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June 2025

Canadian MPS Society
for Mucopolysaccharide & Related Diseases

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Special Announcements

Official Notice:
Canadian MPS Society Annual General Meeting

Canadian MPS Society Annual General Meeting

Date: Sunday, July 20, 2025
Time: 10:30 AM - 12:30 PM EST inclusive of Annual Report review
Location: Hilton Mississauga/Meadowvale, ON

The 2025 Canadian MPS Society Annual General Meeting will be held immediately following the Canadian MPS National Family Conference. All members are invited to attend this important gathering where we will review the past year's activities, present financial reports, and discuss upcoming initiatives.

Further details regarding the agenda and meeting materials will be posted by June 14, 2025.

Call for Board Nominations

The Canadian MPS Society is seeking new board members, and you might be just what we're looking for! Our board is the heart of our organization, and we're

excited to welcome fresh voices and new energy to help guide our community forward.

Many of you are already advocating and spreading awareness for rare diseases and MPS. This is your chance to amplify your existing efforts through teamwork. Board members help set our direction, support important decisions, and ensure we're meeting the needs of our MPS families. It's a great way to connect with other committed volunteers while contributing your unique skills and perspective to something that truly matters.

Email your resume and letter of interest to**info@mpssociety.ca** .

Surprise for Kim Angel From Our MPS Community

Hey Everyone,

This is your opportunity to say good-bye to Kim Angel by helping us create a coffee table book!

Please submit a picture to jocelyn@mpssociety.ca with a short comment if you wish, and we will assemble it into the book for a gift she will always be able to reflect on her (favourite) MPS Community (in Canada).

Deadline for submission will be June 20 as we need time to assemble and send for printing.

Thank you all so much!

Mary Bone
Executive Director

Farewell and Thank You!

We wanted to let everyone know that Debbie our wonderful bookkeeper at the Canadian MPS Society is moving on to her next adventures! She's been such an important part of our MPS Community for years and has been incredibly helpful in so many ways behind the scenes, and we honestly can't thank her enough for all she's done. She will definitely be missed around here.

Thank you, Debbie, for all your years of service and keeping our operations running smoothly. Although we're sad to see you go we are excited for what lies ahead for you!

Do you Know the Right Candidate?
Bookkeeping and Administrative Support

And because Debbie is leaving we now have an opening for a dual-function Bookkeeping and Administrative Support position within the MPS Community!

This remote position combines financial management using QuickBooks with comprehensive administrative support including meeting coordination, and membership assistance.

We're seeking an organised professional who can handle accounts payable/receivable, monthly & year end reconciliations, board reporting, email management, meeting preparations, fundraising processing, and tax receipt generation. Competitive salary based on experience. **View the full job posting** and how to apply.

Focus Group Study For Clinical Trials

ARE YOU A YOUTH WITH A RARE DISEASE, OR A CAREGIVER TO A CHILD OR YOUTH WITH A RARE DISEASE?

WE'D LIKE TO HEAR YOUR PERSPECTIVES ON CLINICAL TRIALS!

WHAT IS THIS FOCUS GROUP STUDY ABOUT?

- We are a team of researchers from the **University of Ottawa** working to better understand the **experiences** of children, youth, and caregivers with **clinical trials**
- **Clinical trials** are research studies that **evaluate treatments** to assess whether they work and are safe
- We aim to explore how participating in clinical trials may **affect the lives** of families managing rare diseases

WHY JOIN THIS STUDY?

- We are interested in what children, youth, and caregivers think about clinical trials that try to make **participating easier** by making them available closer to where people live. **These are called "decentralized trials"**
- By sharing your perspectives, you can help us identify both **benefits and challenges** of these types of clinical trials
- This will provide information that can be used to make **improvements to clinical trials** in the future

WHO ARE WE LOOKING FOR?

- **Youth aged 14-20 years** who live in Canada and have a rare disease diagnosis
- **Caregivers** residing in Canada (for example, parents) to **children aged 0-18 years** with rare diseases
- Have **participated** in or been **invited** to participate in a clinical trial in the past
- Be able to join an **English-speaking** focus group

WHAT'S INVOLVED IN STUDY PARTICIPATION?

- **One virtual focus group** (using Zoom) that will last approximately 60 minutes
- During the focus group, you will be asked to share your **experiences, thoughts, and concerns** about clinical trials
- Participants will be offered a **$50 gift card** as a thank you for participating in this study

WHERE CAN I FIND MORE INFORMATION AND JOIN THE STUDY?

- For more information, to confirm your eligibility, and to learn how to join the study, please **complete this short survey**, or email **Wubalem Muchie** at **wmuch034@uottawa.ca** with the subject line, **"Clinical Trials Study"**
- A research team member will contact you to answer your questions and to confirm your eligibility
- **Please note:** it is possible that not everyone who is eligible will be invited to participate. We are looking for a diverse group of participants from across Canada and with experience with different rare diseases.

Please feel free to share this poster with others. Thank you for considering this opportunity to contribute to important research on rare diseases and clinical trials!

Researchers at the University of Ottawa, led by Dr. Beth Potter and MSc student Wubalem Muchie, are seeking potential participants for a virtual focus group study.
The research team is interested in understanding the experiences of children, youth, and caregivers with clinical trials.

They would like to invite people who reside in Canada: (1) youth aged 14-20 years diagnosed with a rare disease, and (2) caregivers (for example, parents) to children aged 0-18 years with a rare disease to join a focus group. Study participants will take part in one English-language focus group for youth or one for caregivers held on Zoom for approximately 60 minutes. Please see the attached poster for more information.

To confirm your eligibility, and to learn how to join the study, please complete this short survey, or email Wubalem Muchie at **wmuch034@uottawa.ca** with the subject line, "Clinical Trials Study".

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#CanMPSSociety

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