



Canadian  
**MPS**  
Society

for Mucopolysaccharide  
& Related Diseases



**35** Years

Celebrating **35 years of Continued Support** for All Canadians Affected by MPS and Related Diseases.

Annual  
Report **2019**



## 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. (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.mpsociety.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

After a few difficult years, I'm glad to report that the Society is back on track. It took some adjustments and hard work, but it is paying off, as reflected in the last financial statements. We expect this trend to continue in the coming years and look forward to being able to provide even greater assistance to our members, whether it be in the form of financial and emotional assistance, or greater access to educational materials and information about new treatments and research.

This year's Rare Gala was a tremendous success in raising both funds and awareness. Many family members attended and participated - no one can better deliver our message than our affected members (myself included). Monies raised through our fundraising initiatives go directly towards Summer Student Research Grants and our Family Assistance Program.

The staff and Board of the Canadian MPS Society had the opportunity to meet last November for a strategic planning session to establish new goals for the Society. This enabled us to review our existing policies as well as our strengths and weaknesses as an organization.

Our work reflects our desire to provide hope for all those affected by MPS diseases. We invest in research in search of viable treatments and a cure, we communicate and participate in other MPS networks both in Canada and worldwide, we work to educate both medical professionals and the general public about MPS diseases, and we strive to help our member families to live their best life. The Society will continue to evolve with the constant change of treatments and the needs of our members.

Of course, none of this would be possible with the support of our generous sponsors and donors. Their contributions help us as an organization to give you the best services and support.

*Melissa*



# A Decade of Love

## Resignation Letter From Jill Ley

Hello everyone, after more than 10 years of being involved with, and working for, the Canadian MPS Society, it is time for me to move on to other things. My ever-lengthening bucket list is in need of some serious attention!

For the next while I will continue to communicate and work with affected member families - which has always been my favourite thing to do anyway! But I will no longer be working on any administration, fundraising or events.

I had no idea when Kirsten asked me to help all those years ago that I would become so involved, and I thank her and Kim for the opportunity. My entire family has been involved with MPS at one point or another over the years, and I can truly say that we have all learned so much from being a part of the MPS world. Your resilience and strength in the face of some incredible challenges are quite amazing, and have often put life into perspective for us. Thank you!

I'm so glad to once again be able to see so many of you at this year's National Family Conference, and very much look forward to continuing to stay in touch.

With my very best wishes,

*Jill*



# Message From The Executive Director

**Kim Angel:** It is my distinct privilege to present to you the Canadian MPS Society's year in review in our 35th year of service to the Canadian MPS Community.

While the faces, approaches and strategies have changed over the years, the basic premise of the Canadian MPS Society has remained the same – support for families, research for a cure. We are proud of our 35 year history and how we've grown to what we are today. We work towards a future where all people affected by MPS and related diseases are able to receive the best healthcare possible, are connected to one-another, are unburdened from financial hardships, and are able to look to the future for advancements in research that will develop treatments and ultimately cures for MPS and related lysosomal storage diseases.

## Some of our most noteworthy achievements of 2018-19 include:

- ▶ The Canadian MPS Society has **supported several families with direct financial aid**, giving them the opportunity to modify their homes, hire respite care, travel to medical centres, and otherwise manage the financial demands of caring for children or adults with unique needs.
- ▶ Our **monthly electronic newsletter, the e-Connection**, continued its role as a valuable resource for our members, helping them stay 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 with those living in the same geographic region.
- ▶ Along with members from world-wide rare disease communities, we recognized, remembered, and honoured those whose lives are touched by MPS or a rare disease on **International MPS Awareness Day on May 15th and Rare Disease Day on February 28th**.

After a year of positive financial performance, the Canadian MPS Society is poised to begin thinking about its future; how and where best to reinvest, and how to provide increased supports to our members in the years ahead.

