

# 2011 annual report



The Canadian Society for  
Mucopolysaccharide &  
Related Diseases Inc.



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"Aerodynamically, the dragonfly shouldn't be able to fly, but the dragonfly doesn't care so it goes on flying anyway."

- Anonymous



**Above Left:** Matteo Spina (MPS I H) celebrates his first birthday

**Above Right:** Melanie Bourdon (MPS IVA) has fun at the 2010 Family Conference in Alliston, Ontario

**Left:** Avery Purcell (brother of Trey - MPS II) drops the puck at the 2010 MPS CUP as North Vancouver Mayor Richard Walton & MP Andrew Saxton face off

# 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—Judy Byrne**

MPS I Parent, Ontario

**Vice-Chair—Carrie Nimmo**

MPS I Aunt, British Columbia

**Secretary—Jean Linden**

MPS III Parent, British Columbia

**Treasurer—Brenda MacLean**

Professional, British Columbia

**Bernie Geiss**

Professional, British Columbia

**Mary Nelis**

MPS I Parent, Quebec

**Barbara Boland**

MPS III Parent, Newfoundland

**Todd Harkins**

MPS I Parent, British Columbia

**Aubrey Hawton**

MPS III Parent, Ontario

**Randall Linton**

MPS III Parent, Ontario

**Matthew Santos**

Adult with MPS IVB, Ontario

**Dan Priest**

MPS IVB Parent, British Columbia

### 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

**Mark Ludman**

**M.D., F.R.C.P.C., F.C.C.M.G.**

IWK Health Centre

Halifax, Nova Scotia

**Serge Melancon, 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**

kirsten@mpssociety.ca

**Jill Ley, Executive Assistant**

jill@mpssociety.ca



The Canadian Society for  
Mucopolysaccharide &  
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www.mpssociety.ca  
Charity # 12903 0409 RR0001

## SUPPORT FOR FAMILIES

The 2010-2011 fiscal year has been an exciting and busy one for the Canadian MPS Society. Thanks to ongoing and generous financial support from our members, sponsors and donors we were able to continue our



Delphine Genevas (France), Christine Lavery (UK) & Executive Director Kirsten Harkins standing at the International MPS Network's booth at the 11th International MPS Symposium in Adelaide, Australia

hard work to support affected families, educate medical professionals and the general public, and fund research for a cure.

In addition to publishing our quarterly newsletters, website, and Family Referral Directory, new Society bro-



Justin van Herrewegen (MPS VI) with his new niece Paislee

chures were generously created pro-bono by the Communications team at the Ledcor Group.

Three educational/fundraising videos were produced by the Society in conjunction with Barry Pettit and Pettit Inc. and are available for viewing on youtube. Copies will be sent shortly to all members for educational and fundraising purposes.

Our MPS II family resource binder was completed and launched at our 2010 National Family Conference, and a complimentary copy was sent to every MPS II member family.

Our National Family Conference was held in July 2010 at the Nottawasaga Inn in Alliston, Ontario, bringing many affected families together to hear presentations by Dr. Lorne Clarke, Dr. Julian Raiman and Dr. Kendra Bjoraker, tips on independent living and financial resources, financial planning advice, and an overview of the rare disease landscape in Canada. They also met two very inspiring young men: Justin van Herrewegen (MPS VI) and Matthew Santos (MPS IV B), who gave a glimpse into what they've had to overcome to live life to its fullest, and reminded everyone that there are no limits to what those with MPS can accomplish. While the adults were enjoying the conference, the children were busy participating in all kinds of fun activities, which you can view by visiting our website and clicking on "Conferences" under "About us".



Elisa Linton (MPS III B) with volunteer & super-sibling Ashlee Van Herrewegen-Rathwell at the National Family Conference

Throughout the year we supported several families with direct financial aid, allowing them to modify their homes, hire respite care and otherwise cope with the demands of children with unique needs.



