



Canadian **MPS** Society  
for Mucopolysaccharide & Related Diseases



# 2018 Annual Report

[www.mpsociety.ca](http://www.mpsociety.ca)

# Our Vision:

All Canadians affected by MPS and related diseases are supported and empowered to live their best life.

# Our Mission:

The Canadian Society for Mucopolysaccharide and Related Diseases Inc. (The Canadian MPS Society), founded in 1984, serves all Canadians affected by MPS and related diseases through support, education, advocacy and by advancing research.

# Our Values:

- o Community & compassionate support
- o Health & wellness
- o Justice & equality
- o Education & awareness
- o Research & innovation
- o Accountability & transparency

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## Message from Board-Chair Lisa Bosdet

**Dear Canadian MPS Society family,**

From the heart as always, I feel incredibly grateful to be a part of this supportive community of inspiring humans! I am so honoured to be the Chair of the Board of Directors for the Society. This has been a very challenging year for my family as my daughter Maya (MPS 1) underwent a major open-heart surgery and is now facing a big hip surgery. Never a dull moment but we are strong and resilient (my new favourite word) and we will get through it!

I would like to briefly go over some of the highlights of this fiscal year for the Society:

- 2017 Gala - Honouring the Harkins Family and the Vancouver Canucks Alumni Association. A fabulous event that with so many generous donations we raised approximately \$30,000 net!
- 2017 National Family Conference - over 120 MPS family members in attendance in the lovely city of Montreal
- Provided over \$10,000 in Financial Assistance Grants
- Provided over \$16,000 in Travel Bursaries for 2017 National Family Conference

I would like to take this opportunity to give much deserved thanks and appreciation to our Executive Director Kim Angel for her dedication and commitment to people living with MPS and related diseases in Canada. She works tirelessly to support individuals and families living with this disease, always looking for ways to improve their lives. Also a big thank you to my fellow Board Directors who give of their time and energy to make sure that our Society is running well and making a difference.

It is an exciting time for growth and there is much work to be done to support research to discover new and better treatments and ultimately a cure for MPS.

With gratitude,

*Lisa Bosdet*  
*Canadian MPS Society Board Chair*



## Message from Executive Director Kim Angel

It is a great honour to present to you the Canadian MPS Society's year in review. I am proud to report these achievements and continued progress toward improved programs and services.

Some of our most noteworthy achievements of 2017-18 include:

- Our 2017 National Family Conference, held in Montreal, Quebec in July 2017, was a tremendous opportunity for families to connect, and to learn from the many presentations by leaders in the medical community. Attending children had a wonderful time with plenty of fun activities.
- Throughout the year we supported several families with direct financial aid, giving them the opportunity to modify their homes, hire respite care, attend the 2017 Family Conference and otherwise cope with the demands of children with unique needs.
- We welcomed back Jill Ley to the team to assist with administration and member support. Jill's commitment, dedication and compassionate manner are deeply valued and appreciated at the Society.
- The Society's website was re-launched with our new branding in the spring of 2017.
- Our monthly electronic newsletter, the e-Connection, continued its role as a valuable resource for our members, helping them stay up-to-date on MPS news and events.
- Our Family Referral Directory remained an important link for families wishing to connect with others with the same MPS syndrome or with those living in the same geographic region. Extensive work in 2017-2018 brought forward a new member portal that contains direct access to the Family Referral Directory for all affected family members who opt-in to this special feature. This portal also allows affected members to communicate with one another in a number of secure discussion forums.
- Along with members from world-wide MPS and rare disease communities, on International MPS Awareness Day (May 15th) and Rare Disease Day (February 28th) we recognized, remembered, and honoured those whose lives are touched by MPS or a rare disease.

In addition to the positive and encouraging activities of the Society, our community has been faced with many challenges, heartbreaks and disappointments:

We have lost far too many beautiful souls to MPS and we continue to see the devastating progression and impact of these diseases as they tear into the lives of affected children and adults, and their families and loved ones.

In December 2017 we lost one of the world's most inspiring champions for MPS, Christine Lavery. As the CEO of the MPS Society UK, Christine dedicated her life to improving the knowledge, advocacy, support and clinical outlook for patients with MPS. We will always remember her as a strong and courageous woman, who contributed to increasing awareness of, and to raising funds for, the support of scientific and clinical research into rare inherited diseases, especially lysosomal storage disorders.

