

# 2012 annual report



The Canadian Society for  
Mucopolysaccharide &  
Related Diseases Inc.



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**“My friends, love is better  
than anger. Hope is better  
than fear. Optimism is  
better than despair. So let  
us be loving, hopeful and  
optimistic. And we’ll  
change the world.”**

**-Jack Layton**

Left: Loic Bydal (MPS IV A) with some  
friends from the Montreal Canadiens.

# THE CANADIAN MPS SOCIETY

## Our Vision:

We believe in a brighter future for those affected with and by Mucopolysaccharide (MPS) and related lysosomal diseases. We envision a future where patients no longer die from MPS and related diseases because treatments have been developed, cures have been discovered, and our government has made these treatments and cures accessible to those who need and deserve them. In the future we envision, those affected are living long, healthy and fulfilling lives—enjoying the company of their friends, children and grandchildren.

## Our Mission:

Founded in 1984, The Canadian Society for Mucopolysaccharide and Related Diseases Inc. (The Canadian MPS Society) is committed to providing support to individuals and families affected with MPS and related diseases, educating medical professionals and the general public about MPS, and raising funds for research so that one day there will be cures for all types of MPS and related diseases.

## Our Values:

The Canadian MPS Society values:

- community & compassionate support
- health & wellness
- justice & equality
- education & awareness
- research & innovation
- accountability & transparency

## BOARD OF DIRECTORS AND MEDICAL ADVISORY BOARD

### Staff

Executive Director - Kirsten Harkins  
Executive Assistant - Jill Ley

### Board of Directors

**Chair—Bernie Geiss**  
Professional, British Columbia  
**Vice-Chair—Carrie Nimmo**  
MPS I (Aunt), British Columbia  
**Secretary—Jean Linden**  
MPS III (Parent), British Columbia  
**Treasurer—Brenda MacLean**  
Professional, British Columbia  
**Mary Nelis**  
MPS I (Parent), Quebec  
**Barbara Boland**  
MPS III (Parent), Newfoundland  
**Judy Byrne**  
MPS I (Parent), Ontario  
**Todd Harkins**  
MPS I (Parent), British Columbia  
**Aubrey Hawton**  
MPS III (Parent), Ontario  
**Dan Priest**  
MPS IVB (Parent), British Columbia  
**Matthew Santos**  
MPS IVB, Ontario

### Medical Advisory Board

**Chair—Lorne Clarke**  
**M.D., C.M., F.R.C.P.C., F.C.C.M.G.**  
University of British Columbia,  
Vancouver, British Columbia  
**Robin Casey, M.D., M.S.C.**  
Alberta Children's Hospital  
Calgary, Alberta  
**Joe Clarke, M.D., Ph.D.**  
Hospital for Sick Children  
Toronto, Ontario  
**Aneal Khan, M.D.**  
Alberta Children's Hospital  
Calgary, Alberta  
**Mark Ludman**  
**M.D., F.R.C.P.C., F.C.C.M.G.**  
IWK Health Centre  
Halifax, Nova Scotia  
**Eva Mamak, Ph.D.**  
Department of Neuropsychology  
Hospital for Sick Children  
Toronto, Ontario  
**Serge Melancon, M.D.**  
Montreal Children's Hospital  
Montreal, Quebec  
**John Mitchell, M.D.**  
Montreal Children's Hospital  
Montreal, Quebec

### Cheryl Rockman-Greenberg

**M.D., C.M., F.R.C.P.**  
Winnipeg Children's Hospital  
Winnipeg, Manitoba  
**Julian Raiman, M.D.**  
Hospital for Sick Children  
Toronto, Ontario  
**Tony Rupar, M.D.**  
CPRI  
London, Ontario  
**Sylvia Stockler, M.D.**  
BC Children's Hospital  
Vancouver, British Columbia



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Mucopolysaccharide &  
Related Diseases Inc.*

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Charity # 12903 0409 RR0001

## SUPPORT FOR FAMILIES

Families across Canada depend on the Canadian MPS Society for support and education, and generous support from our donors during our 2011-2012 fiscal year allowed us to organize a regional meeting, create a social media community, fund assistance grants, and continue to educate the government about issues important to those living with MPS or a related disease.