Executive Assistant Jill Ley with Anisa Mia Elder (MPS I H/S)

The Society also promoted and participated in many events and meetings including: International MPS Awareness Day (e-cards were sent by the Society); the 11th International Symposium on MPS & Related Diseases in Adelaide, Australia; the Expert Meeting on MPS III (Sanfilippo) hosted by the UK MPS Society; "Action Day" in Ottawa hosted by CORD (a rare disorders conference followed); the WORLD Annual Meeting in Las Vegas, Nevada; and the UBC Patient Fair for Health Professional Educators at the University of British Columbia.



Sarah Hamza, Matthew Santos (MPS IV B) & Kirsten Harkins at CORD's 3rd Action Day in Ottawa entitled "Many Rare Disorders, One Common Voice"

# RESEARCH FOR A CURE

Thanks to our generous supporters, we were able to fund some important and exciting research grants:

## Utilizing neuronal stem cell models to develop small molecule therapies for MPS II

Principal investigator:  
Dr. Emyr Lloyd-Evans  
Institution: University of Cardiff, Wales  
Funds allocated (from the MPS II Research Fund): \$50,000



Trey Purcell (MPS II)

## 2010 CIHR SHOPP Program Partnership Grant

The Canadian MPS Society is partnering with Canadian Institute of Health Research (CIHR) to fund a three year fellowship of 135,000 into Lysosomal Disease Research (\$45,000 per year for 3 years)



Dr. Lorne Clarke with Nicklas Harkins (MPS I H/S) & Jonathan Heppner, a graduate student in the UBC Department of Medical Genetics working in Dr. Clarke's laboratory

## Collaborative research funding

### • SHOPP Program (CIHR)

The SHOPP program grant (for LSD research) was funded jointly by CIHR and the Canadian MPS Society: \$165,000 for three years (\$27,500 per year for 3 years)

## The molecular mechanisms of microglialosis in GM2 ganglioside lysosomal storage diseases

Recipient: Elizabeth J. White  
Institution: McMaster University  
Supervisor: Suleiman A. Igdoura  
Funds allocated: \$22,500 per year for 3 years.

## The Canadian MPS Society's 2010-11 Research Grant

Comprehensive study of pathogenic glycosami-

noglycan storage in a murine model of MPS I

Principal investigator: Dr. Lorne Clarke  
Institution: University of British Columbia, Vancouver, BC  
Funds allocated: \$100,000 (two year grant, \$50,000 per year for 2 years)

## 2010 Summer Studentship Research Grants:

**Mucopolysaccharidosis Type IIIB (Sanfilippo syndrome): Conjugation of Naglu to a synthetic protein transduction domain derived from the HIV-1 transactivator of transcription protein to allow Naglu to cross the BBB**

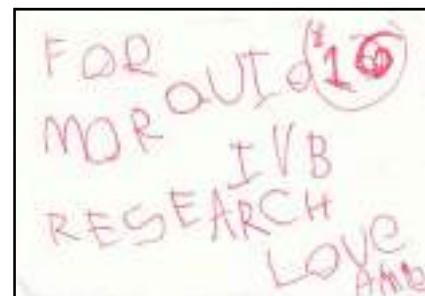
Recipient: Sarah Truelson  
Institution: University of Victoria, Victoria, BC  
Supervisor: Dr. Francis Choy  
Amount funded: \$4,000

## Chaperone Therapy for MPS IIIC

Recipient: Vincent Boudreau  
Institution: University of Montreal  
Supervisor: Dr. Alexey Pshezhetsky  
Amount funded: \$4,000



Dr. Joe Clarke & David MacKay (Mannosidosis) at the 7th Annual WORLD Symposium in Las Vegas, Nevada



## Charting the Experience of Mucopolysaccharide and Related Diseases at the Hospital for Sick Children

Recipient; Maha Safey El-Din Saleh  
Institution: The Hospital for Sick Children, Toronto, Ontario  
Supervisor: Dr. Julian Raiman  
Amount funded: \$4,000