We have seen clinical trials fail to meet endpoints, funding for treatments be denied, and little progression with a National Rare Disease Strategy or Newborn Screening.

As we move into the future, we are committed to expanding our footprint to fund and support research to find treatments and cures for MPS diseases. We strive to ensure that no child, adult, parent, sibling or caregiver in Canada will face MPS alone and in isolation. We will work to educate the medical community and raise awareness about MPS and related diseases. We will fight to advance early detection and diagnosis, and ensure that treatments are available and accessible. We will join forces to partner and collaborate with other foundations, organizations, key stakeholders and the medical community to work toward shared visions and goals. We will place more emphasis on personalized support and member connections through regional and national family gatherings, while continuing to increase connections through the technologies of today. We will strive to make certain that parents are able to focus on their children rather than on financial hardships, and that they are informed, supported and cared for throughout their journey.

All families affected by MPS and related diseases deserve to see the promises of tomorrow become today's reality.

The accomplishments over the past year and the work ahead depend on the support and contributions of our partners, volunteers and dedicated staff. I am immensely grateful to those individuals and partners whose energy and support sustain us. May we move into the future with hope, optimism and a driving commitment to work together to create a brighter future for everyone affected by MPS and related disorders.

Thank you, and I look forward to another progressive year with the Canadian MPS Society.

*Kim Angel*

*Canadian MPS Society Executive Director*

## Conferences & Events Attended

The Society promoted and participated in many events and meetings including::

- The Canadian Organization for Rare Diseases Conference  
*Vancouver, BC and Toronto, Ontario*
- CPAG Conference  
*Washington, DC*
- Canadian Paediatric Conference,  
*Vancouver, BC*
- WORLD Symposium  
*San Diego, California*
- Emma-Rose, Night of Enchantment Gala  
*Toronto, Ontario*

*My hope is...*  
*...to play outside*



*ignite hope and help make it happen*

**Donate Now**

 **Donate**

For more information please visit our website  
[www.mppsociety.ca](http://www.mppsociety.ca)

## Directors, Medical Advisory Board & Staff

### BOARD OF DIRECTORS

Chair – Lisa Bosdet  
*MPS I Parent, BC*

Vice Chair – Marilyn Marchment  
*Communications Consultant, BC*

Secretary – Melissa Bilodeau  
*MPS IVA – Adult, Quebec*

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*MPS I Parent, Ontario*

Mojan Zehtabchi  
*Naturopathic Doctor, Ontario*

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*Mannosidosis parent, Ontario*

Kaitlyn Di Ilio  
*MPS IIIB Sibling, Ontario*

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Kim Angel  
*Executive Director*

Jill Ley  
*Administrative Assistant  
& Member Support*

### MEDICAL ADVISORY BOARD

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*BC Children's Hospital  
Vancouver, British Columbia*

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MD, CM, FRCPC, FCCMG  
*Winnipeg Children's Hospital  
Winnipeg, Manitoba*

Joe T.R. Clarke, MD, Ph.D. (Retired)  
*Hospital for Sick Children (formerly)  
Toronto, Ontario*

Aneal Khan, MD  
*Alberta Children's Hospital  
Calgary, Alberta*

Serge Melancon, MD  
*Montreal Children's Hospital  
Montreal, Quebec*

John Mitchell, MD  
*Montreal Children's Hospital  
Montreal, Quebec*

Eva Mamak, Ph.D.  
*Hospital for Sick Children  
Toronto, Ontario*

Tony Rupar  
*BSc, PhD, FCCMG, CPRI  
London, Ontario*

Sylvia Stockler, MD  
*BC Children's Hospital  
Vancouver, British Columbia*

## Fundraising & Events

### 2017 National Family Conference

On July 21-23 2017, over 120 guests from across Canada joined us in Montreal for the Canadian MPS Society's National Family Conference!

It was a weekend filled with valuable resources, educational presentations, and inspirational experiences to support the courageous children and families affected by MPS and related diseases across Canada.



