Canadian MPS Society
for Mucopolysaccharide & Related Diseases

#ignite hope

Annual Report 2020

living our best lives.

Our Vision

All Canadians affected by MPS and related diseases are supported and empowered to live their best life.

Tous les Canadiens affectés par les MPS et les maladies apparentées sont supportés afin de vivre leur meilleure vie.

Our Mission

The Canadian Society for Mucopolysaccharide and Related Diseases Inc. (The Canadian MPS Society), serves and connects Canadians affected by MPS and related diseases through support, education, advocacy and by advancing research.

La Société canadienne des mucopolysaccharidoses et des maladies apparentées Inc. (la Société Canadienne des MPS), fondée en 1984, accompagne tous les Canadiens affectés par les MPS et les maladies apparentées grâce au soutien, à l'information, au plaidoyer et par l'avancée de la recherche.

Our Values

Everyone deserves equitable access to treatment and support for their disease.

All affected by MPS warrant compassionate understanding of their distinct circumstances.
Individuals with MPS, their families, caregivers and those in the larger MPS community are entitled to optimal health and well-being.

We all benefit from hearing the voice of the MPS community. It is important to hear and amplify that voice.

Our organization operates transparently and accountably.

#ignitehope
www.mpssociety.ca

History of the Canadian MPS Society.

Did you know that the Canadian MPS Society was formed 35 years ago, in 1984? On this special anniversary, we would like to give you a brief history of how it all started.

The Society was founded in 1984 by Sheila Lee, whose daughter Brandy had just been diagnosed with MPS I. Sheila and her husband Loren were told that there was no cure or treatment for MPS diseases, and that Brandy would die before she was 10 years old. It was then that they realized that their eldest daughter, Rachelle, had died in 1979 from MPS without ever having been diagnosed. Shocked, devastated, and desperate for information and support, Sheila discovered that there was no literature or organization in Canada dedicated to MPS or other lysosomal storage diseases. Her desperation to talk to someone else affected by MPS, and the need for more information, compelled her to form the Canadian MPS Society from her home in northern Manitoba.

The goals of the Society were established very early on: provide support for affected families, create awareness in both the medical profession and general public, and fund research for treatments and a cure. Sheila worked hard to find other affected families. She knew that children were dying from this terrible disease, often with no diagnosis. It was her hope for a treatment or cure for Brandy and others like her that kept Sheila going.

Gradually progress was made, and the first National MPS Conference was held in Gimli, Manitoba in 1985. The conference was a huge success, providing the first ever opportunity for Canadian families affected by MPS diseases to come together, meet other affected children and families, and learn from experts in the field.

35 years later, the Canadian MPS Society has funded over $150,000 in Family Assistance grants, over $1.2 million in research, and has helped hundreds of families on their journeys with MPS and related diseases. In 2008, the Society hosted over 1000 delegates from 37 countries at the 10th International MPS Symposium on MPS & Related Diseases in Vancouver. The National Family Conference is still being held every two years, and awareness about MPS diseases has increased tremendously.

Although there is still no cure, there are now four approved enzyme replacement therapies in place for MPS I, II, IVA and VI. Considerable research is underway in the field of genetic therapies, and a cure for this dreadful disease is now hopefully in the foreseeable future. The Society continues to support and connect those affected by MPS and related lysosomal diseases, while working to ensure that all patients have equitable access to the best care and treatment.

Our Board Chair

Melissa Bilodeau

Dear Members,

The last few months have been something. I can't seem to find the right word to qualify it. It is no longer unusual because we're slowly getting used to it; it's terrible for some and for others, not quite. One thing I do know, is that few communities are as strong and resilient as you all are. You know life is not to be taken for granted and that it is fragile. You know how to enjoy every minute of it. You know physical limits can be broken if one simply dares to imagine it.
The MPS Society strives to be innovative in these uncertain times.

As this report must cover a period from April 1, 2019, to March 31, 2020, we must go back in time, before COVID, even if it feels like a different reality. We must highlight some of the activities the Society organized over that period. The first one to mention is the 2019 Rare Gala held in Vancouver. It was a unique occasion to raise awareness and funds for our MPS community. Some of our members also had the opportunity to attend and speak of their own experiences living with MPS.

