



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



# 2017 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:

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

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## Inside the Annual Report:

Message from the Vice-Chair .....	1
Directors, Medical Advisory Board, Staff .....	2
Fundraising & Events.....	3
Financial Statements.....	4
Thank You To Our Donors .....	5
In Memoriam.....	6



## **Message from Vice-Chair Marilyn Marchment**

As I think about the progress the Canadian MPS Society has made over this past year, I'm energized by not only the list of tangible items that have been accomplished, but also by the significant amount of work that has taken place to set the stage for a bright future.

The Board welcomed Kaitlyn Di Illio from Ontario. Kaitlyn is a sibling and will be instrumental alongside Mélissa Bilodeau in steering the development and growth of our youth-focused initiatives, among other things. Retiring from the Board is Aubrey Hawton; we thank him for his tenure, commitment and support. We have an exciting agenda planned and require new board members to round out the team, please contact Kim Angel with your interest (or someone you know who will be a perfect fit). If being a Board member doesn't appeal to you, consider other opportunities to volunteer, including the Editorial Board or digital discussion group leader.

This spring saw the return of the MPS Gala where the Vancouver Alumni Association and the Harkins Family received awards for their long-term and unwavering support of the Canadian MPS Society. The formal affair raised close to \$30,000 and re-established this legacy event. We thank all of our long-term supporters.

Over the coming year we will continue to foster collaborative and supportive working relationships with rare disease-focused organizations nationally and internationally, while networking with affected Canadians to ensure we're doing all we can to support them in living their best lives.

— Marilyn Marchment, Vice-Chair

## Directors, Medical Advisory Board & Staff

### BOARD OF DIRECTORS

Chair – Lisa Bosdet  
*MPS I Parent, BC*

Vice Chair – Marilyn Marchment  
*Communications Consultant, BC*

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

Treasurer – Terry Byrne  
*MPS I Parent, Ontario*

Mojan Zehtabchi  
*Naturopathic Doctor, Ontario*

Larry Revet  
*MPS VI Parent, Saskatchewan*

Kaitlyn Di Ilio  
*MPS IIIB Sibling, Ontario*

### STAFF

Kim Angel  
*Executive Director*

Jill Ley  
*Administrative Assistant  
& Member Support*

### MEDICAL ADVISORY BOARD

Chair – Lorne Clarke  
MD, CM, FRCPC, FCCMG  
*BC Children's Hospital  
Vancouver, British Columbia*

Cheryl Rockman-Greenberg  
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*

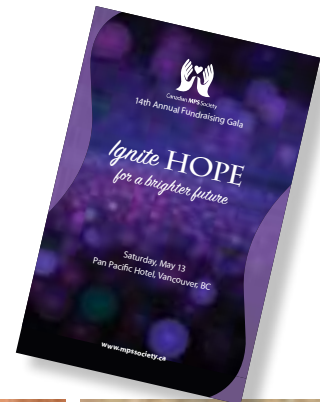
Sylvia Stockler, MD  
*BC Children's Hospital  
Vancouver, British Columbia*

## Fundraising & Events

### 14th Annual Fundraising Gala: Ignite HOPE

On May 13th, 120 guests attended the Canadian MPS Society's 14th Annual Fundraising Gala to support to courageous children and families that are affected by Mucopolysaccharidosis (MPS) and related diseases.

The Gala was a huge success - raising just shy of **\$30,000!**



### 2016-2017 Conferences & Events Attended

The Society attended national and world-wide events & conferences on MPS including:

- International MPS Society Conference, *Germany*
- National MPS Society's Family Conference, *Ohio*
- Global Genes Rare Patient Advocacy Summit, *California*
- Journey of Hope Gala, *Richmond, BC*
- International MPS Consensus Conference, *London*
- WORLD Symposium 2017 *San Diego*
- Rare Disease Day 2017 Conference, *Vancouver, BC*
- International Pediatric Association Congress, *Vancouver, BC*

## Financial Statements

### INDEPENDENT AUDITORS' REPORT

#### 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, 2017 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.

#### Report on Other Legal and Regulatory Requirements

As required by the British Columbia Society Act, we report that, in our opinion, the Organization's financial statements have been prepared following Canadian accounting standards for not-for-profit organizations applied on a consistent basis