#### A big THANK YOU to all our Conference Sponsors, Presenters and Volunteers - we couldn't have done it without you!

##### Sponsors

Shire  
 BioMarin  
 Sanofi Genzyme  
 Ultragenyx  
 REGENXBIO  
 Innomar Strategies  
 Phoenix Nest

##### Presenters

John Mitchell, MD, Pediatric Endocrinologist, *Montreal Children's Hospital*  
 Lorne Clarke, MD, Professor of Medical Genetics, *University of British Columbia*  
 Emil Kakkis, MD & Christine Haller, MD, *Ultragenyx Pharmaceutical*  
 Alexey V. Pshezhetsky, MD, Professor, Department of Pediatrics, CHU Ste-Justine, *University of Montreal*  
 Peter Glavas, MD, Orthopedic Surgeon, *St. Justin & Shriners Hospital, Montreal*  
 Mark Dant, Executive Director, *National MPS Society*

Durhane Wong-Reiger, PhD, President & CEO, *Canadian Organisation for Rare Diseases*  
 Gail Ouellette, PhD, President & CEO, *Quebec Coalition of Orphan Diseases*  
 Eva Mamak, MD, Pediatric Neuropsychologist, *Hospital for Sick Children*  
 Jill Wood, Co-founder, *Jonah's Just Begun & Phoenix Nest*  
 Elisabeth Linton, Co-founder, *Sanfilippo Children's Research Foundation*  
 Stacey Hewson, Genetic Counsellor, *Division of Clinical and Metabolic Genetics*  
 Julie Letendre, PhD, *Centre de Réadaptation Marie Enfant*

##### Volunteers

Coach Jerry Bennett  
 Iffat Amin  
 Fatima Amin  
 Arjun Sehkon  
 Jean Linden  
 Hillary Rosen  
 Sheela Aubeelack  
 Charlie Aubeelack  
 Orvana Sungeelee  
 Katie Di Ilio  
 Mojan Zehtabchi  
 Dhavishen Allken  
 Thomas Hawton  
 Sarah Byrne

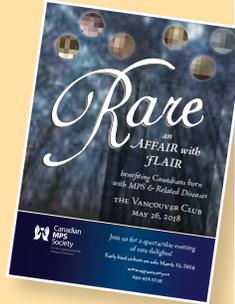
## Fundraising and Events

### 15th Annual Fundraising Gala – RARE

This year's Ignite Hope Fundraising Gala, Rare, was held at The Vancouver Club on May 26th.

120 guests came to honour and raise funds for all the courageous families across Canada living with MPS and related diseases.

Thanks to many generous donors and volunteers, the evening was a wonderful success and raised over \$35,000!



### Canadian MPS Jeans Day

Many MPS Families across Canada organized Jeans Day fund and awareness raisers in their schools and workplaces on May 15th - International MPS Awareness Day!



## Your Donations at Work

This Donor Impact Report highlights examples of how donor dollars have been spent to support affected families in Canada and to advance research for a cure for MPS diseases.

The Canadian MPS Society receives no government funding and relies on private and corporate donations to further its' mission of supporting Canadian Families affected with MPS and related diseases, and to advance research to ultimately find cures.

We are pleased to share with our community the tremendous impact donors have made on the lives of families affected by MPS and related diseases in Canada.

### Financial Assistance Program

Since 1984, the Canadian MPS Society has provided over \$150,000 in financial support to families across Canada through our Financial Assistance Program, helping to offset non-insured costs associated with managing daily living with MPS.

In the 2017-18 fiscal year, your donations directly impacted 9 affected families in Canada. Here are their stories and how your donations have helped:



**Loïc Bydal, MPS IVA (QC):** A Family Assistance grant has allowed this brave young man to expand his horizons.

*"My Super Hero son, Loïc, is a small 15-year-old young man who has been living in the hospital since July 23, 2012. Health complications have required him to undergo a tracheotomy. He breathes through a Trilogy Respiratory Machine. Loïc needed a second battery for his Trilogy and a charger in order to be safe when he leaves the hospital for outings. This accessory allows him to have more freedom without fear that his machine will stop working or always be obliged to find an outlet to recharge his battery. Your financial help was very much appreciated because Loïc's father's insurance doesn't cover this kind of expense. Now, we can go out without any worries. Thank you for being there when we need you!"*

~ Anik Pilon



**Emma Lou Levesque, MPS I-H (QC):** Emma Lou must travel every week from Sault Ste. Marie to Toronto in order to receive her Enzyme Replacement Treatments (ERT) at SickKids Hospital. The Canadian MPS Society was pleased to be able to help alleviate some of this financial burden.