On April 30, 2011, the Society hosted its first **Prairie Provinces Patient Meeting** in conjunction with the Canadian Association for Pompe and the Metabolic Clinic at Alberta Children's Hospital. Pictured above are Savannah Hunik (MPS IV A), Yusuf Idris (MPS II) and Athena Pare.



On June 3rd, 2011, members of the Society's **Medical Advisory Board** met in Vancouver, BC to discuss education and research initiatives. Three physicians joined our MAB during our 2011-2012 fiscal year, and we thank them (Aneal Khan, John Mitchell and Eva Mamak) and all the other long-standing members whose expertise, guidance and service is invaluable. Pictured above: John Mitchell, Julian Raiman, Kirsten Harkins, Serge Melancon, Aneal Khan, Lorne Clarke, Joe Clarke, Robin Casey and Tony Rupar.



On February 29 and March 1, 2012, the Society celebrated **International Rare Disease Day** by participating in Canadian Organization for Rare Disorders' **Action Day on Parliament Hill** and **Rare Disease Conference and Gala** in Ottawa. The Society continues to work with CORD and its member organizations toward a national plan for treatments for rare disorders, and with the International MPS Network on issues of common concern.



Above left: Society Executive Director and CORD Vice-President Kirsten Harkins (2nd from left) with CORD board member Bill Dempster, CORD President Dr. Durhane Wong-Rieger, and Dr. Colin Carrie, MP for Oshawa and Parliamentary Secretary to the Minister of Health; Above right: Kirsten with Lisa Bidulka, Canadian Gaucher Foundation President Christine White, Canadian Fabry Association President Darren Bidulka, and CORD and Niemann-Pick Foundation board member Ashraf Ghadban.

**Join our new social media community!**



Thanks to pro bono assistance from the Ledcor Group's communications team throughout our 2011-2012 fiscal year, you can now join our social media community! Follow us on twitter, like us on facebook, and watch our educational and fundraising videos on YouTube.

Our quarterly newsletter *the Connection*, also received a facelift: our first colour-cover edition was issued in the fall of 2011.



A highlight of our 2011-2012 year was that several Canadian patients - including Lucas and Zane Braun, pictured above - were able to participate in BioMarin's Phase III **enzyme replacement therapy study for the treatment of MPS IV A**. This first-ever treatment study for MPS IV A had Canadian sites in Montreal, Sherbrooke and Toronto. Some data from the study will be available at the end of 2012, and if the drug seems to be safe and effective, paperwork will be filed with regulatory authorities (including Health Canada) in early 2013.

## RESEARCH FOR A CURE

**With our donors' support, we were able to fund the following research grants at the end of our 2011-2012 fiscal year. Thank you for helping us create a brighter future!**

### **2012-1 Research Grant: Overcoming the engraftment defect in MPS I mice to allow non-myeloablative BMT**

- Principal Investigator: Dr. Brian Bigger
- Institution: University of Manchester, UK
- Funds allocated: \$50,000 (one year grant)

### **2012-4 Research Grant: Morquio-Better Project**

*This grant was funded through the Society's MPS IV B Research Fund*

- Principal investigator: Dr. Sylvia Stockler
- Institution: BC Children's Hospital
- Funds allocated: \$50,000 (one year grant)

### **CIHR SHOPP Grant: The molecular mechanisms of microgliosis in GM2 ganglioside lysosomal storage diseases**

*This grant was funded jointly by the Society and the Canadian Institute of Health Research (CIHR). Each contributed \$22,500.00 per year for three years, for a total contribution each of \$67,500.00.*

- Recipient: Elizabeth J. White
- Institution: McMaster University
- Supervisor: Suleiman A. Igdoura
- Funds allocated: \$135,000

### **The Canadian MPS funded two Summer Studentship Research Grants in 2011:**

#### **Characterization of CNS Phenotype of MPS IIIC Mouse Model**

- Recipient: Katrin Resch
- Institution: CHU St-Justine Research Centre, Montreal
- Supervisor: Dr. Alexey Pshezhetsky
- Amount funded: \$4,000

#### **Development of Neuronal Cell Culture Models for MPS III (Sanfilippo syndrome)**

*This grant was funded through a generous donation from the Sanfilippo Children's Research Foundation*

- Recipient: Michael James McLean
- Institution: University of Victoria
- Supervisor: Dr. Francis Choy
- Amount funded: \$4,000

The Society is indebted to amazing community-minded organizations and businesses who care about kids with MPS. The Society was the recipient of funds raised through **YYoga's** February 18th, 2012 **Magic Mountain Meltdown** (pictured at right) and also received the proceeds of all by-donation YYoga classes in greater Vancouver during the months of January - March, 2012. Linda Summers of **Namaste Yoga** (pictured at bottom left of page 5, with sister Sonia Lanese and nephew Andrew - MPS II) also donated the proceeds of a yoga fundraiser.