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**CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.**  
**STATEMENT OF FINANCIAL POSITION**  
**AS AT MARCH 31, 2017**

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	2017	2016
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash	\$ 113,687	\$ 189,335
Investments	187,262	185,863
Accounts receivable	1,764	-
Government remittances receivable	964	-
Prepaid expenses and deposits	4,479	1,622
	<b>\$ 308,156</b>	<b>\$ 376,820</b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued liabilities	\$ 13,469	\$ 17,879
Government remittances payable	1,516	2,597
Deferred revenue (Note 3)	89,172	89,172
	104,157	109,648
<b>NET ASSETS</b>	<b>203,999</b>	<b>267,172</b>
	<b>\$ 308,156</b>	<b>\$ 376,820</b>

## Financial Statements

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

#### STATEMENT OF OPERATIONS

FOR THE YEAR ENDED MARCH 31, 2017

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	2017	2016
<b>REVENUE</b>		
Donations and grants	\$ 101,632	\$ 114,660
Fundraising	10,233	62,693
Membership fees	1,560	2,640
Dividend income	1,399	1,561
MPS II Research Fund	488	-
Restricted grant - MPS II Project	-	72,828
Other	-	1,058
	<hr/> 115,312	<hr/> 255,440
<b>EXPENSES</b>		
Salaries and contract fees	65,128	68,737
Professional fees	36,650	5,646
Travel	19,515	7,501
Advertising, communication and promotion	13,418	1,065
Family Assistance Program	12,666	4,900
Meetings	10,960	728
Office and miscellaneous	5,286	4,378
Join the Search	4,149	6,910
Computer	2,657	5,239
Telephone and Internet	2,512	2,314
Printing and postage	1,580	2,528
Office lease	1,560	1,000
Conference	1,500	582
Insurance	834	1,872
Membership dues	70	159
Goods and services tax	-	3,608
Research grants	-	2,000
Fundraising	-	20,344
MPS II Project	-	72,828
	<hr/> 178,485	<hr/> 212,339
<b>(DEFICIENCY) EXCESS OF REVENUE OVER EXPENSES</b>		
<b>FOR THE YEAR</b>	<hr/> \$ (63,173)	<hr/> \$ 43,101

## Thank you to our donors

Thank you so much to everyone who made contributions to the Society during our April 2016 - March 2017 fiscal year. Special thanks to the following major sponsors and donors, and to the organizers of major fundraisers:

### Industry Partners – Donations of \$25,000 - \$50,000

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 Shire

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### Donations of \$2,500 - \$4,999

Anonymous  
Vancouver Canucks  
Alumni Foundation

### Donations of \$500 - \$999

Linda Thomson – IMB  
Robert Regan-Pollock  
Maria Beriault



## Thank you to our donors

### Donations up to \$499

Aaron & Susan Gaudon	Ian Bryan	Mark & Yvonne Armstrong
Adrienne D'Ercole	Jack & Kathy Wharton	Mark Goldie
Alice Taylor	James Rosenthal	Mark Swan
Andrea McCallum	Jamie Kwiatkowski	Mary Ann Nelis
Andrea Rathwell	Jan Davis	Melody Johnson
Anne L. Davix	Jenifer Gentle	Mike Graham
Benjamin Seaman	Jenny Komorowski	Mike North
Bill & Marilyn Moore	Jill Yvonne Ley	Nancy Sawyer
Brendan Duffy	John & Marion Lee	Niall Rodgers
Bruce Gordon	John Goegan	Nick & Harriet Christon
Carolyn Dion	John Lawson	Nicolas Heldmann
Carolyn Rodgers	Jolene Livingston	Paul & Karen Mashinter
Chris & Lesley	Jonathan Spina	Pete & Flo Copelanad
Christodoulou	Judith & John	Peter & Angela Sherbanow
Connie Schill	Howard & Micallef	Ralph & Cathy Bankert
Daniel WWW	Julie Elgie	Rick & Marjorie Allan
Daniel & Irene Gibson	Ken Green	Robert & Barbara Carey
Dave Geiss	Ken Perry	Robin Howe
David & Johanna Bryant	Kirsten Harkins	Ronald & Elizabeth Perry
Donald & Angela Gunton	Laura Fryer	Rosemarie Tisnousky
Dustan Woodhouse	Leona Duffy	Sandra Hiliard
E. Dianne Rathwell	Linda & Jerry Johnston	Sebastian Hamberger
Earl & Heather Cooper	Lisa Rea	Serge B. Melancon
Ed Vasso	Lorene Hildrop	Shelley Rosen
Edna Sandberg	Lori & Robert Di Ilio	Steve Sachs
Elizabeth & Ronald Perry	Lorraine & Robert Harding	Suzanne Taylor
Gary & Sherry Robinson	Lynda M. Reeds	Verle & Frank Kaweski
Gordon Rae	Lynne O'Brien	Véronique Riopel
Heather Griffin	Margaret Farnan	Virginia Mielke
Heather Rivet	Margaret McFarland	William & Better Nesbitt
Henry & Pat Schmitz	Marilyn Kameka	Zsuzsi Gartner
		<i>Anonymous</i>

