2004-2005 **Annual Report**



The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

MDS

Celebrating Twenty Years

Twenty years after its inception in 1984. The Canadian MPS Society celebrated its twentieth anniversary and its accomplishments under the dedicated leadership of its founding executive director, Sheila Lee, and her successor, Lori Di Ilio. Both Sheila and Lori found inspiration in their MPS children -Brandy and Matthew re-

spectively and supported hundreds of Canadian families affected with MPS and related diseases over their years of dedicated service.

Their com-

mitment to making a difference in the lives of Canadian MPS families is to be admired and deeply appreciated, and now have representatives now we strive to continue the work Sheila and Lori with the support of their boards of directors - began.

From our new head office in North Vancouver, into which the society moved in September of 2004, we are striving to build on the past success of the society and move toward our ultimate goal of finding cures for MPS and related disorders, while continuing to support our families along the way.

Over the past year, we have witnessed the approval of enzyme replacement therapy for MPS I, the first of what we hope will be a long list of new treatments for our MPS children.



Sheila Lee in 1985 with daughters Brandy (MPS I) and Karen Ann.

Our Board of Directors practically doubled to ten and we are pleased to on the Board from most of the MPS disorders. We have also implemented a number of committees in order to better meet our goals, and to provide a greater opportunity for involvement for both the Board and our general members. We now have five committees consisting

of: Fundraising, Public Relations, Advocacy, Family Support, and Conference.

As always, we are grateful for the expertise of our medical advisory board and thank them all, including new members Dr. Mark Ludman and Dr. Elly Hetty, for their time and support of our society's families and mandate.

We are pleased to



Society founder Sheila Lee with husband Loren in 2005.

share the past fiscal year's highlights with you on the following pages, and hope you will join us in both celebrating our society's tremendous growth and in anticipating a brighter future for our very special children.

Judy Fowler Byrne Chairperson

Kirsten Harkins **Executive Director**

Inside the Annual Report:

Letter from the Chairperson and Executive Director

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Major Donors, Board of Directors. & Medical Advisory Board

Coming together is the beginning. Keeping together is progress.

Working together is success.

-Henry Ford

Our Mission: The Canadian Society for Mucopolysaccharide & Related Diseases (The Canadian MPS Society) is committed to supporting families affected with MPS and related diseases, educating medical professionals and the general public about MPS and related diseases, and raising funds for research so that one day there will be cures for all types of MPS and related diseases.

What are MPS and Related Diseases?

Mucopolysaccharide (MPS) and related diseases are lysosomal storage disorders (LSDs) caused by genetically inherited enzyme deficiencies. Because affected individuals lack particular enzymes necessary for normal cell degradation and recycling, substances store throughout their bodies, causing progressive damage to their hearts, bones, joints, respiratory systems and, sometimes, central nervous systems. While babies affected with MPS or related diseases often show no signs of disease, symptoms appear and intensify as storage increases.

HOW ARE MPS AND RELATED DISEASES INHERITED?

Lysosomal storage diseases are usually autosomal recessive disorders, inherited from healthy parents who have no idea they carry a common recessive gene: For carrier parents there is a one in four chance with every pregnancy that their child will inherit one recessive gene from each parent and suffer from

the carried disease. MPS II (Hunter Syndrome) and Fabry Disease are xlinked recessive disorders, meaning they are transmitted by carrier mothers to her sons: For carrier mothers, there is a one in two chance of an x-linked disorder occurring in the birth of a son. Parents of an affected child have the option of prenatal testing to determine if their next child will be affected by the same disease, and should seek genetic counseling before planning to have additional children or to inquire about available carrier testing for their healthy children. The occurrence of MPS in the population is estimated to be one in 25,000 births.

WHAT ARE THE MAJOR CHARACTERISTICS OF MPS?

A wide spectrum of clinical involvement is seen in all MPS and related diseases ranging from onset of symptoms at birth leading to death in early childhood to later onset with a near normal life span. While specific en-

zyme deficiencies, and effects, vary from syndrome to syndrome, characteristics are often shared by individuals with MPS including: course facial features, short stature, corneal clouding, speech and hearing impairment, chronic runny nose and diarrhea, hernias, heart disease, bone disease, stiff joints, liver and spleen enlargement, hyperactivity, mental retardation, and shortened life expectancy.