Kirsten Harkins (middle) with Jenifer Gentle & daughter Christina (mom & sister of Jessica - MPS I H), Tina Priest (Tina & her husband Dan are parents of Steven - MPS IV B - and founders of our new MPS IV B Research Fund) and Dr. Sylvia Stockler at the MPS IV B Journey of Hope Starry Night Gala

# FUNDRAISING - THANK YOU FOR YOUR SUPPORT!

Thank you to everyone who helped organize and contributed to the many fundraising events held this year. Here are some highlights of just a few:



**The 2010 MPS CUP Fantasy Hockey Game & Gala**, which was held on International MPS Awareness Day, netted over \$96,000. We were honoured to be joined by Mark Dant, who came all the way from Texas to tell his family's inspiring and courageous story.



**Canadian MPS Jeans Days** took place in various schools and businesses across Canada.



**Just Singin' Round**, which took place in February, featured an amazing performance by Jared Suitor, hockey-teammate of Nicklas Harkins (MPS I H/S). The entire hockey team came out in support!



Nicklas Harkins & Olympian Cammi Granato at the 2010 Vancouver MPS CUP



Team MPS participated for the fourth year in the **Scotiabank Toronto Waterfront Marathon**. Thanks to our seventeen amazing runners and walkers and the many supporters who turned out to cheer them on, just under \$5,000 was raised for the Canadian MPS Society!



The Scotiabank Toronto Waterfront Marathon. Team MPS believes!

**Tacos for Trey**, always a fun event, was established by Deb & Ryan Purcell, and this year raised almost \$39,000 for our MPS II Research Fund.

The inaugural and very successful **MPS IVB Journey of Hope** fundraising gala, *Starry Night*, was organized by Dan and Tina Priest to raise funds for our newly-established MPS IV B Research Fund.

The 9th annual **Great Lake Walk** was a huge success, with participants raising money for their charities of choice. Brooke Hodson once again completed this 56 km. walk around Lake Cowichan on Vancouver Island, BC, raising over \$600 in donations and pledges for the Canadian MPS Society.

The Nelis-Dupont family with the help of their daughter Monika (MPS I H/S) raised over \$250 at their **Corn and Lemonade Fundraiser** in Bedford, Quebec.

The **Pumas soccer team** in Laval, Quebec, held a fundraiser in honour of their goalie's cousin, Matteo Spina (MPS I H) and donated \$500 to the Canadian MPS Society, with a promise to donate 10% of all future fundraising proceeds.

This year **Holiday Greeting Cards**, chosen and produced from winning entries in our Holiday Art Contest, were sold as a fundraiser.

The Society is also fortunate to have been the recipient of funds from various foundations, charities, and third-party charitable events. We gratefully received proceeds from the **BC Hockey**



The Pumas soccer team, Laval Quebec

**Benevolent Association** (The Vancouver Canucks Alumni), the **Little League Celebrity Golf Classic**, **Friends of Ferrari**, and the **Darwin Construction Annual Charity Golf Tournament**, to name just a few.



Jeans Day at Cove Cliff Elementary School in North Vancouver, BC



Monika Nelis-Dupont (MPS I H/S) sells lemonade for MPS!

# FINANCIAL STATEMENTS FOR YEAR ENDED MARCH 31, 2011

## 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, 2011, 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  
August 22, 2011

## Balance Sheet as at March 31, 2011 (Unaudited)

March 31	2011	2010
<b>Assets</b>		
Current Assets		
Cash and short term deposits	168,815	120,276
Sales tax recoverable	1,346	423
Accrued interest receivable	407	826
Prepaid Expenses	<u>3,756</u>	<u>11,910</u>
<b>Total Current Assets</b>	<b>174,324</b>	<b>133,435</b>
<b>Liabilities</b>		
Current Liabilities		
Accounts Payable & Accrued Liabilities	<u>1,000</u>	<u>1,000</u>
<b>Total Current Liabilities</b>	<b>1,000</b>	<b>1,000</b>
<b>Surplus (Deficit)</b>	<b><u>173,324</u></b>	<b><u>132,435</u></b>
	<b><u>174,324</u></b>	<b><u>133,435</u></b>

On behalf of the Board of Directors,

*Brenda MacLean*  
Treasurer

*Judy Fowler Byrne*  
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 \$72,435 which bears interest at 1.90% semi-annually and matures March 13, 2012.