## In Memoriam

*They shall not grow old, as we that are left grow old;  
Age shall not weary them nor the years condemn.  
At the going down of the sun, and in the morning,  
We will remember them.*

- Laurence Binyon



### **Warren Edward Dendekker**

*July 4, 2005 - October 1, 2015*

Warren was the beloved son of Peter & Sandra Dendekker of Dundas, and dear brother of Emma, Noah, and Katherine. Cherished grandson of Simon & Henny Kranendonk of Ancaster and Peter Dendekker Sr. of Copetown. Warren was also much loved by many aunts' uncles & cousins. Predeceased by his Nana, Nellie Dendekker (2005), and cousin, Byron Kloetstra (2006). Also missed by countless family and friends from near and far.



### **Raza Amin**

*January 25, 1999 - June 28, 2016*

For Raza....

I was suppose to spend the rest of my life with you and then realized...that you spent the rest of your life with me. Holding you closer to my heart until we meet again In sha Allah.



### **Justin Van Herrewegan**

*November 19, 1981 - July 1, 2016*

Beloved son of Paul and Debi. Loved brother of Ashlee (Scott) Rathwell. Adored uncle of Paislee and Brooklyn. Cherished grandson of Rupert "Slim" and the late Connie Graham, and Maria and the late Mike Van Herrewegan. Dear nephew of Lynda (Ed) Jones, Pat Green, Doug (Kathy) Graham, Brian (Lorri) Graham, and Mike (Karen) Graham. He will also be missed by his great aunt, many cousins, extended family, friends, and his online buddies. Justin was a devoted member of several car clubs, and the open road will not be the same without him. His loving, selfless, adventurous and sentimental spirit will be terribly missed by all, and his gentle hugs will be treasured forever.

## In Memoriam

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### Elisa Linton

Affectionately nicknamed Lissy, Woogs, and Woogie by her family, Elisa passed peacefully into her new life in Heaven, early in the morning of Monday, October 31, 2016. Elisa was in her 23rd year. The daughter of Randall and Elisabeth Linton, and sister to Jessica and Connor, Elisa was born with Sanfilippo syndrome, a rare, regressive and terminal disease. Despite her physical and cognitive challenges, Lissy became a symbol of hope and inspiration to everyone.

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### Kobe Michael Taylor

*January 12, 2005 - November 7, 2016*

Kobe passed away peacefully on November 7, 2016 at the age of 11 in the arms of his loving and devoted parents, Candice and Michael. Kobe will be missed by his great grandmother Betty (GG); his grandparents: Mini (Grandma) and Gary (Motorcycle Grandpa), and Cathy (Grandma Cathy), Stan (Grandpa Taylor) and the late Giselle; his aunts and uncles Adam, Dwayne, Laurie and Anne; as well as his extended family, cousins and many, many friends.

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### Billy Bottineau

*October 9, 1987 - January 7, 2017*

Billy Bottineau passed away on January 7, 2017 at the age of 29. Survived by his parents Michael, Aubrey, and Matilda and the late Joseph. Brother of Thomas, Tommy, Emily, Cory, Donna, Rachel, April, Joseph, P.J., Bobby, Jessie, and the late Tessie. He will be missed by the Snively, Hawton, Bottineau, and the Dumont Families and by his friends.

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### Simon Ibell

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

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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**Contact us**

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VISIT OUR WEBSITE:	<a href="http://www.mpssociety.ca">www.mpssociety.ca</a>