TREATMENTS:

Currently there is no cure for MPS or related lysosomal storage disorders and until recently, treatment for MPS and related diseases has been primarily symptomatic, with bone marrow transplantation considered a successful, although high-risk, procedure in some cases; however, research in the past decade has led to exciting advancements in gene therapy as well as to the development of enzyme replacement therapies (ERTs). Continued research is necessary in order to find cures for all types of MPS and related diseases.

LYSOSOMAL STORAGE DISORDERS:

Mucopolysaccharide Storage Diseases:

MPS I - H (HURLER SYNDROME)

MPS I - HS (HURLER-SCHEIE SYNDROME)

MPS I - S (SCHEIE SYNDROME)

MPS II (HUNTER SYNDROME)

MPS IIIA, IIIB, IIIC & IIID (SANFILIPPO SYNDROME)

MPS IVA & IVB (MORQUIO SYNDROME)

MPS VI (MAROTEAUX-LAMY SYNDROME)

MPS VII (SLY SYNDROME)

MPS IX (HYALURONIDASE DEFICIENCY)

Complex Carbohydrate Storage Disorders: MUCOLIPIDOSES:

- ML I (SIALIDOSIS)
- ML II (I CELL DISEASE)
- ML III (PSEUDO-HURLER POLYDYSTROPHY)
- ML IV (BERMAN SYNDROME)

OLIGOSACCHARIDOSES:

- MANNOSIDOSIS A & B
- FUCOSIDOSIS
- ASPARTYLGLYCOSAMINURIA
- MULTIPLE SULPHATASE DEFICIENCY

SCHINDLER DISEASE

SIALURIA

SIALIC ACID STORAGE

GALACTOSIALIDOSIS COBALAMIN F MUTATION GSD II (POMPE DISEASE)

Complex Lipid Storage Disorders:

GLYCOSPHINGOLIPIDOSES:

- GM I GANGLIOSIDOSIS (LANDING'S DISEASE)
- GM 2 GANGLIOSIDOSIS (TAY-SACHS & SANHOFF'S DISEASES)
- FABRY DISEASE (TRIHEXOSYLCERAMIDOSIS)
- GAUCHER DISEASE (GLUCOSYLCERAMIDOSIS)
- NIEMANN-PICK DISEASE A, B &C
- (SPHINGOMYELINOSIS)METACHROMATIC LEUKODYSTROI
- METACHROMATIC LEUKODYSTROPHY (MLD SULFATIDOSIS)
- KRABBE SYNDROME
 - (GALACTOSYLCERAMIDOSIS)
- FARBER'S DISEASE (LIPOGRANULOMATOSIS)

WOLMAN'S DISEASE

FUCOSIDOSIS

SCHINDLER DISEASE

MULTIPLE SULFATASE DEFICIENCY

SPHINGOLIPID ACTIVATOR DEFICIENCY

CHOLESTEROL ESTER STORAGE DISEASE

GMZ ACTIVATOR DEFICIENCY

CYSTINOSIS

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Providing vital family support and education

SUPPORT:

The generous financial support of our committed membership, sponsors and donors made it possible for us to continue and further develop our family support programs over the past fiscal year:

- Our website and 1-800# continued to provide immediate access to information to newly-diagnosed families as well as members and non-members alike. We get a significant number of international requests for information, as well, due to our internet presence, and because of our relationships with our sister organizations around the world, can often help those people make connections with societies closer to home.
- Our quarterly newsletter, the Connection, continued its role as a valuable resource for our members, helping them stay connected with each other and 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

Former executive director Lori Di Ilio with son Matthew (MPS III) in 2004.

those living in the same geographic region.