### Note 3. Fundraising

Fundraising revenue is comprised of gross revenue in the amount of \$126,422 (2010—\$133,231) less expenditures in the amount of \$26,330 (2010—\$22,150).

### 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, 2011

For year ended March 31, 2011	2011	2010
<b>Revenue</b>		
Fundraising, Net of related expenses (Note 3)	100,092	111,081
Donations	116,017	56,248
MPS II Research Fund, Net of Related Expenses (Note 4)	45,161	13,972
Membership Fees	3,364	3,360
Interest	2,312	2,750
Sales	1,501	1,197
Miscellaneous Income	4,075	890
MPS IV B Research Fund, Net of Related Expenses (Note 4)	28,370	-
Conference Revenue	<u>27,015</u>	<u>-</u>
<b>Total Revenue</b>	<u><b>328,177</b></u>	<u><b>189,768</b></u>
<b>Expenditures</b>		
Salaries and Contract Fees	70,415	73,428
Conference Expenses	31,101	-
Consulting Fees	24,067	2,870
Travel	12,161	7,534
Family Assistance Program	11,424	4,587
Printing and Postage	7,540	6,498
Office Lease	5,761	5,655
Office Expense	5,370	4,747
Non-recoverable GST/HST	4,350	1,225
Telephone and internet	3,268	2,995
Computer Software	2,060	1,750
Professional Fees	1,125-	1,175
Office equipment	709	235
Promotional Items	682	413
Meetings	629	1,222
Membership Dues	433	720
Insurance	<u>1,001</u>	<u>1,001</u>
	181,455	116,055
Research Grants	<u>105,833</u>	<u>150,000</u>
<b>Total Expenditures</b>	<u><b>287,288</b></u>	<u><b>266,055</b></u>
<b>Excess/(deficiency) of revenue over expenditures for the year</b>	<u><b>40,889</b></u>	<u><b>(76,287)</b></u>
<b>Surplus, beginning of year</b>	132,435	208,722
<b>Surplus, end of year</b>	<u><b>173,324</b></u>	<u><b>132,435</b></u>

# THANK YOU FOR HELPING OUR CHILDREN!

Thank you so much to *everyone* who made contributions to the Society during our April 2010-March 2011 fiscal year!  
And special thanks to the following major sponsors and donors, and to the organizers of major fundraisers:

**DIAMOND** (Donations of \$10,000+)  
Biomarin Pharmaceutical Inc (Canada)

Genzyme Canada Inc.  
Ledcor Construction Limited  
Shire Human Genetic Therapies  
(Canada) Inc.

**The MPS Cup Fantasy Hockey Game & Gala**-The Harkins Family

**Tacos for Trey\***-The Purcell Family  
**Journey of Hope Starry Night\*\***-The Priest Family

**PLATINUM** (Donations of \$5,000+)  
Vidalin Family Foundation  
Sick Kids Foundation

**GOLD** (Donations of \$2,500—\$4,999)  
Bill Adams  
Black Gold Lodge  
Betty Done  
Maxwell Alexander Settari Memorial Fund  
at The Calgary Foundation

McCarthy Tetrault Foundation  
North Shore News  
Synergy Foundation  
The SanFilippo Children's Research  
Foundation

The Sutton Place Hotel  
Gordon & Rita Thomas\*\*

**Team MPS at the Scotiabank Toronto Waterfront Marathon-**  
The Byrne Family

**SILVER** (Donations of \$1000—\$2499)

Anonymous  
James Adamson  
Air Canada  
Wade Bartok  
BC Hockey Benevolent Association  
Chris & Cindy Bouchard  
Columbus Meats  
Darwin Construction (Canada) Ltd.\*  
Chris D'Odorico\*\*

