



Register
today



Canadian
MPS
Society
for Mucopolysaccharide
& Related Diseases



2019 *Registration Package*
National Family Conference

April 2019

Founded in 1984, the Canadian Society for Mucopolysaccharide and Related Diseases Inc. (Canadian MPS Society) is committed to providing support to individuals and families affected with Mucopolysaccharide (MPS) and related diseases. Our bi-annual conferences give families affected by MPS & related diseases an opportunity to learn about new research, treatment and care, and to share information and experiences with other affected families and individuals. Because MPS diseases are very rare, our conferences often represent the only opportunities families have to meet others whose family members share the same disease. The rarity of MPS diseases also means that published literature is hard to come by, making in-person communication vital.

Basic aspects of the 2019 National Family Conference:

It is expected that the conference will be attended by 100 affected individuals and family members from across Canada, 10 medical professionals, 50 affected children/siblings, and 20 volunteers. The conference will take place over 3 days: the first day of the conference will consist of afternoon registration and an evening welcome reception, the 2nd day will consist of knowledge translation sessions and syndrome breakout sessions, and the 3rd day will consist of a half day of knowledge translation sessions. A child/youth program for affected children and their siblings will take place concurrent to the conference sessions.

Plenary/Knowledge Translation Sessions:

These sessions represent lectures directed to parents of affected individuals and adults affected with MPS or a related disease. Topics will include key advances in disease pathophysiology, management and treatment best practices, current and upcoming research and clinical trials, educational and financial issues, and psycho-social issues such as dealing with grief and loss, adolescence, transition to adulthood, and independent living. There will also be opportunities for affected individuals to present their perspectives.

Syndrome Breakout sessions:

These sessions give affected individuals and parents of affected individuals an opportunity to meet in an informal setting and share information and experiences.

Child/Youth Program:

The children affected by MPS and related diseases are our inspiration and we want them to leave the conference with new friendships and memories to last their lifetimes. We will provide an entertaining program for them and their siblings in a safe environment concurrent to the Plenary/Knowledge Translation and Syndrome Breakout Sessions.

Artwork from the children attending the 2017 National Family Conference.





Information Dissemination:

Information from the conference will be published in our on-line newsletter. Presentations will be posted on our website (www.mpssociety.ca), pending approval from speakers. We plan to film interviews with doctors and other medical professionals in attendance, as well as with families representing various types of MPS.

Outcomes/Conclusion:

We expect that parents, affected adult delegates, and professional delegates will leave the Canadian MPS Society's 2019 National Family Conference with a broader understanding of MPS diseases and the particular issues important to them, and that Society members who are not able attend will benefit from the materials disseminated after the event. We hope that delegates will leave with a feeling of connectedness to others who are facing similar challenges and a sense of hope for the future, and that the children in attendance will leave the conference with new friendships and an understanding that there are other children in Canada who are dealing with similar circumstances, whether as another affected child or a sibling. Undoubtedly new collaborative possibilities will emerge between the Society and the various stakeholders in attendance, and we welcome the chance to work together toward a brighter future for those Canadians affected with and by MPS and related diseases.

Register Today for the 2019 National Family Conference.

July 26 - 28

Nottawasaga Inn

6015 ON-89

Alliston, ON L9R 1A4, Canada

Please do not hesitate to contact us should you require any additional information at info@mpsociety.ca or by calling 1-800-667-1846 (toll free)

With sincere thanks,



Kim Angel
Executive Director
Canadian MPS Society



**Support for families.
Research for a cure.**



2019 National Family Conference Registration Form:

Adult Registrants:

First Name	Last Name	Type of MPS or related disease (or relationship to affected individual). If professional, state occupation.