Another event was the 2019 National Family Conference, held in Ontario. Few words need to be said about this event because it is faithful to its usual formula: informative conferences, unique meetings that last a lifetime and a lot of fun.

Furthermore, the International MPS Network (IMPSN), of which the Society has representation on its board, will be formalizing in Canada. This event brings concrete and symbolic importance of Canada's role in the global sphere. Additionally, the Society has been partnering with Inform Rare to bring out patient perspective in clinical researches and working to develop a patient registry specific to MPS.

Melissa

Message From The Executive Director

Kim Angel:

As many of you are aware, fiscal year-end for us is March and a very different world has since emerged. I will address COVID-19 but do not wish to begin by overshadowing the many successes we achieved this past year.

The Canadian MPS Society had a very productive 2019 remaining committed to awareness, education, research and support while strengthening relationships and exploring new partnerships.

Our first major event in 2019 was the annual RARE Gala held on May 15th, International MPS Day. With the generosity and contributions of the Ley family and many other fabulous individuals, groups and attendees, we combined our efforts to create a magical and inspirational evening, raising funds and creating a ripple effect of awareness.

With May 15th, being International MPS Day, a day honoured by all international, national and local MPS communities, we literally lit up BC Place with the Canadian MPS Society colours and our families dressed to iMPreSs at schools and workplaces. It was a busy and memorable day, raising awareness about the children and adults affected with and by MPS, honouring those who have gained their wings and thanking those who provide care and who work to develop research and treatments.

Next, we hosted our National Family Conference at the Nottawasaga Inn and Resort (Canadian version of Hogwarts).
Over the 36 years of our existence, the Canadian MPS Society's most proud accomplishment is bringing our families together for a weekend of connection, education and inspiration at our National Family Conference. It was an absolutely 'magical' weekend!!

Throughout the year we worked towards our strategic goals.
We sought and shared information. We developed partnerships to advance the development of a national registry, to advocate for newborn screening and to create a digital resource guide. We worked to raise awareness and funds through our multiple campaigns throughout the year. We welcomed new families, supported them as best as we could and felt the pain in times of loss.

And then…. COVID-19 happened….

Our focuses were shifted to deal with this unprecedented situation.

Throughout the year, we welcomed new families and reached out in times of loss. We shared information and stories through our e-connection, social media and website. We strove to ensure that our lines of communication were always open and were there to provide support in every way we could.

Moving into 2020, when confronted by COVID-19, we made a plan. Some of the ways we acted on this plan was by:

- Providing up to date information on COVID-19 through social media and our website.
- Surveying Canadian physicians and healthcare providers along with International MPS organizations to gather data on the impact of COVID-19 on the MPS Community.
- Developing a series named "Townhall Tuesday" consisting of webinars and meetings with leading physicians and healthcare providers to address our member's questions and concerns.
- Reducing our operating expenses

Not unlike our daily lives, the plan of the Canadian MPS Society is evolving, yet we remain committed to finding the best ways to serve and support the MPS community in our ultimate goal of curing this disease. Life is full of surprises of all kinds. From one end of the spectrum to the other. Our community is one of remarkable resilience and courage, at its very best. While we cannot yet gather together, rest assured that we will continue to honour, educate, elevate and above all support each other.

As we all proceed to carve out our new realities, the Canadian MPS Society's support for and commitment to our members will push on to evolve, adapt and above all grow. I look forward to another year of evolution, innovation and forward progress and most of all, I look forward to our connections.

Stay safe, stay well but know that we are here. Kim

Directors, Advisory Board + Staff

Executive:

Mélissa Bilodeau, Chair
Montreal, Quebec
MPS IVA – Adult

Marilyn Marchment, Vice-Chair
Vancouver, BC
Communications Consultant

Terry Byrne, Treasurer
Guelph, Ontario
MPS I – Parent

Julie Lariviere, Secretary
Rockland, ON
MPS I Parent

Directors at Large:

Ruben Krishnamurthy
Ontario
Alpha Mannosidosis – Parent

Mojan Zehtabchi
Toronto, Ontario
Naturopathic Doctor

Staff

Kim Angel, Executive Director
kimangel@mpssociety.ca

Medical Advisory Board – 2019/2020

Medical Advisory Board Chair

Lorne Clarke, MD, CM, FRCPC
Director, Provincial Medical Genetics Programme
Department of Medical Genetics
BC Children's Hospital
Vancouver, BC

Medical Advisory Board Members

Cheryl Rockman-Greenberg, MD, CM, FRCPC, FCCMG
Professor and Head, Department of Pediatrics
and Child Health University of Manitoba,
Director, Metabolic Service Program in Genetics and Metabolism
Children's Hospital, Winnipeg, Manitoba

J.T.R. Clarke MD, Ph D (Retired)
The Hospital for Sick Children (formerly)
Toronto, ON

Aneal Khan, MD
Inherited Metabolic Clinic, Alberta Children's Hospital
Calgary, AB

Serge Melancon, MD
Biochemical Genetics Unit, Montreal Children's Hospital
Montreal, QC

John Mitchell, MD
Biochemical Genetics Unit, Montreal Children's Hospital
Montreal, QC

Eva Mamak, Ph D
Department of Neuropsychology, Hospital for Sick Children
Toronto, ON

Tony Rupar, B.Sc., Ph.D.
Chairman, Division of Clinical Biochemistry
Chair, Human Molecular Genetics Program,
Child Health Research Institute
Director, Biochemical Genetics Laboratory, CPRI
London, ON

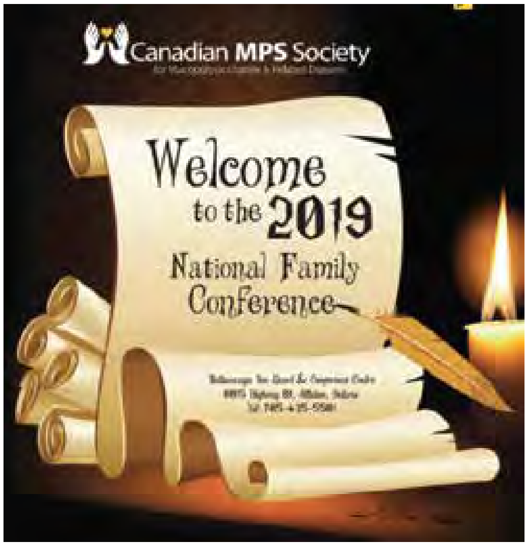
Michal Inbar-Feigenberg, MD, FCCMG
The Hospital for Sick Children, Staff Physician – Clinical and Metabolic
Genetics Research Institute, Project Investigator – Research Institute
University of Toronto, Assistant Professor – Department of Paediatrics

Pranesh Chakraborty
Metabolic Physician, CHEO
Medical Director, Newborn Screening
Ottawa, Ontario, KlH 8MB

Fundraising + Events

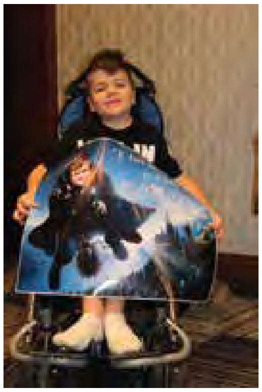
National Family Conference 2019

The Canadian MPS Society's 2019 National Family Conference hosted esteemed speakers, collaborative partners and families from across Canada.



The weekend included sessions on the latest research, social and emotional supports, education, and advocacy with a children's program that explored the underwater world of Ripley's Aquarium.

Our families came together during this magical Conference weekend to learn, experience, share and spend time with friends, old and new.



Fundraising + Events

RARE 2019 - 16th Annual Ignite hope Gala

What a fun and inspiring evening! **143 guests joined us** for cocktails and a delicious Vancouver Club dinner, wonderful entertainment, live and silent auctions, and some very moving presentations.

BC Place lights up blue and yellow for MPS Awareness.

Thank you to everyone who came, bought, bid, donated, volunteered, sponsored and contributed to this wonderful evening!

We were delighted and honoured to present **Jessica Gentle (MPS I-H) and her family with this year's Rare Heroes Award.**

Jessica gave a powerful speech about the challenges and sometimes heartbreak of growing up, and now she's a teenager with an MPS disease.