**The staff + Board of Directors came together in Vancouver in November 2018 to develop our 2019 - 2021 Strategic Plan, which led to the collective acceptance of our overarching strategic goals and objectives. These are:**

### Improved outcomes and experiences for Canadians affected by MPS and related diseases by:

- ▶ Leveraging Canadian MPS & related LSD patient data to improve access to treatments and/or clinical trials
- ▶ Reducing the impact of disease progression through early diagnosis and detection
- ▶ Developing directed funds to advance research toward treatments and cures

### All Canadians affected by MPS are supported, connected, informed, and empowered by:

- ▶ Expanding financial, emotional and social supports to affected families in Canada
- ▶ Ensuring that programs provide relevant service, support, and assistance to those we serve

### The Canadian MPS Society is strengthened and sustainable by:

- ▶ Increasing funds for operations, programs and research
- ▶ Strengthening our organizational capacity

**As winds of change swirl around us, smart collaboration within our industry is vital. Our staff and Board of Directors has embraced that spirit of collaboration with the following initiatives and partnerships:**

#### The International MPS Network (IMPSN)

The Canadian MPS Society formally joined forces with the International MPS Community's support and advocacy organizations. In August of 2018 the Network formed a Board of Directors consisting of leaders from Canada, the United States, the United Kingdom, New Zealand, Australia, Malaysia and Brazil. At an IMPSN meeting held in Serbia in July 2019, the network recently approved the formalization of an International MPS Network not-for-profit organization to be established in Canada. As a global entity, the IMPSN's mission is to be the primary platform for MPS and Related Diseases. IMPSN is a global community of informed and empowered organizations who promote access to medicines, new research and programs leading to better quality of life for patients and those affected by these diseases.

#### The Canadian Lysosomal Disease Network (CLSDN)

The Canadian LSD Network is a collaborative organization led by founding members; Canadian Fabry Association, the Canadian MPS Society, Canadian Association of Pompe, and the National Gaucher Foundation of Canada. Our respective organizations meet regularly to discuss best practices and possibilities for collaboration with fundraising, awareness campaigns and organizational development.

**In 2018-19, the Society collaborated with industry partners, organizations and students to develop abstracts, posters, papers and studies, including:**

- ▶ MPS II Consensus Positions Statement for the Diagnosis and Management of MPS II in Canada - Shire. Authors: Julian Raiman, Tony Rupa, John Mitchell, Hanna Faghfoury
- ▶ Burden of Illness in MPS I & II - REGENXBIO
- ▶ Burden of Illness in Sanfilippo Disease (MPS III) – results from an international caregiver survey - MPS Society UK
- ▶ Stakeholder Engagement Summary: Supplemental Process for Complex and Specialized Drugs - The Expensive Drugs for Rare Diseases (EDRD) Working Group
- ▶ Access to Orphan Drugs in Canada: Integrating Patient and Policy Perspectives - Nahya Awada, PhD Candidate, School of Public Policy and Administration, Carleton University

We are very proud of these many achievements, which represent the work of so many dedicated people, but we aren't resting on those laurels. We look forward to a future of even more growth, with cutting-edge research and increased support to families, because we insist on a better life for our children. We wish to extend our sincere appreciation to the sponsors, donors, volunteers, families and friends for their invaluable contributions and for making a positive difference in many people's lives. With the continued help of our extended community we look forward to many successes in 2019 – 2020.

*Kim*



# Directors, Advisory Board + Staff

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**Sue Davis**  
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Semi-Retired Health Care Manager

## Staff

**Kim Angel**, Executive Director  
kimangel@mpsociety.ca

**Jill Ley**, Administration & Member Support  
jill@mpsociety.ca

**Pablita Thomas**, Fund Development Director  
pablita@mpsociety.ca

## Medical Advisory Board – 2018/2019

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Vancouver, BC

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University of Toronto, Assistant Professor – Department of Paediatrics

Pranesh Chakraborty  
Metabolic Physician, CHEO  
Medical Director, Newborn Screening  
Ottawa, Ontario, K1H 8MB



# 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.



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.**



BC Place lights up blue and yellow for MPS Awareness.