- Our Family Assistance Program provided almost \$3,000.00 in financial aid to member families to help alleviate the financial burdens often associated with treating and caring for an MPS child.
- Our 2004 family conference, "Celebrating 20 Years" was held in July of 2004 in Mississauga, Ontario. This conference brought together families and professionals and gave them an opportunity to learn more about new research, treatment and care strategies, and to meet and strengthen their relationships. For many of our members, the opportunity to meet, share information, and celebrate unique joys and challenges with other MPS families is an essential element of their being able to successfully deal with MPS and related diseases in their daily lives.
- Advocacy support has become a critical component of our mandate: As new treatments have been developed and licensed for use in Canada, we have strived to ensure Canadian MPS children have access to those treatments they need and deserve to live longer and healthier lives. The Executive Director and board members attended a one-day media workshop in Toronto in the spring of 2004 to develop their advocacy skills, and letter-writing campaigns and petitions to government officials, along with media releases and public awareness initiatives, have resulted in many MPS children receiving treatments that are now halting the progression of their disease. Since treatments are not yet avail-

able for all Canadian children with MPS and related diseases, we are aware that we must also ensure that those children for whom treatments have not been developed receive the medical care and services necessary to provide the best quality of life for them and their families.

Our new bereavement program was implemented in July 2004 and provides a series of booklets to bereaved families as they move through the various stages of grief associated with the devastating death of a child to MPS or a related disorder.

EDUCATION:

The society continues to supply families and professionals with educational resources and society-published booklets surrounding MPS and related diseases.

- Thanks to the financial support of Bike 4 MPS and the hard work of Lori Di Ilio, a new "Everyday Booklet" was written after Tracey Halford, contracted by the society, compiled the results of a survey sent to members of both the Canadian and National (USA) MPS Societies. The Canadian MPS Society has partnered with the National MPS Society, who will provide funding for editing and publishing of the booklet, which should be available for our members in the winter of 2005.
- We have issued a number of press releases in the past year, informing the public of important news surrounding MPS. In April of 2004, we announced the date of the 2004 MPS CUP Fantasy Hockey Game and Gala, and in May we were excited to announce that we had raised almost \$40,000.00 from our second annual event. Also in May 2004, we issued a release expressing our delight in the licensing of Aldurazyme enzyme replacement therapy by Health Canada, which, as the first treatment approved to treat an MPS disease, represented a major milestone in the road toward our ultimate goal of finding cures for our MPS children. Many of our MPS children have been involved in



Lori Di Ilio and Chairperson Judy Byrne MPS Jeans celebrating the Society's 20th Anniversary Days were held at our 2004 Family Conference.

local telethons and have been the focus of media stories over the past year and awareness of MPS continues to grow across the coun-

Canadian across Canada on our national

date, October 8th, and on other dates as well, to raise awareness of MPS and raise funds for the Society.

Our 2004 family conference provided an excellent educational experience for families and professionals alike.

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2004-2005 Fundraising and Research

Due to the enthusiastic support of several of our member families, many local fundraisers—including **Canadian MPS**

Jeans Days, golf tournaments, nature walks, and other innovative events like a Sadie Hawkins Bowl and a Miracle Move Nightraised thousands of dollars to help fund the society's initiatives and increase our



Nicklas Harkins (MPS I) with Brad May of the Vancouver Canucks at the 2004 MPS CUP Fantasy Hockey Game

research budget. The second annual 2004 MPS CUP Fantasy Hockey Game and Gala netted almost \$40,000.00 for the society, and altogether the society netted over \$50,000.00 in fundraising revenue during the 2004-2005 fiscal year. Due to the increase in our budget, we were able to award \$47,302.00 in research grants during 2004/2005. Thank you for your support.

2004-2005 RESEARCH GRANTS:

\$4,000.00 - Summer Studentship Research Grant awarded to Soohun Chun, University of Toronto.

Mr. Chun's research focused on Metachromatic Leukodystrophy (MLD) – a rare lysosomal storage disease caused by a deficiency of Arylsulfatase A – and achieving delivery of Arylsulfatase A (ARSA A) to the central nervous system using a fusion protein composed of ARSA A attached to a protein know to have access to all organs including the brain, a soluble form of melanotrasferrin (sMTf.)