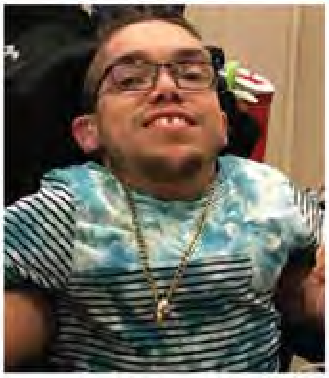
We were thrilled to realize a net profit of over $40,000 + to have the opportunity to raise awareness for MPS diseases.

Angie Lombardo and Matteo (MPS I-H), whose face you will have seen on all our event materials this year, joined us. Angie talked about their lives since Matteo's diagnosis nine years ago, and Matteo helped the Air Canada Foundation draw the winning raffle ticket for two Air Canada tickets.

Natasha Kaweski (MPS IVA), who was recently interviewed on Global TV, was with us, both volunteering and as our guest. Our Board Chair Melissa Bilodeau and two other board members were there, as well as some affected families from Vancouver Island, and many interested and generous guests.

In Memoriam...

Sophie Marie Hamza (MPS IIIB)
March 14, 2008 to August 23, 2018



Simon Laforest (MPS IIIB)
December 07, 1993 to Jul 27, 2019

Your Donations At Work

The Canadian MPS Society receives no government funding and relies on private and corporate donations to continue its mission to support Canadian families affected with and by MPS and related diseases, and to help advance research for cures.

We are delighted to share with you the tremendous impact donors have made in the lives many of our affected member families across Canada through our Family Assistance Program.

We would also like to announce that in addition to providing assistance to the following families, **we have been able to provide over $46,000 in bursaries and financial assistance to recipients.**

2019 Summer Studentship Research Grants

The Canadian MPS Society provided funding to three students this fiscal year.

Student: Camila Etchart
Institution and Supervisor(s)
MUHC, Dr. John Mitchell
MUHC, Dr. Farah El Turk

Research Project:
Analysis of serum cytokine profile in Mucopolysaccharidoses

Student: Orfeo Harrison
Institution and Supervisor:
MUHC, Dr. John Mitchell
MUHC, Dr. Farah El Turk

Research Project:
Development and validation of a robust dried blood spot ceramide profiling method to study metabolism in Mucopolysaccharidoses

Student: TianMeng Xu
Institution and Supervisor:
CHU Sainte-Justine, Dr. Alexey Pshezhetsky

Research Project:
Testing the efficacy of hematopoietic progenitor stem cell/LV gene transfer in the mouse model of Mucopolysaccharidosis III type Cprogenitor stem cell/LV gene transfer in the mouse model

Thank You To Our Donors

Thank you so much to everyone who made contributions to the Society during our **April 2019 - March 2020 fiscal year.**

♥ Special thanks to the following major sponsors and donors, and to the organizers of independant fundraisers:

Industry Partners Donations of $50,000 - $75,000

Takeda

Donations of $25,000 - $49,999

SANOFI GENZYME

BIOMARIN

Donations of $5,000 - $10,000

REGENEXBIO Inc.
AbeonaTherapeutics

PayPal Giving Fund
Emma-Rose Fund

Lysogene
Ultragenyx

Donations of $1,000 - $4,999

Anonymous Donor
The Calgary Foundation

Ley, J + G
Trott, N
Young, R + S

Angel, K
Rosen, H
Stewart, A

Donations of $500 - $999

Lucas, G
United Way - Lower Mainland
United Way - Victoria

Kennedy, Keith
Benevity Community Impact Fund
Di Ilio, K

Eakins, D
Linton, E + R
Phillips, E
Roth, G

Donations of up to $499

My Tribute Gift Donation
Byrne, T
Boland, S
United Way - Greater Toronto
Canada Helps
Di Ilio, R + L
Ecole Secondaire Catholique
Budd, Crystal
Kaweski, V + F
Sherbanow, A + P
Larocque, J
Bailey, C
Bruemmer, N
Kiwanis Club Timmons
Silveri, E
Snow / Lush
Weima, P
Horvath, J
Serviss, T + J
Aubin, L
Huszar-Wolff, A
Manning, S
Pickering, L
Lariviere, J
Pugwash Gospel
United Way - Calgary
Skiba, S
Byrne, J + T
Chesney, D
Dickson, E + A
Sandberg, E
Elgie, J
Fraser, B
Gambrill, B + R
Lawson / Campbell
Lucas, T
Makhlouf, T
Nelis, M
Pickford L + P
Rae, I + L
Carson, S
Waters, B
Westmount Public School
Cairns, A + A
Conley, L
Mahon, S
Sheldan, C
Barrie, A + M
Blackburn, L + M
C.U.P.W.
Cameron, M
Collins, M + K
Furoy, L + S
Gordon, B
Johnson, T + H
Reeds, L
Madani, A
Perry, K + D
Regie, J
Drake, T
Tkachuk, Y
Walters, S
Wharton, J + K
Archibald, J
Cole, H
Gunton, J
Snow, M
Amin, Saira
Parker, A
Racicot, S
Klotins, M
Pahlavan, N
Bauerie, U
Burton, C + R
Husberg, P
Johnson, M
Knox, E + D
Sachs, S
Bley, A

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I donated hope
Canadian MPS Society
for Mucopolysaccharide & Related Diseases

Fundraising + Events

Education + Awareness

You Can Make a Difference

International MPS Day

May 15

On May 15, we honour, celebrate and remember every one affected by MPS diseases.

There is still no cure.

Learn more by visiting www.mpssociety.ca

Canadian MPS Society

INTERNATIONAL

MPS AWARENESS DAY

MAY 15

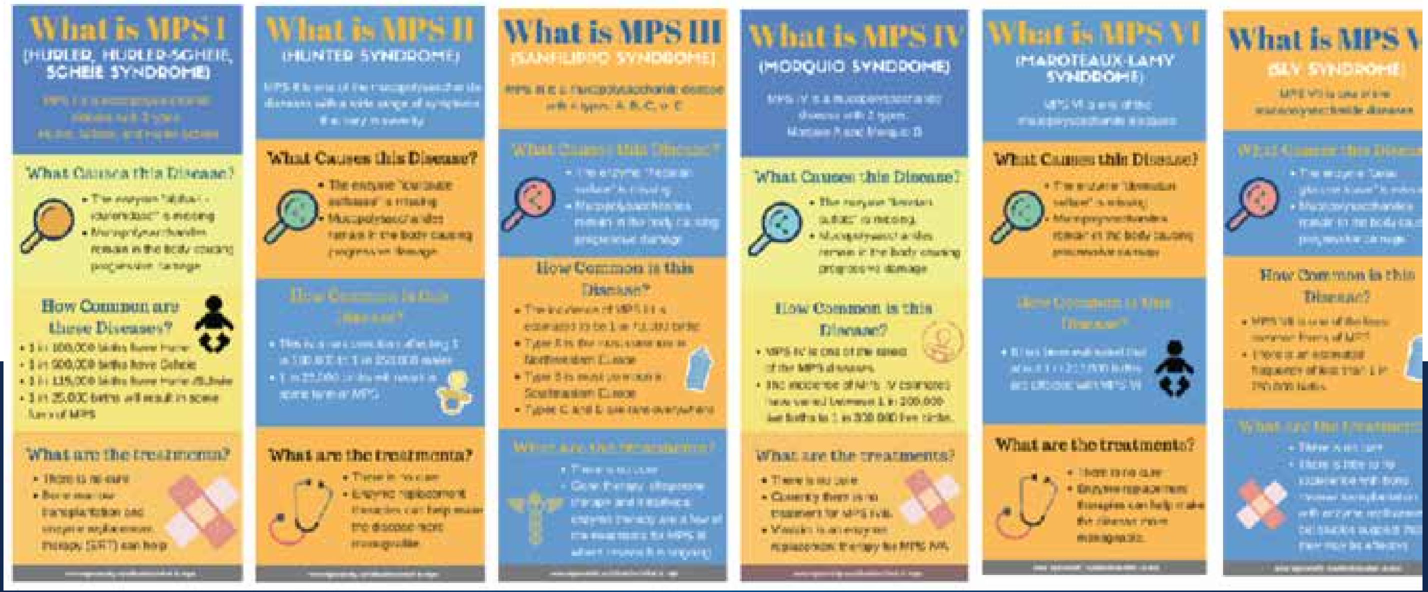
WHAT IS MPS?