*"The Canadian MPS society has been a very great resource to our family from the day of Emma's diagnosis. I was able to connect with families and to read other families stories. The have helped us financially as well providing funds for the repeated flights we had to take to the nearest hospital 8 hours away from our home. Emma had to receive weekly ERT infusions until she was ready for a transplant. We then had to live for 5 months away from our home and the Canadian MPS society was an extremely helpful organization. We are very fortunate to have access to this and are very grateful."*

~ The Levesque family



**Melissa Clare, MPS I H-S (ON):** Melissa was diagnosed with MPS I H-S in 1994 when she was six years old. She is now 29, and was no longer able to climb the stairs to her bedroom. A stair lift has given Melissa back her independence.

*"I would like to take this opportunity to thank the Canadian MPS Society for providing some fund-ing towards a custom stair lift for my daughter Melissa. Last year, due to complications from the MPS she was no longer able to climb stairs. She had to be carried up by her father, and when he was at work she either had to stay in her bedroom or stay downstairs with no access to the up-per floor until he came home. We made the decision to install a stair lift for her. It was very costly, and we had to do fundraising to be able to pay for it. The stair lift was installed last year in June, a day before Melissa's 29th birthday. It has been the best purchase we have ever made. She is now able to go up and down*

the stairs whenever she wishes and no longer needs to wait for her father to carry her. She is much happier because she is able to be more independent. Thank you, Canadian MPS Society, for being able to provide our family with some funding towards Melissa's stair lift. It was very much appreciated."

~ Joan & Walter Clare



**Justin Massicotte, MPS I-H (ON):** Justin loves boxing, and a Family Assistance grant has given him the opportunity to spend three months learning to box with a personal trainer at a local fitness club. He also very much wanted, and was able, to attend his school's summer camp program

"We would like to thank the Canadian MPS Society for funding our son's summer activity. Justin (MPS1 Hurler's) wanted to try a new activity for the summer. With the financial assistance from the MPS Society, Justin worked with a personal trainer at Ironworks Fitness Gym (Point Edward, Ontario) and learned some basic boxing techniques. Weekly, he would get the red boxing gloves on, and practice some routines with his trainer, Lukas. He loved every second! It helped with stress relief and coordination. Without the assistance, Justin wouldn't have discovered a new sport. Thank You again."

~ Chantal Massicotte

**Heston Letcher, MPS IIIA (BC):** Heston was becoming too heavy for his parents to safely lift him in and out of the bathtub. The Society was able to assist with funding renovations to the family bathroom, including installation of curved overhead tracking for a lift system and a hand-held shower.



"Thanks to the Canadian MPS Society's Financial Assistance Program we were able to purchase vital components required for a ceiling track lift system in our bathroom. Our 8 year old son Heston has Sanfilippo Syndrome (MPS IIIa) and has lost the ability to walk. He is currently over 65 lbs and for his, and our safety it was recommended that we install a track lift system for transporting him to and from the bathtub. While our provincial government funded the lift,

there were key elements needed to make it work in our bathroom that were not covered. A curved section of track, as well as an adjustable curtain rod were two things that were required and we are so grateful to the Canadian MPS society for funding them for us. We are now able to safely transfer Heston to and from the bathtub."

~ Kerena Letcher



**Alex-Olivier Fidalgo, MPS I-H (QC):** Alex-Olivier has undergone more surgeries in his short life (he is only just 4) than anyone should have to undergo in a lifetime. Travel costs to and from the hospitals for his various surgeries and treatments are a huge financial drain on the family.

"The Canadian MPS Society's Financial Assistance Program helped

my family by reimbursing our daily travelling expenses, due to my son's 8-month hospitalization and due to the many weekly follow-up appointments he still has to this day at three different hospitals since his MPS I-H diagnosis in the summer of 2016.

It has also helped us financially during our son's 8-month hospitalization and during the following year, as both my boyfriend and I stayed by his side every day. The bills kept coming in while our income had significantly decreased. The Canadian MPS Society's Financial Assistance Program helped us keep our heads above water financially during this tough time."

~ Caroline Marie Fidalgo

**Hallie and Colter MacLean, MPS VI (AB):** As the MacLean family lives in rural Alberta, the cost of travel to medical appointments for their two affected children is exorbitant and financially draining. The Society was pleased to have been able to help with some of these costs.