\$30,000.00 - Dr. Lorne Clarke, University of British Columbia.

Dr. Clarke and his team of researchers will use micro array analysis and isotope-coded affinity tag (ICAT) proteomics to investigate the pathogenesis of MPS I utilizing the murine MPS I model.

Ultimately their hope is to identify serum biomarkers of disease that may be useful in the evaluation of disease progression and response to therapy in children with MPS I. In addition, their more exploratory approach will lead to identification of other factors that may underlie the pathophysiology of MPS diseases. ICAT analysis of both immunocompetent and immunocompromised MPS I mice will represent one of the first applications of this type of proteomic analysis to a mouse model of disease.

\$13,302.00 (\$10,000.00 USD) – Lysosomal Storage Disease Research Consortium (LSDRC).

The Canadian MPS Society is proud to be a member of the LSD Research Consortium (LSDRC), which has partnered with the American National Institute of Neurological Disorders and Stroke (NINDS) for the purpose of a jointly sponsored program to provide funding towards preclinical or translational research specifically addressing the neurological aspects of LSDs. On July 2, 2004, a Program Announcement (PA) was released by the NINDS soliciting applications for funding for research "focused on improving central nervous system (CNS) treatment outcomes, enhancing the effectiveness of delivery and targeting of cells, enzymes, drugs and genes into the brain."*, with the expectation that grants will be funded early this year. A total of approximately \$1,050,000.00 US in grants will be available from the NINDS and the Office of Rare Diseases (ORD). Applications not funded by the NINDS will be turned over to our group for consideration for funding within our funding capabilities. Several applications have been received by the



Monika Nelis (MPS I) at her family's Walk with Nature for MPS Kids

NINDS: the review process is underway and the LSDRC has established a grant review committee.

The Canadian MPS Society contributed \$10,000.00 US toward this consortium: a total of \$310,000.00 US has been contributed by the following American organizations: the National MPS Society, the National Tay Sachs and Allied Diseases Association, the Sanfilippo Syndrome Medical Research Foundation, Hunter's Hope Foundation, and the National Neimann-Pick Disease Foundation. The LSDRC will be represented by a three member Executive Committee consisting of Barbara Wedehase (ED of Na-

tional MPS Society), Jayne Gershkowitz (ED of National Tay Sachs and Allied Diseases), and Sissi Langford (Chair of Committee on Federal Legislation, National MPS Society). We are excited to be a part of this collaboration and will update you as the grants are funded. For more information on the LSDRC, please visit www.lsdresearch.org. To read the complete Program Announcement, visit Http://grants.nih.gov/grants/guide/pa-files/PAS-04-120.html

*CENTRAL NERVOUS SYSTEM THERAPY DEVELOP-MENT FOR LYSOSOMAL STORAGE DISORDERS (PAS-04-120) Lysosomal Storage Disease Research Consortium(LSDRC), National Institue of Neurological Disorders and Stroke (NINDS), Office of Rare Diseases (ORD)

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2004-2005 Partnerships-Working together for MPS kids

Throughout 2004-2005, the Canadian MPS Society developed its working relationships with allied national and international organizations and networks to further its mission. In addition to the LSDRC, the Canadian MPS Society worked with:

National MPS Society
(USA) Executive Director
Barbara Wedehase with
Canadian MPS Society
Executive Director
Kirsten Harkins at the
National MPS Society's
2004 Disney Conference



LEARN (Lysosomal Education and Research Network) – A group of organizations, including those involved with the LSDRC, have joined forces in order to participate in an overall lysosomal storage disease (LSD) educational intiative. Members of LEARN met at the American Society of Human Genetics meeting, held in Toronto in October of 2004.

CORD (The Canadian Organization for Rare Diseases) – Our society continues to support CORD in its effort to have orphan drug policy implemented in Canada.

GOLD (Global Organization for Rare Diseases) -

We are happy to be members of this new international organization, aimed at improving education and knowledge about LDSs, fostering collaborative research, creating standards for diagnosis and testing for LSDs and fostering coordination amongst existing patient registries to develop a global resource. www.goldinfo.org.

