

# 2013 annual report



The Canadian Society for  
Mucopolysaccharide &  
Related Diseases Inc.



## Inside the Annual Report

The Canadian MPS Society's  
Vision, Mission and Values,  
Board of Directors &  
Medical Advisory Board

Support for families.

Research for a Cure.

Fundraising: your support  
means the world to us!

Financial Statements

Major Donors: making a world  
of difference!

**“To the world you  
may be just one  
person, but to one  
person you may be  
the world.”**

**-Josephine Billings**

Left: Violet Revet (MPS VI) at our  
2012 National Family Conference

# 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

### 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  
**Treasurer—Brent Nichols**  
Professional, British Columbia  
**Barbara Boland**  
MPS III, Parent, Newfoundland  
**Judy Byrne**  
MPS I, Parent, Ontario  
**Warren Campbell**  
Professional, British Columbia  
**Todd Harkins**  
MPS I, Parent, British Columbia  
**Aubrey Hawton**  
MPS III, Parent, Ontario  
**Mary Nelis**  
MPS I, Parent, Quebec  
**Dan Priest**  
MPS IVB, Parent, British Columbia  
**Matthew Santos**  
Adult with 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  
**Eva Mamak, Ph.D.**  
**(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

### Staff

**Kirsten Harkins, Executive Director**  
**Jill Ley, Executive Assistant**



*The Canadian Society for  
Mucopolysaccharide &  
Related Diseases Inc.*

PO Box 30034, RPO Parkgate  
North Vancouver, BC V7H 2Y8  
Phone: 604.924.5130 / 1.800.667.1846  
Fax: 604.924.5131  
Email: [info@mpssociety.ca](mailto:info@mpssociety.ca)  
[www.mpssociety.ca](http://www.mpssociety.ca)  
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 2012-2013 fiscal year allowed us to bring families together through an incredible national conference and a more connected virtual community. We launched a new monthly e-newsletter, developed new family resource binders, and funded assistance grants for families in need. And, to ensure access to necessary treatments, we continued to educate the government about issues important to those living with MPS or a related disease.

## WORKING TOGETHER FOR A BETTER FUTURE FOR ALL

In October 2012, the Canadian MPS Society joined Canadian Organization for Rare Disorders who, on behalf of the 2.8 million Canadians with rare disorders, welcomed Health Minister Aglukkaq's announcement of the "first ever Canadian framework to increase access to new treatments and information" and the launch of Orphanet-Canada.



In celebration of **Rare Disease Day**, Canadian Organization for Rare Disorders (CORD) hosted the **5th Annual Rare Disease Day Conference and Awards Dinner Gala** in Toronto February 28 & March 1, 2013.

Two Canadian MPS Society Medical Advisory Board members were honoured with "Rarity Awards". Congratulations to:

Dr. Cheryl Rockman-Greenberg: Rarity Award for Health Professional Leadership for excellence in service to the rare disease community

Dr. Lorne Clarke: Rarity Award for Scientific Excellence for significant contribution to advancing research in rare diseases



**Home infusions** made receiving enzyme replacement therapy less onerous for kids like Maya Bosdet (MPS I), pictured above at home with her brother Owen. And if you look carefully at the top photo, you can see Maya's photo (& Dr. Julian Raiman's) at the **International MPS Symposium**, held in the Netherlands.

### Join our virtual community!



Follow us on twitter (@CanMPSSociety)



Like us on facebook (Canadian MPS Society)



Watch our videos on YouTube.

In May 2012, we launched our new e-newsletter, *the e-connection*.



Join our mailing list to keep up -to-date on Canadian MPS Society news throughout the year!



Throughout our 2012-2013 fiscal year, several Canadian patients - including Lukas and Zane Braun, pictured above with a friend from the Blue Jays - continued their participation in BioMarin's **Phase III enzyme replacement therapy study for the treatment of MPS IV A**.

On November 5th, 2012, BioMarin announced that the trial met the primary endpoint of change in six-minute walk distance and, based on the results, will be submitted marketing applications in Canada at the end of 2013.

# RESEARCH FOR A CURE

**With our donors' support, we were able to fund the following research grants at the end of our 2012-2013 fiscal year. Hope means the world to us!**

## **2013 Summer Studentship Research Grants:**

### **Identification of potential pharmacological chaperones for treatment of MPS by high-throughput screening for inhibitors of human iduronidase**

- Recipient: Michael Jew
- Institution: UBC
- Supervisor: Prof. SG Withers
- Amount funded: \$4,000



### **Purification and uptake studies of alpha-N-acetylglucosaminidase**

- Recipient: Geoffrey Morris
- Institution: Uvic
- Supervisor: Dr. Francis Choy
- Amount funded: \$4,000

*This grant was funded by a generous donation to the Canadian MPS Society by the Sanfilippo Children's Research Foundation.*



## **2013-4 Research Grant:**

The Canadian MPS Society, through its MPS IV B Research Fund, funded the following research grant for research into MPS IV B (Morquio B syndrome):

### **Morquio-Better Project - 2: Novel chaperones for GLB1-deficient diseases**

Principal investigator: Dr. Eduard Paschke  
Institution: Medical University of Graz (Austria)



The beautiful photos on this page were taken at our 2012 National Family Conference. From left to top right: Sebastien & Kobe (both MPS II), Shawn (MPS III), Melissa (MPS IVA) & her dog Papuk, Monika & Anisa (both MPS I) with Lawson, Jasper (MPS VI).