SYMPTOMS & EFFECTS

CAUSES & HEREDITY

GET INVOLVED

Canadian MPS Society



Financial Statements

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, 2018 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.

Chartered Professional Accountants Vancouver, British Columbia

The Canadian Society For Mucopoysacchararide & Related Diseases Inc.
Statement of Financial Position
as at March 31, 2020

Assets	**2020**	**2019**
Current Assets		
Cash	$161,410	$74,231
Investments	-	$140,902
Accounts Recievable	$28,662	$11,504
Government Remittances Recievable	$10,664	$3,818
Prepaid Expenses and Deposits	$14,523	$2,386
	$215,259	**$232,841**
Liabilities + Net Assets		
Current Liabilities		
Accounts Payable + Accrued Liabilities	$20,305	$13,138
Government Remittances Payable	$5,239	$1,505
Deferred Revenue (Note 4)	$45,000	$45,000
	-	-
	$70,544	$59,643
Net Assets	**$144,715**	**$173,198**
	$215,259	**$232,841**

Financial Statements Con't. *You Can Make a Difference*

The Canadian Society For Mucopoysacchararide & Related Diseases Inc.
Statement of Financial Position
as at March 31, 2020

Revenue	**2020**	**2019**
Conference	$106,153	-
Donations + Grants	$79,602	$124,406
Fundraising	$78,519	$65,150
MPS II Research Fund	$3,057	$89,172
Dividend Income	$1,191	$2,521
Membership Fees	$244	$160
Miscellaneous Income	-	$880
	$268,766	**$282,289**

Expenses		
Salaries + Contract Fees	$80,845	$74,746
Meetings	$70,352	$5,018
Professional Fees	$57,666	$36,577
Fundraising	$33,106	$38,441
Research Grants	$12,000	$12,964
Office + Miscellaneous	$11,325	$13,307
Family Assistance Program	$8,837	$7,329
Travel	$8,695	$10,970
Computer	$7,223	$4,730
Telephone + Internet	$3,008	$3,465
Office Lease	$1,560	$1,560
Insurance	$1,479	$1,306
Advertising, Communication + Promotion	$572	$4,586
Printing + Postage	$342	$356
Membership Dues	$239	$599
MPS II Project	-	$175
	-	$50,130
	$297,249	**$264,259**

Excess (Deficiency) of Revenue Over Expenses For The Year	**($28,483)**	**$18,030**

Notes To Financial Statements

NATURE OF OPERATIONS

The Canadian Society for Mucopolysaccharide & Related Diseases Inc. (The Canadian MPS Society) ("the Society") incorporated under the Canada Not-for-Profit Corporations Act as of October 10, 2014 and was previously incorporated under Part II of the Canada Corporations Act. The Society is a registered charity for the purposes of the Income Tax Act and is accordingly, exempt from income taxes

.

The 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. The Society is governed by its Board of Directors with the support and expertise of its Medical Advisory Board.

The Canadian Society For Mucopolysaccharide & Related Diseases Inc. Notes To Financial Statements For The Year Ended March 31, 2019

SIGNIFICANT ACCOUNTING POLICIES

These financial statements have been prepared in accordance with Canadian accounting standards for not-for-profit organizations ("ASNPO") under Part III of the CPA Canada Handbook - Accounting. Financial statements prepared in accordance with ASNPO are also in accordance with Canadian generally accepted accounting principles ("GAAP"). These financial statements have, in management's opinion, been prepared within reasonable limits of materiality using the significant accounting policies noted below:

Financial instruments

- Measurement

The Society's financial instruments consist of cash, investments, accounts receivable and accounts payable.
The Society initially measures all of its financial assets and liabilities at fair value, except for certain non-arm's length transactions. The Society subsequently measures all of its financial assets and liabilities at amortized cost, except for investments in equity instruments that are quoted in an active market, which the Society has elected to measure at fair value. Changes in fair value of financial instruments carried at fair value are recognized in the statement of operations.

