



Canadian Morphea Registry

Registre Canadien des morphées



# 1<sup>st</sup> Annual Canadian Morphea Research Summit

October 18, 2025

Warwick Le Crystal,  
Montreal, QC

*A celebration of growth, innovation, and teamwork  
for Canada's first morphea registry!*

**PROGRAM**



**Canadian Morphea Registry**  
**Registre Canadien des morphées**

## Meeting Chairs

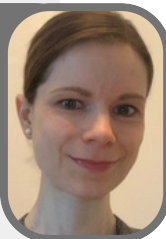


**Dr. Elena Netchiporouk**

Division of Dermatology, McGill University  
RI-MUHC, Montreal General Hospital site  
Infectious Diseases and Immunity in Global Health  
Program, Centre for Translational Biology

**Dr. Cathryn Sibbald**

Division of Dermatology, University of Toronto  
Division of Dermatology, Department of  
Pediatrics, Hospital for Sick Children, Toronto

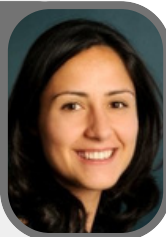


**Dr. Anastasiya Muntyanu**

Division of Dermatology, University of Toronto  
Dermatology, Women's College Hospital and  
St. Joseph's Hospital, Toronto

**Dr. Maryam Piram**

Division of Pediatrics, Université de Montréal  
Department of Pediatric Dermatology,  
CHU Sainte-Justine



**Dr. Mohamed Osman**

Division of Rheumatology, University of Alberta



## Keynote Speakers



**Dr. Heidi Jacobe**

University of Texas Southwestern Medical Center, Department of Dermatology, Dallas, TX, USA

Morphea Adult and Children Registry



**Dr. Kathryn Torok**

Division of Pediatric Rheumatology, UPMC Children's Hospital of Pittsburgh, Pittsburgh, USA

Department of Pediatrics, University of Pittsburgh School of Medicine, University of Pittsburgh Scleroderma Center, Pennsylvania, USA

National Registry for Childhood Onset Scleroderma

## Organizing Committee & Volunteers

### *Organizing Committee*

Camilla Tajzler  
Jessica Muha  
Fedor Pastoukhov

### *Student Volunteers*

Xin Xin Yu  
Cathy Li  
Laura Xu

***A special thank  
you to our patient  
volunteers!***



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## Research Summit Agenda

### 8:00 am – 9:00 am *Breakfast & Registration*

#### **Steering Committee Meeting**

Updates on C-MORE governance, registry operations, and sustainability planning

### 9:00 am – 9:15 am *Welcome & Opening Remarks*

*Dr. Elena Netchiporouk and Dr. Cathryn Sibbald*

Overview of registry: objectives, sites, and recruitment numbers

### 9:15 am – 10:15 am *Plenary Session*

*Dr. Kathryn Torok and Dr. Heidi Jacobe*

Establishing and Sustaining Prospective Registries and Biobanks for Rare Diseases: Examples from the Morphea Adult and Children (MAC) Cohort and the National Registry for Childhood Onset Scleroderma (NRCOS)

### 10:15 am – 10:25 am *Coffee Break*

# 1<sup>st</sup> Annual Canadian Morphea Research Summit

## 10:25 am – 12:00 pm *C-MORE Panel Discussion: Multidisciplinary Perspectives on Localized Scleroderma*

- Epidemiology – *Dr. A Muntyanu*
- Pathogenesis – *Dr. E Netchiporouk*
- Morphea vs Eosinophilic fasciitis – *Dr. C Sibbald*
- Classification – *Dr. R Laxer*
- Treatment – *Dr. J Dutz*
- Quality of Life – *Dr. N Luca*
- Diagnostics (MRI, US, CT) – *Dr. E Pope*
- Interactive Q&A

## 12:00 pm – 1:00 pm *Lunch*

Presentation by Scleroderma Canada

## 1:00 pm – 3:00 pm *Interactive Educational Workshop: Training in Disease Activity and Severity Scoring for LS (LoSCAT and PGA-A/D)*

### **1-2 pm – Training Session (recorded)**

- Dr. Heidi Jacobe

### **2-3 pm – Hands-on Training Session**

- Patients with morphea
- Facilitators: Dr. Heidi Jacobe, Dr. Kathryn Torok, Dr. Elena Pope, Dr. Cathryn Sibbald, Dr. Elena Netchiporouk, Dr. Anastasiya Muntyanu, Dr. Maryam Piram



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Registre Canadien des morphées

**3:00 pm – 3:10 pm**    *Coffee Break*

**3:10 pm – 3:55 pm**    *Afternoon Session 1: Oral  
Presentations by C-MORE Sites*

- Registry Patient Descriptives – *Xin Xin Yu*
- Adult Quality of Life, Mental Health, and Productivity – *Jessica Muha*
- Pediatric Quality of Life – *Shanti Mehta and Cathy Li*
- Transcriptomics – *Dr. Elena Netchiporouk*
- Feedback and Challenges
- Interactive Discussion: Integrating Patient Perspectives into Research – *Dr. Mohamed Osman*

**3:55 pm – 5:20 pm**    *Afternoon Session 2: Strategic  
Planning Session*

*Dr. Netchiporouk, Camilla Tajzler, Dr. Piram*

*Moderators: Dr. Sibbald, Dr. Muntyanu*

Development of key operational  
frameworks for the next five years

Clinical management guidelines for  
adult localized scleroderma

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## 5:20 pm *Closing Remarks*

*Dr. Maryam Piram and Dr. Anastasiya Muntyanu*

Summary of key discussions and outcomes

Next steps for the morphea community

## 5:30 pm – 7:00 pm *Wine & Cheese Networking Reception*

## 7:00 pm *Dinner Reception (Invitation Only)*

Invitees: Investigators, Presenters, Organizing Committee, and Invited Guests

**Thank you for attending the  
1<sup>st</sup> Annual Canadian Morphea  
Research Summit!**



# Canadian Morphea Research Summit

This activity is accredited by the Office for Continuing Professional Development, School of Medicine, McGill University, which is accredited by the Committee on Accreditation of Canadian Medical Education (CACME) of which the Collège des médecins du Québec (CMQ) is a partner.

This Group Learning program meets the accreditation criteria as defined by the Maintenance of Certification program of the Royal College of Physicians and Surgeons of Canada and has been approved for up to 6.75 MOC Section 1 credits/hours.

Through an agreement between the Royal College of Physicians and Surgeons of Canada and the American Medical Association, physicians may convert Royal College MOC credits to AMA PRA Category 1 Credits™.

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<https://edhub.amaassn.org/pages/applications>



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