# 10 YEARS OF SCORING GOALS FOR KIDS WITH MPS

At the 2012 MPS CUP in Vancouver, we celebrated 10 years of helping kids raise their arms in victory over MPS. Fundraising events, big and small, make a difference for kids with MPS. Thanks to everyone who organized, participated in, or contributed to any of the many events that took place during our 2012-2013 fiscal year.



David Jones & Stefan Elliott with Nicklas Harkins (MPS I) at the 2012 MPS CUP



Toronto Maple Leafs Alumni with Sarah Byrne (MPS I) at the 2012 MPS CUP Toronto, held during our conference at the Nottawasaga Inn in Alliston, Ontario.

Players who received recognition certificates at the 2012 MPS CUP Gala for being members of our team for five or more years: Mike MacWilliam, Rod Nimmo, Gary Lewis, Tony Tanti, Garry Valk, Dave Babych (who had played in 9 of 10 games!), Peter Hrdlitschka, Ken Dixon and Dave Tomlinson. Other players who have been members of our team for five or more years but couldn't attend the event in 2012 are: Glen Barker, Steve Bolton, Chris Bouchard, Mike Greschner, Stephen Jungaro, Michael Urbani. Thanks, guys!



The society was the featured charity at the February 2013 **Just Singin Round** event at the Vancouver Rowing Club. We are so grateful to the many talented musicians (pictured above) who volunteered their time to entertain the crowd and help us raise funds and awareness.



Far left: Allan Pyl (Dad of Shawn, pictured on page 4) and Peter Weima were members of **Team MPS** in the **Scotiabank Toronto Waterfront Marathon** in October 2012, as was Becky Hardman (pictured with daughter Emma, who has MPS I).

Sadly, Shawn Pyl passed away on February 13, 2013.

# FINANCIAL STATEMENTS FOR YEAR ENDED MARCH 31, 2013

## 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, 2013, and Statement of Revenue, Expenditures and Surplus for the year then ended.

Our review was made in accordance with Canadian 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  
September 9, 2013

## Balance Sheet as at March 31, 2013 (Unaudited)

March 31	2013	2012
<b>Assets</b>		
Current Assets		
Cash and short term deposits	168,881	222,322
TD Waterhouse Investment	50,031	-
Sales tax recoverable	2,406	1,334
Accrued interest receivable	404	-
Prepaid Expenses	2,500	13,300
<b>Total Current Assets</b>	<b>224,222</b>	<b>236,956</b>
<b>Liabilities</b>		
Current Liabilities		
Accounts Payable & Accrued Liabilities	1,100	1,100
Deferred Revenue-MPS CUP	100	-
<b>Total Current Liabilities</b>	<b>1,200</b>	<b>1,100</b>
<b>Surplus/ (Deficit)</b>	<b>223,022</b>	<b>235,856</b>
	<b>224,222</b>	<b>236,956</b>

On behalf of the Board of Directors,

*Brent Nichols*  
Treasurer

*Bernie Geiss*  
Chair

## 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 \$124,768 (2012—\$170,886) less expenditures in the amount of \$33,463 (2012—\$52,532).

### 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).

# FINANCIAL STATEMENTS FOR YEAR ENDED MARCH 31, 2013

For year ended March 31, 2013	2013	2012
<b>Revenue</b>		
Donations	125,276	59,817
Fundraising, Net of Related Expenses (Note 3)	91,305	118,354
Conference Revenue	24,250	-
MPS IV B Research Fund, Net of Related Expenses (Note 4)	10,867	19,949
MPS II Research Fund, Net of Related Expenses (Note 4)	9,762	81,489
Membership Fees	3,395	4,245
Miscellaneous Income	1,106	9,455
Sales	957	2,126
Interest	435	1,315
<b>Total Revenue</b>	<b>267,353</b>	<b>296,750</b>
<b>Expenditures</b>		
Salaries and Contract Fees	82,311	77,912
Consulting Fees	27,232	2,000
Conference Expenses	21,591	-
Printing and Postage	10,804	8,834
Travel	9,972	8,577
Office Lease	7,530	6,072
Office Expense	6,703	8,823
Non-recoverable GST/HST	5,710	3,895
Family Assistance Program	4,958	8,359
Telephone and Internet	2,665	3,379
Promotional Items	2,553	2,497
Insurance	2,244	1,953
Computer Software	2,018	1,650
Professional Fees	1,268	1,330
Office Equipment	1,012	-
Meetings	986	1,571
Membership Dues	130	130
	189,687	136,982
Research Grants	90,500	97,236
<b>Total Expenditures</b>	<b>280,187</b>	<b>234,218</b>
<b>Excess/(deficiency) of revenue over expenditures for the year</b>	<b>(12,834)</b>	<b>62,532</b>
<b>Surplus, beginning of year</b>	<b>235,856</b>	<b>173,324</b>
<b>Surplus, end of year</b>	<b>223,022</b>	<b>235,856</b>