The International MPS Network -

A group of international MPS society leaders met in Mainz, Germany following the international MPS symposium in May of 2004 after an initial meeting in Manchester, England in the Fall of 2003 and continue to share ideas surrounding patient groups.

Judy and Terry Byrne attended the International MPS Symposium in Mainz, where Judy hosted a Canadian MPS Society information booth in addition to participating in the International MPS Network's working meeting. Judy and Terry also took part in the first annual general meeting of GOLD.

The Canadian Fabry Society and The Canadian Gaucher Society -

The Canadian MPS Society works closely with these societies toward our common goals, particularly those surrounding access to available treatments. In May of 2004, the first BC Lysosomal Storage Disease (LSD) patient meeting was held in Vancouver to bring together families

affected with various LSDs in BC.

The National MPS Society -

Our society has established an extremely effective working relationship with the USA's National MPS Society, sharing information and experiences and partnering on new publications like our upcoming "Everyday Book." Our board's chairperson, Judy Byrne, board member Todd Harkins and executive director Kirsten Harkins attended the National MPS Society's Disney Conference in Orlando, Florida in December 2004 and sat in on their committee and board meetings in order to gain perspective on their working board's governance and their society's programs and policies. The conference—with an attendance of almost 800-provided an excellent opportunity to meet many other families whose lives are affected by these extremely rare diseases. We hope to have a larger Canadian contingent at the next Disney conference, tentatively scheduled for 2009. The knowledge and friendships we gain at international conferences is immeasurable.



Mélissa and Olivier Bilodeau (MPS IV)



Andrew (MPS II) and Bradley Lanese at St. Alexander Catholic School's Canadian MPS Jeans Day



Daniel and Sarah (MPS I) Byrne and Trevor MacDonald (MPS I) at the Sarah Byrne Celebrity Pro-Am for MPS kids

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Financial Statements for the year ended March 31, 2005

To the Members 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, 2005 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. August 16, 2005

Balance Sheet			
(Unaudited)			
March 31	2005	2004	
Assets			
Cash and short term deposits	\$92,551	96,535	
Sales tax receivable	419	299	
Accrued interest receivable	600	378	
Total current assets	\$93,571	97,212	
Liabilities			
Accounts payable	500	500	
Surplus	\$93,071	96,712	
	\$93,571	97,212	
On behalf of the Board of Directors,			
Carrie Nimmo			
Treasurer			
Judy Fowler Byrne			
Judy I OWIEL DYTHE			
Chairperson			

Notes to Financial Statements:

Note 1. Organization

The Canadian Society for Mucopolysaccharide & Related Diseases Inc. is incorporated under 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 acharitable organization and as such is not subject to income taxes. The Society's aim is to provide support for families whose children are affected with storage diseases, to bring about more public support for families whose children are affected with storage diseases, and to raise funds to further research into storage diseases.

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 only capital assets of the Society consist of office equipment.

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 recognised 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 totalling \$71,169 which bears interest at 2.70%, semi-annually and matures December 2006.

Note 3. Fundraising

Fundraising revenue is comprised of gross revenue in the amount of \$60,947 (2004 - \$58,261) less expenditures in the amount of \$10,389 (2004 - \$13,423).

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Financial Statements for the year ended March 31, 2005

For year ending March 31	2005	2004
Revenue		
Donations	69,698	83,857
Fundraising, net of related expenses (Note 3)	50,558	44,838
Subscriptions	2,727	2,430
Interest	1,353	1,688
Sundry	624	824
	126,390	133,637
Expenditures		
Salaries and contract fees	34,197	34,128
Conferences	20,441	_
Telephone and internet	6,795	3,998
Printing and postage	6,280	5,196
Family assistance donations	2,885	3,000
Travel	2,708	2,824
Office expense	2,630	1,954
Consulting fees	2,197	9,000
Non-recoverable GST	1,477	801
Meetings	1,391	3,404
Insurance	1,100	_
Professional fees	600	600
Registration fees	30	30
Office equipment		2,945
	82,730	67,880
Research grants	47,302	43,000
	130,032	110,880
Excess/(Deficiency) of revenue over expenditures for the year	(3,642)	22,757
Surplus, beginning of year	96,712	73,955
Surplus, end of year	93,071	96,712