**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.

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

## "Message From Coach Jerry Bennett..."

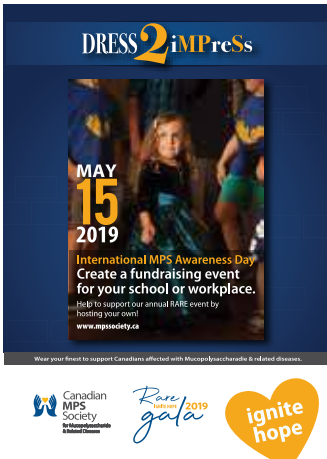
Many of you will remember Coach Jerry Bennett from our previous conferences. Jerry, who runs a behavioural modification fitness program in California for kids with disabilities, has travelled on his motorbike to Calgary and Montreal for our last two conferences to lead our children's programs. Jerry and Kimberly's son, Jack, has MPS II. Jack's battle with MPS has been especially difficult for the past while, and Jerry is unable to join us this year. Please join us in sending love and positive energy to Jack, Jerry and Kimberly.

Thank you all for helping to raise awareness today, I feel the love and support! - Coach Jerry Bennett



# Fundraising + Events Con't.

## Dress to IMPreSs on International MPS Awareness Day



Our Dress to iMPreSs fundraiser was lots of fun! Both Matteo Spina (MPS I-H) and Charlotte Quesnel (MPS IIIC)'s schools supported this fun day and helped raise money for the Canadian MPS Society.

Haylee Sayner's super-gramma Hillary Rosen held a raffle for one of her beautiful paintings.

Top Left: Charlotte and friends  
Top Right: Haylee draws the winning ticket  
Bottom Left: Matteo  
Bottom Right: Haylee and Hillary



### Jerry posted the following on Facebook on MPS Awareness Day. We would like to share it with you:



'I waited until towards the end of MPS Awareness day to post this:

Last night as Kimberly and I got Jack ready for bed, as he was sitting in the bathroom with me standing guard over him and Kim preparing his bed and machines, Jack turned to me with those beautiful blue eyes and said 'I'm not scared, I'm still alive'.....it choked me up, obviously, however since then I have thought about the meaning behind such a simple message and this is what I have come up with:

While today has been incredibly important to raising awareness of MPS, it is MORE important that all of us NOT inflicted with this monster disease understand that those afflicted battle this monster every second of every minute of every hour/day/week/year for as long as their earthly bodies will hold out. None of us will ever be able to comprehend what those afflicted go through physically, emotionally or mentally, all we as outsiders can do is be in awe, support them, encourage them, care for them, and at the end mourn them. MPS is a deadly monster that kills slowly, and yet a young man like Jack, after all he has been through especially recently, can STILL look at me with those beautiful innocent blue eyes and state simply and without anger or malice 'I'm not afraid, I'm still alive'

I challenge all of you who have read this to think about MPS and those it afflicts more than just once every year on May 15th, start with 2-3x a year, talk about it with others, and help our families find a cure to put an end to this monster named MPS.

# 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 \$17,000 in travel bursaries for member families to attend this year's National Family Conference!**

► **Isaiah Rose, MPS II (ON):**

Isaiah and his family were renting a three story townhome. They had hoped to make alterations to the bathroom and to install a stair lift, but unfortunately their landlord would not permit them to do this. The family found the perfect home for Isaiah - all on one level and fully accessible, as the previous owner was in a wheelchair, but needed help with moving costs and for the deposit. The Canadian MPS Society was pleased to be able to help with these costs.

► **The Phaneuf/Bernais Family, MPS II (PQ):**

Nathaniel lost his long battle with MPS II in September of 2018. This was, of course, an incredibly difficult time for his family. As a single mum, Lisa was already finding it hard to make ends meet, and the tremendous cost of Nathaniel's funeral was causing both financial and emotional stress. The Society was able to help with a large portion of this cost.

► **Mason Rae, MPS I-H (BC):**

Mason was scheduled for hip replacement surgery, which meant travelling to, and staying in, Vancouver (with the resulting loss of income) and the need for renting some special equipment - electric bed, mattress and walker. Our Family Assistance Program was able to help with these expenses.