# THANKS TO OUR DONORS—YOU MEAN THE WORLD TO US!

Thank you so much to *everyone* who made contributions to the Society during our April 2012-March 2013 fiscal year. Special thanks to the following major sponsors and donors, and to the organizers of major fundraisers:

## MONTHLY GIVING CLUB:\*

Stephen Boland  
Judy Byrne  
Bernie & Christie Geiss  
Junk Suk Cho

## DIAMOND DONORS:

**(Donations of \$10,000+)**  
Biomarin Pharmaceutical Inc.  
(Canada)  
CTV  
Genzyme Canada Inc. (a Sanofi  
Company)  
Shire Human Genetic Therapies  
Inc. (Canada)  
Team Radio  
**The MPS CUP Fantasy Hockey  
Game & Gala** -The Harkins  
Family

## PLATINUM DONORS:

**(Donations of \$5,000+)**  
Cove Financial Planning Ltd.  
Ledcor Group  
**Team MPS at the Scotiabank  
Toronto Waterfront  
Marathon**—The Pyl Family  
& The Hardman Family

## GOLD DONORS:

**(Donations of \$2,500 - \$4,999)**  
Air Canada Foundation  
Bill Adams  
Black Gold Lodge  
McCarthy Tetrault Foundation  
Pure Freedom YYoga  
Wellness Inc.  
Kent Scarborough & Krista  
Nickel  
TBG The Bicycle Group Inc.  
(Kona Bicycle Co.)  
The Sanfilippo Children's  
Research Foundation  
Robert Carlyle\*  
Heather Cehak\*  
Hans & Cas Holst\*  
Lana Parrilla\*  
Emilie de Ravin\*  
**Just Singin' Round**—  
Synergy Collective Society



## SILVER DONORS:

**Donations of \$1000 - \$2499)**  
Anonymous  
James Adamson  
BC Hockey Benevolent  
Foundation (Canucks  
Alumni)  
Kaitlyn Bogas  
Ron Bonsoleil  
Dr. Mark Crossman  
David Lloyd Consulting Inc.  
Bernie & Christie Geiss  
Bob & Priya Gill  
Neal Harkins  
Peter Hrdlitschka  
Todd & Kirsten Harkins  
The Horsepower Sports &  
Entertainment Group Inc.  
(Barrie Colts)  
Isherwood Associates  
JCA Communications Inc.  
JC Studio  
Linda Jones  
Little League BC Celebrity Golf  
Classic  
Maxwell Alexander Settari  
Fund-Calgary Foundation  
Mike Smedstad, Golf BC  
M.O. Productions  
Brent Nichols  
North Shore News  
Pacific Coastal Airlines

Earl & Barbara Phillips  
Richmond Olympic Oval  
Robertson Floors  
Charles Scarborough  
Speedbolt Printing Solutions  
Stormtech Performance  
Apparel  
Sutton Place Hotel Vancouver  
Nancy Trott & Ian  
Hanoomansingh  
Vancouver Canucks  
West Shore Constructors Ltd.

## BRONZE DONORS:

**(Donations of \$500 - \$999)**  
Judy Byrne  
Canyon Laser & Skin Care  
Carrie Marshall Photography  
& Rocket Repro  
Leslie Carter  
Mrs. Betty Done  
Fairmont Pacific Rim  
Fawcett Insurance  
Olivia Ford  
Bob Foulkes  
Greater Vancouver  
Powersports  
Judith Hager  
Hockey Now  
Kitchen Culinaire  
Kiwanis Club of Timmins Inc.  
Yolanda Lillquist  
Amanda MacCaskell

Mayfair Lakes Golf & Country  
Club  
Mex Y Can  
North Shore Winter Club  
Pro-formance Goalie Schools  
Rotary Women's Association  
Karen & Tim Saxvik  
Robert Schneider  
Jack Segal  
The Vancouver Club  
Tin Wis Resort Lodge  
Michael Urbani  
Ilse Cehak\*  
Krista Purcell\*  
**Great Lake Walk**—Brooke  
Hodson & Yvonne Nimmo

Pictured above: delegates at our 2012 National Family Conference. Visit [www.mpsociety.ca](http://www.mpsociety.ca), [www.mpscup.ca](http://www.mpscup.ca) and our facebook page for more great event photos. Thanks so much for your support!

\*You can join our monthly-giving club online or by calling us at 1-800-667-1846.

\* indicates MPS II Research Fund Donation