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Thank you for supporting our mission in 2004/2005:

We sincerely thank all donors who helped make a difference in the lives of MPS children during our April 2004—March 2005 fiscal year, and graciously acknowledge the following major donors and the organizers of major fundraisers:

PLATINUM (Donations of \$10,000 and higher)

Bike 4 MPS Society Genzyme Canada

The MPS CUP Fantasy Hockey Game and Gala

GOLD (Donations of \$3,000–\$10,000)

Brad May and Friends Charity Hockey Challenge

The Trevor MacDonald Foundation

Sarah Byrne Charity Pro-Am for MPS Kids-Byrne Family

SILVER (Donations of \$1,000–\$3,000)

Betty and Barry Done

Fondation Mélissa et Olivier Bilodeau

Foundation for Youth

Mercer Human Resource Consulting

Port Colborne High School's Wake-a-Thon

Robertson Floors Ltd.

Rotary Women's Auxiliary Inner Circle Society (Vancouver)

Sadie Hawkins Day Bingo Bowl-Jim and Alice Taylor

The BLG Foundation

The Calgary Foundation—The Maxwell Alexander Settari

Memorial Fund

The Great Lake Walk-Brooke Hodson

The '95 Pacific Vipers Hockey Team Transkaryotic Therapies Canada Inc.

BRONZE (Donations of \$500–\$1,000)

Anonymous

Anonymous

A-Wear-Ness Fund

Aggressive Timber Fallling

Arlene and Steve Jungaro

Brent Malcolm

Chris and Cindy Bouchard

Cove Cliff Elementary School's Canadian MPS Jeans Day-

Kirsten Harkins

Dan and Lori Roth

Deborah and Robert Jones, Jr.

Irma Kinsmen Club

Kay Bernstein

Lynn and Brian Casper

Mills Printing & Stationery Co. Ltd.

Premier Bridal Show of Cambridge and Area-

Saginaw Golf Club, Gifted Fine Floral and Gifts, and Avalon

Bridal Boutique

St. Alexander Catholic School's Canadian MPS Jeans Day-

Sonia Lanese

Silex Contracting Ltd.

TD Marathon

Troy and Karen Issigonis

Vancouver International Marathon-Kelly Gardner

Walk with Nature for MPS Kids-Mary Nelis

Xi Delta Beta Sigma Phi (St. John's)

Our Board of Directors and Medical Advisory Board:

BOARD OF DIRECTORS:

Judy Fowler Byrne

Chairperson/MPS I parent, ON

Debbie Braun

Vice-chairperson/MPS IV parent, ON

Carrie Nimmo

Treasurer/MPS I aunt, BC

Kathie Stephens

Secretary/MPS III parent, ON

Barb Boland

MPS III parent, NL

Todd Harkins

MPS I parent, BC

Aubrey Hawton

MPS III parent, ON

Simon Ibell

MPS II adult, ON

Jean Linden

MPS III parent, BC

Mary Nelis

MPS I parent, QC

EXECUTIVE DIRECTOR:

Lori Di Ilio (April 2004-August 2004)

Kirsten Harkins (September 2004-March 2005)

MEDICAL ADVISORY BOARD:

Lorne Clarke, MD, CM, FRCPC, FCCMG

Chair/University of British Columbia, BC

Beverley Antle, PhD

Hospital for Sick Children, ON

Derek Applegarth, PhD, FCCMG

BC Children's Hospital, BC

Robin Casev, MD, MSC

Alberta Children's Hospital, AB

Joe Clarke, MD, PhD

Hospital for Sick Children, ON

Bruce Gordon, MD, CM, PhD

London, ON

Cheryl Rockman Greenberg, MD, CM, FRCP

Winnipeg Children's Hospital, MB

Elly Hetty, MD, CCRP

University of British Columbia, BC

Mark Ludman, MD, FRCPC, FCCMG

IWK Health Centre, NS



The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

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