**Ella Andrews, MLD (ON):**

Melissa needs full-time care as she is G-tube fed, has no voluntary movement of her extremities, is non-verbal and needs to be held upright approximately 95% of her day for saliva management. The

family's annual government funding had run out and they were facing three months of severe financial difficulties.

"Thank you very much for the respite funding for our daughter Ella. Your financial support is great appreciated. We are very thankful to have your support!"

~ The Andrews Family

**Ozzy Aubrey (Rhodes), MPS I-H (ON):** The Aubrey/Rhodes family needed to renovate their bathroom to make it wheelchair accessible for Ozzy. The Society was pleased to be able to contribute to the cost of a roll-in shower.

## Advancing Research

The Canadian MPS Society’s research program began with yearly Summer Studentship Research Grants, which are still offered to undergraduate students in the hope of fostering future careers in lysosomal storage disease (LSD) research.

To date, we have funded over \$1 million dollars in research grants to find treatments and hopefully, eventually, cures for all types of MPS and related diseases.

In 2017, your donations assisted in providing 2 summer student research grants.

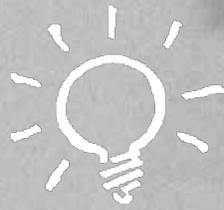
Student Researcher	Institution & Supervisor	Name & Description of Project
<p>Rachel Heron-Roberts</p>	<p>CHU Sainte-Justine Mother and Child University Hospital Montreal, QC</p> <p>Dr. Alexey Pshezetsky</p>	<p><b>Phenotypic characterisation of the novel HGSNATP283L knock-in mouse model for MPS IIIC</b></p> <p>The characterization will be conducted through study of the pathophysiology of the disease and comparison with the previously described knock-out MPS IIIC mouse model, which was determined to be a good representation of the human condition (Martins et al., 2015).</p>
<p>Ryan Thomas</p>	<p>SFU Simon Fraser University Burnaby BC Department of Biological Sciences</p> <p>Dr. Allison Kermode, Professor</p>	<p><b>Investigations into the therapeutic efficacy of the novel drug lead X-372 in an MPS I human cell model</b></p> <p>To achieve validation of our lead compound effects in human cells, MPS I patient derived primary skin fibro-blasts will be employed to: i) Determine the dose-dependent effectiveness of X-372 on enhancing intracellular/lysosomal IDUA activities in MPS I fibroblasts (P533R- and R383H-homozygous lines) - the wild type IDUA line will serve as one control. ii) It is the glycosaminoglycan (GAG) storage that leads to MPS I pathology; therefore a reduction of intracellular GAGs represents a bonafide measure of the therapeutic efficacy of a lead molecule. Measurement of GAGs (heparan sulphate and dermatan sulphate and the associated derived oligosaccharides) will be determined by electrospray ionization-tandem mass spectrometry</p>

## Family Support Travel Bursary Program

For 34 years, the Canadian MPS Society has held regional family meetings and biannual national family conferences, providing opportunities for families to connect with others living with MPS, and to learn of the latest developments from experts. We have funded over \$50,000 in conference travel bursaries to assist families with the costs of attending conferences.

Over \$16,000 in Travel Bursaries were provided to families to attend the National MPS Society Family Conference in Montreal, Quebec, in July 2017.





*My hope is...  
... to make a difference*

*ignite hope and help make it happen*

**Donate Now**

 **Donate**

For more information please visit our website  
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## Financial Statements

### Qualified Opinion

In our opinion, except for the possible effects of the matter described in the Basis for Qualified Opinion paragraph, the financial statements present fairly, in all material respects, the financial position of The Canadian Society for Mucopolysaccharide & Related Diseases Inc. as at March 31, 2018 and the results of its operations and its cash flows for the year then ended in accordance with Canadian accounting standards for not-for-profit organizations.