Child Registrants:***

Sex	First Name	Last Name	Date of Birth	Type of MPS or related disease (or sibling)

***Please complete a child information form, a parental disclaimer, and a consent form for EACH child attending.

Address:	
Postal Code:	
Phone:	
Email:	

Photography and Release:

I/We understand that photographs may be taken of ourselves and/or our child/children during the conference. I/We agree that any photos taken of ourselves and/or our child/children may be used by the Canadian Society for Mucopolysaccharide and Related Diseases Inc. for the purposes of their newsletter, website, a newsletter of another MPS Society, the media, or for the general promotion of the Society and its aims.

I/We agree to abide by all rules and regulations of the Nottawasaga Inn Resort and the Canadian Society for Mucopolysaccharide and Related Diseases Inc. I/We hereby release the Canadian MPS Society from any liability that may arise from any injury or loss sustained during the course of this conference by myself/ourselves or our child/children.

Signature: _____ Date: _____

PAYMENT:*	By June 15, 2019**	After June 15, 2019	TOTAL
Adult: affected family (member)	X \$75.00	X \$90.00	
Adult: relative or caregiver (non-member)	X \$100.00	X \$125.00	
Child: affected (member)	X \$0.00	X \$0.00	
Child: unaffected (member)	X \$25.00	X \$25.00	
Professional (member)	X \$200.00	X \$250.00	
Professional (non-member)	X \$300.00	X \$350.00	
Add breakfast buffet *per adult, per day	X \$20.00	X \$20.00	
Add breakfast buffet *per child, per day	X \$17.00	X \$17.00	
TOTAL COST:			

Conference attendees are responsible for costs related to transportation and hotel accommodations.

Registration payment includes:

- Friday night registration and reception
- Saturday, coffee break, buffet lunch, banquet dinner
- Sunday, coffee break
- Saturday and Sunday morning Child and Youth Program, including snacks, for registered children and youth
- All conference presentations

* Breakfast is not included with general registration payment, but can be added for an extra fee (see above).

To book your hotel room, please call:

Nottawasaga Inn

Tel: 705-435-5501 Toll Free: 800-669-5501

Reference Folio #: 117388

a group rate of \$180.00 per night is available until June 23, 2019.

☐ Cheque enclosed payable to The Canadian MPS Society ☐ Charge my: ☐ Visa ☐ MC ☐ Amex

☐

CARD NUMBER

EXP. DATE / CVV

CARDHOLDER NAME

SIGNATURE

Please mail all registration forms to the Canadian MPS Society at: 218-2055 Commercial Drive, Vancouver, BC V5N 0C7, or email to info@mpssociety.ca.

**Support for families.
Research for a cure.**

 **www.mpssociety.ca**

PARENTAL DISCLAIMER

Canadian MPS Society's 2019 National Family Conference **Nottawasaga Inn, Alliston, Ontario**

Friday, July 26 – Sunday, July 28, 2019

This document has been prepared for the benefit of parents who are attending the 2019 Canadian MPS Society Family Conference at the Nottawasaga Inn, Alliston Ontario. Outlined below is some important information about the Conference and the support the Society is able to provide at the time of sending this information.

Please read through the information, sign at the bottom and return this and all other registration and information forms to the Canadian MPS office **no later than June 15, 2019.**

In addition to the Child and Youth Program administered by the Canadian MPS Society at the Nottawasaga Inn during the Conference, there will be an outing planned on Saturday, July 27. Children with special needs will be assigned volunteers depending on their individual needs. Children will eat their meals with their parents/guardians, except for a snack and lunch at the outing location for those participating. There will be family activities on Friday, July 26, in the early evening. Children will participate in the Child and Youth Program all day on Saturday, July 27, and on Sunday morning, July 28, while their parents/guardians are attending the Conference.

Infants and toddlers up to 2 years of age will not have planned activities; however, volunteers will be with them in the Child Care Rooms at all times.

Children 2 years of age and up will participate in a variety of activities such as story time, age appropriate arts and crafts and games in a Child Care Room as well as going on the outing on Saturday, July 27 (with parental permission). There will be a ratio of one volunteer to 8 children; however, children with special needs will be in the care of a volunteer assigned to them, if requested on the Child Information Form.