That's Amore! On October 22nd, 2011, **A Journey of Hope's An Evening in Italy** - a fundraiser for the MPS IV B Research Fund - was held in Richmond, BC.

Pictured above are organizers Tina and Dan Priest, Kirsten Harkins, Laura Guerrero and Arthur Cabral (MPS IV B), Dr. Sylvia Stockler, Hans Hamberger and Jenifer Gentle.



# TOGETHER WE ARE CREATING A BRIGHTER FUTURE

Fundraising events, big and small, help us create a better world for kids with MPS. Thanks to everyone who organized, participated in, or contributed to any of the many events that took place during our 2011-2012 fiscal year. Here are some highlights:



The 9th annual MPS CUP Fantasy Hockey Game & Gala took place in Vancouver May 14th, the day before International MPS Awareness Day. And the puck dropped for the inaugural MPS CUP Toronto on June 4th, 2011. Thanks to all who joined our teams to help kids raise their arms in victory over MPS - visit [www.mpscup.ca](http://www.mpscup.ca) to view more amazing photos of both events. Above left: North Vancouver District Councillor Roger Bassam with Todd Harkins and Kirk McLean; Above right: Oakville MP Terence Young with Leafs Alumni Bill Derlago and Mike Gartner.



The stars came out on September 24th, 2011 for **Once Upon a Cure** - a fundraiser for the Society's MPS II Research Fund. Held in Vancouver, BC and organized by Ryan and Deb Purcell (pictured above), the spectacular event was attended by the cast of TV's *Once Upon a Time* (pictured above).



On October 16th, 2011, Team MPS took part in the **Scotiabank Toronto Waterfront Marathon**. Inspired by Jasper (MPS VI) the More family's "NO MORE MPS" team (above) raised over 12,000!

**Canadian MPS Jeans Days** continue to take place across the country at schools and businesses. Pictured above, Stefan Gacic (MPS IV A) raised awareness and over \$1,500 with his classmates at Kensal Park French Immersion school in London, Ontario.



# FINANCIAL STATEMENTS FOR YEAR ENDED MARCH 31, 2012

## To the Directors of The Canadian Society for Mucopolysaccharide & Related Diseases Inc.,

We have reviewed the Balance Sheet of The Canadian Society for Mucopolysaccharide & Related Diseases Inc. as at March 31, 2012, and the Statement of Revenue, Expenditures and Surplus for the year then ended.

Our review was made in accordance with generally accepted standards for review engagements and accordingly consisted primarily of enquiry, analytical procedures and discussion related to information supplied to us by the Society.

A review does not constitute an audit and consequently we do not express an audit opinion on these Financial Statements.

Based on our review, nothing has come to our attention that causes us to believe that these Financial Statements are not, in all material respects, in accordance with Canadian generally accepted accounting principles.

*Quantum Accounting Services Inc.*  
Vancouver, BC  
July 26, 2012

## Balance Sheet as at March 31, 2012 (Unaudited)

March 31	2012	2011
<b>Assets</b>		
Current Assets		
Cash and short term deposits	222,322	168,815
Sales tax recoverable	1,334	1,346
Accrued interest receivable	-	407
Prepaid Expenses	13,300	3,756
<b>Total Current Assets</b>	<b>236,956</b>	<b>174,324</b>
<b>Liabilities</b>		
Current Liabilities		
Accounts Payable & Accrued Liabilities	1,100	1,000
<b>Total Current Liabilities</b>	<b>1,100</b>	<b>1,000</b>
<b>Surplus (Deficit)</b>	<b>235,856</b>	<b>173,324</b>
	<b>236,956</b>	<b>174,324</b>

On behalf of the Board of Directors,

*Brenda MacLean*  
Treasurer

*Bernie Gleiss*  
Chairperson

## Notes to Financial Statements: (Unaudited)

### Note 1. Organization

The Canadian Society for Mucopolysaccharide & Related Diseases Inc. is incorporated under the laws of Canada as a not-for-profit organization and is registered under the Income Tax Act as a charitable organization and as such is not subject to income taxes. The Society's aim is to provide support to Canadians affected by lysosomal storage diseases (LSDs), to raise public and professional awareness of LSDs, and to fund research for a cure.