ECM Espresso Machine  
Bob Foulkes  
G.F.H. Enterprises Ltd.\*  
Neal Harkins  
Todd & Kirsten Harkins  
Hans & Cas Holst\*  
JCA Communications Inc.  
Johnsen Archer LLP\*\*

Linda Jones  
Little League BC Celebrity Golf Classic  
Lyle S. Grant Digitally Assisted Design  
Makita Canada Inc.\*\*

John & Joanne Marquis  
MDE Mechanical  
Miller Thomson LLP  
Peter Muirhead  
National Concrete  
Krista Nickel

North Shore Winter Club  
Northern Building Supply Ltd.\*\*  
Mark & Kim Ramsey\*\*  
Robertson Floors  
Grizz Salzl\*  
Israel Zev Shafran\*\*  
Southwest Contracting Ltd.  
Speedy Printing Centres  
David Stafford\*\*  
TBG The Bicycle Group Inc.  
(Kona Bicycle Co.)

The Destination Slope & Surf Outfitters  
J.B. Thomas\*\*  
The Dynamics  
Vancouver Canucks  
Mendel Vysholid  
Allan White\*\*

**River Run for Ryan**-The Hunt Family

**BRONZE** (Donations of \$500—\$999)

Anonymous\*  
All Axis Systems Inc.\*  
Luciana Alvarez  
Iffat & Nadeem Amin  
Shirley Anderson\*  
Carmelo & Mirella Boeri\*\*  
Andrea Brann\*  
Breakout Pictures Inc.\*  
Linda & Graham Brown  
Carrie Marshall Photography  
Romilly Cavanaugh\*  
Ilse Cehak\*  
Rufina Chang\*\*  
Betty Done\*\*  
EA Canada  
Eighth Avenue Development Group Ltd.\*  
Robert Finnigan\*

Full Suspension Films Inc.\*  
Bernie & Christie Geiss  
Humphrey Buildings Inc.\*\*  
Imperial Paving  
JC Studio  
John Henry Bikes  
Len & Norma Linton  
Randall & Elisabeth Linton  
M.E. Thomas Ltd.\*\*  
Tracy Majhen

Malinka Financial Corporation\*  
Michael Mann\*\*

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MCM Motion Photography Ltd.\*  
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Paul Mullie\*  
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Ivan Priest\*\*  
Gayle Purcell\*  
Michelle Reining\*  
Rotary Women's Association  
Shimano Canada  
Ross & Diane Smith\*  
Audrey Spielmann\*  
Dr. Victor Spielmann\*  
Cari & Derek Stadel\*\*

Stormtech Performance Apparel  
John & Laura Swift  
David & Melissa Thomas\*\*  
John & Sharon Thomas\*\*  
Nancy Trott & Ian Hanoomansingh  
Dan & Sandi Turner  
Paul & Deb Van Herrewegen  
Vancouver Board Of Trade  
Vancouver Police Foundation\*  
Peeyush & Poonam Varshney\*  
Ventana Construction Corporation\*\*  
West Shore Constructors Ltd.  
Wicke Herfst Maver Consulting Inc.\*

**Corn & Lemonade Fundraiser**-The Nelis-Dupont Family

**Cove Cliff Elementary Jeans Day**-The Harkins Family

**Granville Island Jeans Day**-Carrie Nimmo

**Pumas Soccer Team**-The Spina/Lombardo Family

**The Great Lake Walk**-Brooke & Wilma Hodson

**Friends of Ferrari**-Franco & Suzann Corona  
Arcprint & Imaging  
BC Hockey Now  
Classic Rock 101  
Westview Esso  
Fawcett Insurance  
Mex-Y-Can Flowers  
North Shore Winter Club  
Okanagan Spring Brewery

\*MPS II Research Fund donation

\*\* MPS IVB Research Fund donation