All parents must complete and sign one Child Information Form for every child attending the conference.

- All children will be cared for in the Child Care Rooms at the Nottawasaga Inn, or elsewhere as programmed.
- Depending on the needs of the individual child and the support available, children will be provided with individual or group caregivers or volunteers.
- No child will be allowed to roam the hotel without a parent or guardian and must be cared for in the Child Care Rooms. Only in exceptional circumstances and with the agreement of the Canadian MPS Society can this rule be altered.
- Caregivers and volunteers will not be responsible for administering medications.
- Caregivers and volunteers will not be responsible for changing diapers.
- Caregivers and volunteers will not be responsible for lifting any child.
- All parents are responsible for their child when they are out of the care of their caregiver/volunteer. Children must be supervised at all times.
- All volunteers will be allocated to children based on their experience and expertise. All will have had a criminal records check.

I agree to the above terms.

Signature _____

Name _____

Date _____

CANADIAN MPS SOCIETY'S 2019 NATIONAL FAMILY CONFERENCE

July 26 - July 28, 2019

CONSENT FORM FOR THE SHARING OF YOUR CHILD'S INFORMATION FORM AND CARE PLAN WITH THEIR ALLOCATED VOLUNTEER

I/We, _____ the parent(s) and/or guardian(s)
of _____ (child's name) confirm that I/we consent to the
Canadian MPS Society collecting and using the completed Children's Information Form
and care plan and disclosing this personal information to the volunteer assigned to
care for them, for the purpose of providing the necessary and appropriate care for my/
our child during the conference.

I/We understand that my/our child's volunteer will be in possession of information up to
and including the conference weekend (all volunteers will sign an agreement that care
plans and information sheets are confidential documents and will confirm that they will
remain secure and in their possession at all times).

Signed: _____

Date: _____

Canadian MPS Society's 2019 National Family Conference Child Information Form

Please complete one form for each child attending.

Please take a few minutes to complete this form with as much detail as possible, and return to the Canadian MPS Society with your registration form. This information will help us to ensure that your child's needs are thoroughly met during the conference.

Child's Full

Name: _____

Birth date: _____ **Age at time of conference:** _____

Is this child affected with MPS or a related lysosomal storage disorder? _____

If yes: Please state the syndrome: _____

Does your child require one-to-one care? _____

Is your child likely to wander? _____

Is your child able to walk? _____

Children will eat their meals with their parents/guardians except during Saturday's outing; however, the following information will inform us and the hotel of any specific dietary needs:

Does your child have any specific dietary requirements (eg. vegetarian, halal)?

Does your child have any known food allergies?

Does your child have any dietary restrictions?

Does your child need food prepared in any special way (eg. liquidified)?

Children will be given a snack during their Saturday & Sunday morning activities, and those participating in Saturday's outing will be provided with lunch. Do you give your permission for them to have this snack/lunch?

Does your child require medication throughout the day? *Please note, parents will be responsible for administering any medications, except with written permission for a designated volunteer to administer during Saturday's outing.*

Does your child require a nap/rest? _____

If yes, do you require a crib or cot? _____

Please describe any difficult behavioural problems or learning difficulties. Please give details of how this is managed, eg. distraction, removal of stimuli, etc. This is particularly important if there are behavioural problems such as hyperactivity, hitting, spitting, swearing, grabbing, running off, putting things in mouth, shyness, panic attacks, crying episodes, etc.

Any other information relating to your child's behaviour that would be beneficial for our volunteers to know:

How does your child communicate with others? Please provide us with information about any specific signs, gestures or body language they may use and what they may mean:

Is there any other information you can think of that you feel may help a volunteer who is caring for your child, eg. likes/dislikes, characteristics, temperament, games they enjoy, comforting gestures, etc:

Please note: Your responses will help our volunteers take the best possible care of your child. We are sure your child's experience at the Nottawasaga Inn will be a memorable one!