*Manning Elliott LLP*

Chartered Professional Accountants Vancouver, British Columbia

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**CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.**  
**STATEMENT OF FINANCIAL POSITION**  
**AS AT MARCH 31, 2018**

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	<b>2018</b>	<b>2017</b>
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash	\$ 57,726	\$ 113,687
Investments	188,643	187,262
Accounts receivable	964	1,764
Government remittances receivable	4,885	964
Prepaid expenses and deposits	3,765	4,479
	<hr/>	<hr/>
	\$ 255,983	\$ 308,156
	<hr/>	<hr/>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued liabilities	\$ 9,633	\$ 13,469
Government remittances payable	1,510	1,516
Deferred revenue (Note 3)	89,172	89,172
Deposits received in advance	500	-
	<hr/>	<hr/>
	100,815	104,157
<b>NET ASSETS</b>	<hr/>	<hr/>
	155,168	203,999
	<hr/>	<hr/>
	\$ 255,983	\$ 308,156
	<hr/>	<hr/>

## Financial Statements

### CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.

#### STATEMENT OF OPERATIONS

FOR THE YEAR ENDED MARCH 31, 2018

	2018	2017
<b>REVENUE</b>		
Donations and grants	\$ 99,693	\$ 101,632
Conference	83,337	-
Fundraising	43,855	10,233
Miscellaneous income	4,567	-
Dividend income	1,644	1,399
Membership fees	1,460	1,560
MPS II Research Fund	-	488
	234,556	115,312
<b>EXPENSES</b>		
Meetings	94,276	10,960
Salaries and contract fees	83,799	65,128
Fundraising	27,373	-
Professional fees	25,554	36,650
Family Assistance Program	10,612	12,666
Office and miscellaneous	9,145	5,286
Research grants	8,000	-
Travel	6,993	19,515
Computer	5,100	2,657
Conference	3,537	1,500
Telephone and internet	3,323	2,512
Advertising, communication and promotion	1,832	13,418
Office lease	1,560	1,560
Insurance	1,479	834
Printing and postage	754	1,580
Membership dues	50	70
Join the Search	-	4,149
	283,387	178,485
<b>DEFICIENCY OF REVENUE OVER EXPENSES</b>		
FOR THE YEAR	\$ (48,831)	\$ (63,173)

## Thank you to our donors

Thank you so much to everyone who made contributions to the Society during our April 2017 - March 2018 fiscal year. Special thanks to the following major sponsors and donors, and to the organizers of independent fundraisers:

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### INDUSTRY PARTNERS – Donation of \$50,000 - \$75,000



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### Donation of \$25,000 - \$50,000



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### Donations of \$5,000 - \$10,000