### Note 2. Significant Accounting Policies

#### Revenue Recognition

The Society follows the deferral method of accounting for contributions.

#### Capital Assets

Capital assets are not recorded on the balance sheet. Expenditures for capital assets in the year are recorded as expenses and disclosed in the statement of operations. The capital assets of the Society consist of office equipment and computer software.

#### Volunteer Services

The work of the Society is dependent on the efforts of many volunteers. Because these services are not normally purchased by the Society and because of the difficulty of determining their fair value, donated services are not recognized in these financial statements.

#### Financial Instruments

Unless otherwise noted, it is management's opinion that the Society is not exposed to significant interest rate or credit risks arising from its financial instruments. Significant cash balances are being held at one major financial institution. The Society has a term deposit totaling \$74,157 which bears interest at 1.30% and matures on March 13, 2014.

### Note 3. Fundraising

Fundraising revenue is comprised of gross revenue in the amount of \$170,886 (2011—\$126,422) less expenditures in the amount of \$52,532 (2011—\$26,330).

### Note 4. Donor Advised Funds

Donor Advised Fund Revenue is comprised of each fund's gross revenue less expenditures (including a 5% administrative fee per fund). The MPS IV B Fund also funded \$33,264 toward a 2012 research grant awarded to Dr. Sylvia Stockler at UBC.

# FINANCIAL STATEMENTS FOR YEAR ENDED MARCH 31, 2012

For year ended March 31, 2012	2012	2011
<b>Revenue</b>		
Fundraising, Net of Related Expenses (Note 3)	118,354	100,092
Donations	59,817	116,017
MPS II Research Fund, Net of Related Expenses (Note 4)	81,489	45,161
Membership Fees	4,245	3,634
Interest	1,315	2,312
Sales	2,126	1,501
Miscellaneous Income	9,455	4,075
MPS IV B Research Fund, Net of Related Expenses (Note 4)	19,949	28,370
Conference Revenue	-	27,015
<b>Total Revenue</b>	<b>296,750</b>	<b>328,177</b>
<b>Expenditures</b>		
Salaries and Contract Fees	77,912	70,415
Printing and Postage	8,834	7,540
Office Expense	8,823	5,730
Travel	8,577	12,161
Family Assistance Program	8,359	11,424
Office Lease	6,072	5,761
Non-recoverable GST/HST	3,895	4,350
Telephone and Internet	3,379	3,268
Promotional Items	2,497	682
Consulting Fees	2,000	24,067
Insurance	1,953	-
Computer Software	1,650	2,060
Meetings	1,571	629
Professional Fees	1,330	1,125
Membership Dues	130	433
Conference Expenses	-	31,101
Office Equipment	-	709
	<b>136,982</b>	<b>181,455</b>
Research Grants	97,236	105,833
<b>Total Expenditures</b>	<b>234,218</b>	<b>287,288</b>
<b>Excess/(deficiency) of revenue over expenditures for the year</b>	<b>62,532</b>	<b>40,889</b>
<b>Surplus, beginning of year</b>	<b>173,324</b>	<b>132,435</b>
<b>Surplus, end of year</b>	<b>235,856</b>	<b>173,324</b>

# THANK YOU FOR HELPING US CHANGE THE WORLD!

Thank you so much to everyone who made contributions to the Society during our April 2011-March 2012 fiscal year. Special thanks to the following major sponsors and donors, and to the organizers of major fundraisers:

## **DIAMOND**

### **(Donations of \$10,000+)**

Shire Human Genetic Therapies Inc. (Canada)

Genzyme Canada Inc.