- Impairment

The preparation of the financial statements in conformity with ASNPO requires management to make estimates and assumptions about future events that affect the reported amounts of assets, liabilities, revenues and expenses as at the end of or during the reporting period. Management believes that the estimates used are reasonable and prudent, however, actual results could differ from those estimates. Significant areas requiring the use of management estimates is the valuation of accounts receivable, recognition of deferred revenue and the amounts recorded as accrued liabilities.

Revenue Recognition

The Society follows the deferral method of accounting for contributions. Restricted contributions are recognized as revenue in the year in which the related expenses are incurred. Unrestricted contributions are recognized as revenue when received or receivable if the amount to be received can be reasonably estimated and collection is reasonably assured.

Membership fees are recognized as revenue in the year to which they apply.
The Society benefits greatly from donated services in the form of volunteer time, the value of which is not determinable. Donated services are consequently not recognized in these financial statements.

The Society records contributed materials at their fair value when fair value is readily determinable and when the materials and services are used in the normal course of operations and would otherwise have been purchased.

- Cash and Cash Equivalents

Cash and cash equivalents consist of cash on deposit.

- Use of Estimates

Financial assets measured at cost are tested for impairment when there are indicators of impairment. The amount of any write-down that is determined is recognized in the statement of operations. A previously recognized impairment loss may be reversed to the extent of any improvement, provided it is no greater than the amount that would have been reported at the date of the reversal had the impairment not been recognized previously. The amount of the reversal is recognized in the statement of operations in the period in which it is determined.

FINANCIAL INSTRUMENTS RISK

The Society's financial instruments are described in Note 1(a). In management's opinion, the Society is not exposed to significant currency, credit, liquidity, interest rate or other market risks arising from these financial instruments.

In addition, the Society is not exposed to any material concentrations of risk and there has been no change in risk exposures from the prior year.

- Credit Risk

Credit risk is the risk that a counterparty may default on its contractual obligations resulting in a financial loss. The Society is exposed to credit risk primarily through its accounts receivable. The Society mitigates risk by maintaining a low balance of accounts receivable.

- Liquidity Risk

Liquidity risk is the risk that an entity will encounter difficulty meeting obligations associated with financial liabilities. The Society is exposed to this risk mainly in respect of its receipt of funds from donors and other related sources in order to meet its obligations associated with its accounts payable. The Society mitigates its exposure to liquidity risk by ensuring that it documents when authorized payments become due and monitors its cash balances and cash flows generated from operations against its anticipated, committed and contemplated outflows.

- Market Risk

Market risk is the risk that the fair value or future cash flows of a financial instrument will fluctuate because of changes in market prices. Market risk comprises three types of risk: interest rate risk, currency risk, and other price risk.

- Currency Risk

Currency risk is the risk to the Society's earnings that might arise from fluctuations in foreign exchange rates and the degree of volatility of these rates. The Society is exposed to currency risk through receipts of certain grants. The Society mitigates this risk by transacting primarily in Canadian dollars.

- Interest Rate Risk

Interest rate risk is the risk that the value of a financial instrument might be adversely affected by a change in interest rates. The Society is not exposed to significant interest rate risk.

- Other price risk

Other price risk is the risk that the fair value or future cash flows of a financial instrument will fluctuate because of changes in market prices (other than those arising from interest rate risk or currency risk), whether those changes are caused by factors specific to the individual financial instrument or its issuer, or factors affecting all similar financial instruments traded in the market. The Society is exposed to other price risk through its investments.

RESTRICTED NET ASSETS

Internally Restricted Net Assets

The Board of Directors approved a motion that $30,000 from general surplus funds be held in an internally restricted fund for research expenditures in future years. The Board made this decision in light of underspending in the area of research in 2014-15 and a commitment to ensuring that a portion of the Society's accumulated surplus be held in reserve for research activities.

Externally Restricted Net Assets

During 2015 and 2017 donations of $976 and $488, respectively, were received from outside charities designated for the MPS II Research Fund. The MPS II project was completed as of March 31, 2019 and therefore the funds were utilized.

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

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