Shriners Hospitals for Children - Canada, research efforts are underway to improve the care provided to children with AMC and their families, to identify the best treatment options, and to partner with families to conduct research that is meaningful to you. As part of our research program, we may approach you to be part of one of our research projects. You may choose to participate or not to participate. Your child's care will not be affected by your decision.

## **Questions?**

### **Nursing Care Coordinator**

**Jean-François Richard, RN, BScN, CPN(C)**

Tel : 514-282-8537,

email: jfrichard@shrinenet.org

### **Rehabilitation Services Coordinator**

**Emily Lecker, MSc OT**

Tel : 514-282-8537,

email: elecker@shrinenet.org

### **Clinical Research Coordinator**

**Noémi Dahan-Ollel, PhD OT,**

Tel.: 514-842-4464 extension 2278,

email: ndahan@shrinenet.org



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# Conclusion

- Use of the COPM & MPOC for intervention planning clinic is useful
  - Benefits will be evaluated as an ongoing process
  - Re-administer COPM one year after initial visit
  - Monitor and implement improvements based on MPOC results



# THANK YOU

Families & Youth

Dr. Hamdy, Chief of Staff

Dr. Rauch, Molecular Lab

Dr. Campeau, Geneticist

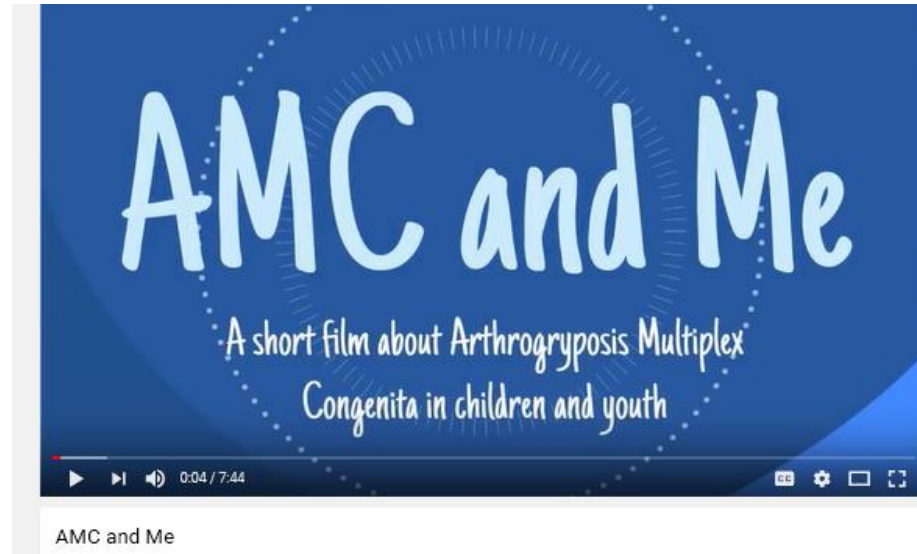
Rita Yap, PT

Natalie Bilodeau, OT

Emily Lecker, Manager Rehabilitation

Kelly Thorstad, Director Nursing & Patient Care Services

Caroline Elfassy, OT, PhD Student





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## Study Schema