Biomarin Pharmaceutical Inc. (Canada)

John & Catherine Sheridan

Ledcor Group

CTV

Team 1040 Radio

### **The MPS CUP Fantasy Hockey**

**Game & Gala** -The Harkins Family

**Once Upon a Cure\*** - The Purcell Family

**Journey of Hope's An Evening in Italy\*\*** - The Priest Family

**Team MPS at the Scotiabank Toronto Waterfront**

**Marathon** - The More Family

## **PLATINUM**

### **(Donations of \$5,000+)**

Mrs. Betty Done\*\*

The Priest MPS IVB Donor Advised Fund\*\*

Anonymous

Graeme & Carolyn Sewell

Scotiabank

North Shore News

The Sutton Place Hotel

TVCogeco

## **GOLD**

### **(Donations of \$2,500 - \$4,999)**

Bill Adams

Kent Scarborough & Krista Nickel

Black Gold Lodge

Miller Thomson LLP

Synergy Foundation

Creation Entertainment\*

Cove Financial Planning Ltd.

Braden Haggerty\*

Andrew Knight\*\*

McCarthy Tetrault Foundation

TBG The Bicycle Group Inc.

(Kona Bicycle Co.)

Amanda Tapping\*

Ledcor Construction Limited

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London Drugs\*\*

Enterprise Holdings Foundation\*

The Dynamics

SPEEDBOLT Printing Solutions

## **Emma Rose Gala** - Lara & Rudy

Pietrolungo & the Grenon/

LeMaitre Family

## **SILVER**

### **(Donations of \$1000 - \$2499)**

Ginnifer Goodwin\*

Y Yoga - Northshore Elements

Jared Padalecki\*

Patricia Marquis\*

Michelle Cehak\*

Stephen & Anne Meyer\*\*

JCA Communications Inc.

Danneel Grawl-Ackles\*

Oliver Webbe\*

Linda Jones

Charles Scarborough

Rick & Anna Marks

Mavel Sanu\*

Chris D'Odorico\*\*

The Nemetz Foundation\*\*

Heather Cehak\*

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Bob Foulkes

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James & Leslie Carter

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Halley & Don Prestage\*

Judith Hager

Grenville Pinto

Gordon & Rita Thomas\*\*

Canucks Sports & Entertainment

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Brian J. Sobie

Doug & Andrea Froese\*

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Hans & Cas Holst\*

Neal Harkins

All Axis Systems Inc.\*

G.F.H. Enterprises Ltd.\*

Glen Abbey Golf Resort

Pawsabilities Holdings

Corporation\*

Little League BC Celebrity Golf

Classic



Nicklas Harkins (MPS I) and

Cole Todd with Orland Kur-

tenbach at the Little League

BC Celebrity Golf Classic

**Steps to a Cure** - Sara Halliday & the Hunt Family

**Kensal Park Public School**

**Jeans Day** - Verica Gacic

## **BRONZE**

### **(Donations of \$500 - \$999)**

Darren & Leanne Bernaerdt\*\*

Peter & AnneMarie DeLuise\*

Melanie Bridle\*\*

The Sanfilippo Children's

Research Foundation

Alexander Thomas\*\*

Salim Hirji\*

NHLPA

Nancy & David Johnson\*

Ian & Julie Thomas\*\*

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Imperial Paving

Intuit\*

Norm Williams\*\*

Dustan Woodhouse\*

Marpole Drywalling Ltd.\*\*

Stormtech Performance Apparel

Wade Bartok

Elizabeth Werner\*

Konrad Tittler\*

Vancouver Canucks

Canlan Ice Sports

Dr. Victor Spielmann\*

David Stafford\*\*

Karyn Baltzer\*

Harbour Air Seaplanes

Bernie & Christie Geiss

Walter Gretzky

John & Lynda Noble\*

Gurjit Parmar\*

Dana Johl\*

Rob Regan-Pollock\*\*

Linda Summers\*

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Carolyn Hubbard

Happy Scissors\*\*

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Ross & Diane Smith

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Howard Graphic Equipment Ltd.

Sonoco

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Ledingham Design Consultants\*

Lugaro Jewellers\*

Premier Marine

North Shore Winter Club

Mex Y Can Flowers

BC Hockey Now

West Shore Constructors

Fawcett Insurance

Rocket Repro

Carrie Marshall Photography

Top Notch Prep & Print

**The Great Lake Walk** - Brooke &

Wilma Hodson

**St. Augustine Catholic School**

**Fundraiser in memory of**

**Matthew Di Ilio** - Kaitlyn

Di Ilio

\*MPS II Research Fund donation

\*\* MPS IVB Research Fund donation