### Donations of \$1,000 to \$4,999

Alpha Entertainment  
Vancouver Canucks Alumni  
Jacob Heilbron  
Anonymous

### Donations of \$500 to \$999

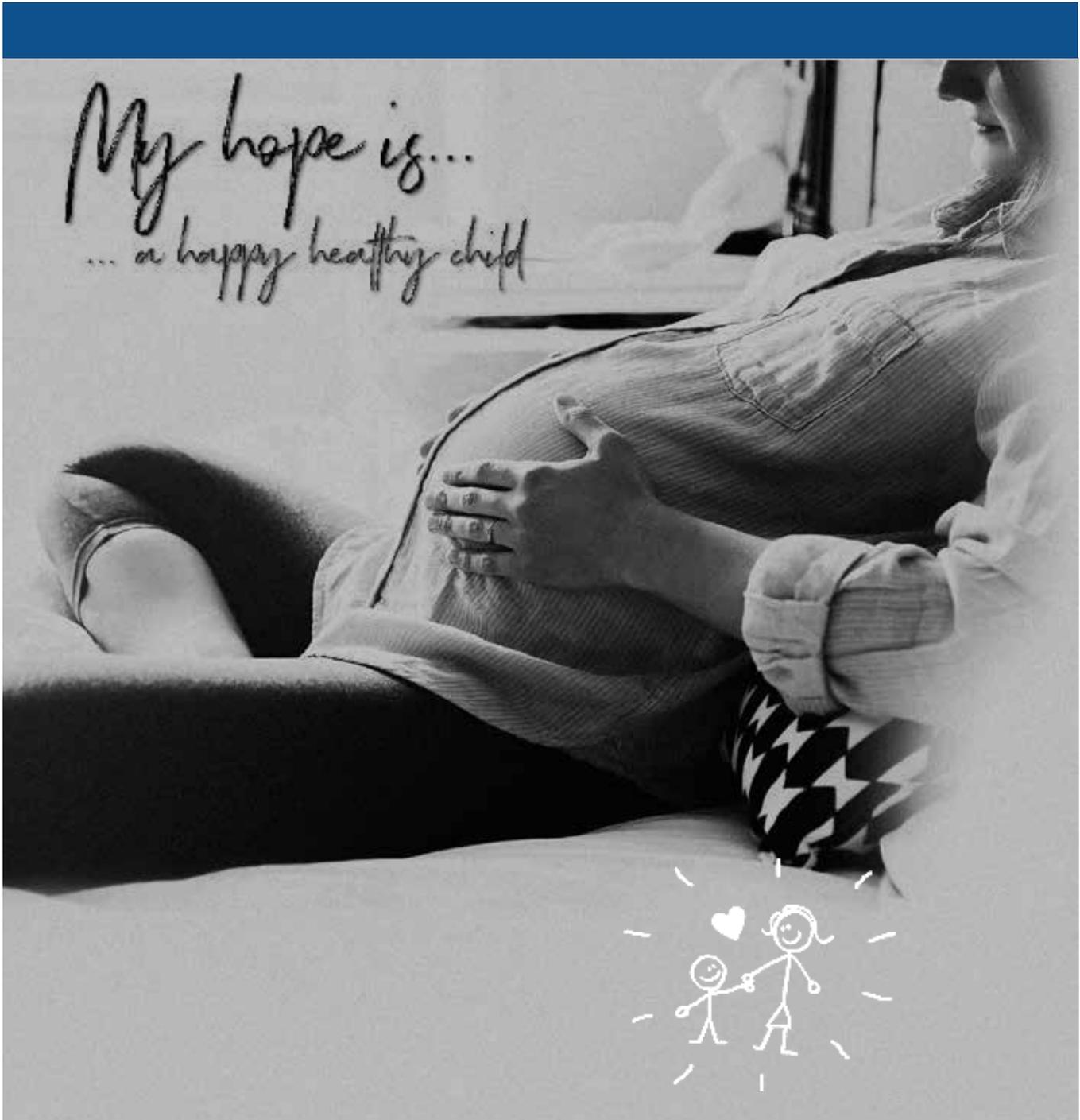
Nancy A. Trott  
James Carter  
Terry M. Byrne  
Maria Beriault

Elisabeth Linton  
Grace Roth  
Pam Fellows  
Mincom Solutions

## Thank you to our donors

### DONATIONS UP TO \$499

Alan & Sandra Humber	Fiore Aliperti	Lesley Brager	Robert Barry Gambrill
Alice & Jim Taylor	Forest Hills Public School	Lesley Evans-Ogden	Robyn A Goldie
Andrea Bergen	Gary Hawton	Lloyd & Myrna Blackburn	Ron & Cheryl Riedstra
Andrew Matyas	Gary & Jill Ley	Lorraine Harding	Ronald & Elizabeth Perry
Angie Lombardo	Glenn & Carolyn Kelly	Luigia Goegan	Shawn Maurice Gillingham
Annie D Boucher	Guy Larente	Lynda M. Reeds	Shirley Buffet
Annie Wiseman	Henry & Pat Schmitz	Lynn Pickering	Stephen Boland
Anu Rehtlane	Hillary Rosen	Marcus J Flor	Steve Sachs
Benevity Community Impact Fund	Ines Freeman	Margaret Chislett	Taimi Van de Polder
Braden Haggerty	International Union of Bricklayers & Allied Craftworkers, Local #1	Maria Foo	Teresa A Lake
C.U.P.W. Hamilton Local 548	Iqbal Mann	Marilyn S. MacDonald	Thomas Gradin
Canadian Union of Postal Workers, Hamilton Local 548	Jack & Kathy Wharton	Marion Lee	Tiffany & Co
Catholic Women's League - OLPH Council	Jamie Kwiatkowski	Marisa Filiberti	Tim Cormode
Cesare Maniago	Janette Richmond	Mark K Goldie	Tracey & Mark Porter
Christina Fazzina	Jason Scultety	Marrian Bertin	Verle & Frank Kaweski
Christine Andrade	Jean Linden	Mary Davis	Victor Lee
Claudette & Benoit Chartier	Jennifer Garrett	Mary Cavanagh	Victoria Park Golf Club
Colleen Zimmer	Jim Doyle	Mary Nelis	Viviane E Hébert/Rosemarie Tisnousky
Dan Sims	Johanne Racine	Maurice Gillingham	Sandra Hiliard
Daniel and Irene Gibson	John and Susan Lawson/Campbell	Merilyn Fox	Sebastian Hamberger
David Charlebois	John & Laura Swift	Michael & Marilyn Moore	Serge B. Melancon
Dawn Loewen	Joyce B Barraclough	Miller Thomson	Shelley Rosen
Deb Withers	Judith & John Howard & Micallef	Mohammad Choudhry	Steve Sachs
Delphine Woodland	Judy Byrne	Narinder Kaur	Suzanne Taylor
Diane Gratrix	Kaitlyn Di Ilio	Nory French	Verle & Frank Kaweski
Diane Owen	Katherine Ervin	Olivera D. Garia	Véronique Riopel
Dr. Cara Warrington	Katrina M Hill	Pamela MacDonald-Wolk	Virginia Mielke
Earl Phillips	Kay McLoughlin	Pat & Donna Davis	William & Better Nesbitt
Ecole Elementaire Catholique Paul VI	Keith & Maria Bartlett	Peter & Angela Sherbanow	Zsuzsi Gartner
Elizabeth Watson	Kendra Edstrand	Pierre Chayer	Anonymous
Emily Milne	Kim Angel	Provincial Employees Community Services Fund	
Eric & Louise Penney	Krista Karn	Rebecca Cousineau	
Erika Sigurdson	Laura Kaplan	Rebecca Cousineau	
	Lenard & Jane Boggio	Reginald & Bernice Woodland	
		Rick Allan	
		Rob & Lori Di Ilio	
		Robert & Lillian Wong	



*ignite hope and help make it happen*

**Donate Now**

 **Donate**

For more information please visit our website  
[www.mppsociety.ca](http://www.mppsociety.ca)

## In Memoriam

*"Perhaps they are not stars in the sky, but rather openings  
where our loved ones shine down to let us know they are happy."*

*~ Eskimo Saying*

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### **Francis Laforest (MPS IVA)**

passed away at the age of 26 after participating in an aquatic activity organized by the camp he was attending. Francis loved going to camp every year, even though his doctor had warned that his heart was weak.

Francis died happy and with his friends, doing what he loved best - enjoying life! His funeral was packed with people wearing Montreal Canadiens t-shirts to honour his favourite team.

---



### **Darren More**

father of **Jasper More (MPS VI)**, passed away suddenly at the age of 43 as a result of an automobile accident in Palmerston, Ontario on July 11, 2018.

Darren is much missed by his many family members and friends.

---



### **Rachel Lynn Gilhuis (MPS IIIB)**

born December 5th 2007, passed away peacefully at home on August 27th in her 10th year.

Rachel will be deeply missed by her Mom & Dad and siblings Ben, Nathan, Hannah, and Mathew.

Rachel was a Huge Fan of Barney! She loved spending time with Family and Friends. And of course her brother Mathew who is one year younger and is also affected by Sanfilippo Syndrome.

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### **Simon Ibell (MPS II)**

Simon R. Ibell passed away peacefully in his sleep on Friday, May 26, 2017. Survived by his devoted mother Marie, father Roger, sister Olivia, brother-in-law Cameron, niece Emily and nephew Andrew. He will be missed by his many friends. He will be remembered forever as a loving son, brother, best "unkie" and friend.

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### **Luke Braun (MPS IVA)**

Luke Braun, passed away on Saturday, May 27, 2017, at Toronto General Hospital. Luke was 20 years. Cherished and beloved son of Debbie and Jason Kerley of RR 3, Whitechurch, and Mitch Braun of Kincardine. Loving brother to Nicole and Gary Finlay of Lucknow, Alexa Braun and Zack Bedard of Exeter, Zane Braun of Whitechurch and Damen, Amber and Jordan Kerley, all of Listowel. Special uncle of Keegan. Dear grandson of Audrey and Murray Johnston of Bluevale and Lynda and David Kerley of Blyth. Luke will be lovingly remembered by his very special support workers, Colleen and Marcel Stadelmann; and his many aunts, uncles, cousins, and friends.

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Canadian **MPS** Society  
for Mucopolysaccharide & Related Diseases

## Contact us

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