► **Mackenzie Olsen, MPS I-H (AB)**

Mackenzie had been accepted for a clinical trial in the US, but the travel and living costs were prohibitive. The Society was delighted to be able to provide some funding towards these expenses.

► **Kamie Babineau, MPS VI (NB):**

Kamie was scheduled for her second open-heart surgery at a hospital some distance from their home. The family was facing the expense of travel, hotels and meals during her stay. The Canadian MPS Society's Family Assistance Program was able to help with much of this cost.

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# Thank You To Our Donors

Thank you so much to everyone who made contributions to the Society during our **April 2018 - March 2019 fiscal year.**

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

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**BIOMARIN**



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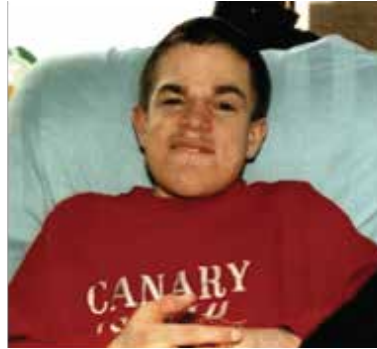
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 Knox, Elizabeth & Derek  
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 Nadarajoh, Salini  
 O'Hara, Linda  
 Sachs, S & Cavanaugh, J  
 Bergen, Andrea  
 Godin, Brooke Adrian

♥ 'Nothing can ever take away a love the heart holds dear.'

# In Memoriam...

## Colin Collins (MPS IIIA)

It has been a long journey for us, starting in the early days of working with Sheila Lee, travelling the country for MPS meetings, doing radio, newspaper and TV interviews to help inform the general public, educators and medical professionals about MPS, and trying to support families who would be just learning that their child was affected.



With all forms of MPS, it is hard for parents to endure as they watch their child slowly slip away. Colin made us laugh when he was younger but like all parents, we rode the emotional roller coast of MPS. However, through it all, it has been an amazing journey: to call Colin our son, brother, and uncle, to love him, care for him and support him, over the last almost 44 years. We are better people for having known him. He enriched our lives and now we believe he is an Angel, free from pain and MPS....dancing, running, laughing and talking in his heavenly home!!

Kharis & Malcolm Collins

## Emma-Rose Grenon-LeMaitre (MPS I)



Emma-Rose is a champion. She shone her light for but a brief time and in that time she ignited the hope and belief, in so many around her, that life is precious and it is our connection to others that makes life beautiful.

'Emma-Rose passed away peacefully on October 30, 2018, surrounded by her resilient family.

Our hearts will forever remember Emma-Rose as someone who taught us to appreciate life, and to 'not sweat the small stuff'. Her legacy and memory will continue on earth through the Emma-Rose Fund and the support that it provides to all families of children with MPS diseases. Rest in peach our little angel!

Lara and Rudy Pietrolungo, Founders, Emma-Rose Fund

## Melissa Clare (MPS I H)

With overwhelming grief we would like you to know that our daughter Melissa Clare passed away on October 17th due to complications of pneumonia and MPS I. She went peacefully with her Mom and Dad by her side. She was a beautiful loving daughter and a wonderful big sister to Jennifer.

She will be greatly missed by her family, friends and her pets.



She touched many lives. Her favourite things to do were to go shopping, play computer games with her sister and play with her many pets. No words can express how much she will be missed. She will be forever in our hearts.

Joan, Walter and Jennifer Clare



# In Memoriam Con't...



## Nathaniel Alexander 'Moose' Phaneuf (MPS II)

Nathaniel passed away peacefully at the CHUS-Fleurimont on Saturday, September 22, 2018 at the age of 16. He was the precious son of Lisa Bernais and the late Russell Phaneuf. He leaves to mourn his loving Mom, his brother Josh (Vanessa) and sisters Ashlee and Chelsea. He was the adored grandson of Alex and the late Marielle Bernais and of the late Albert and Ardell Phaneuf. He will be dearly missed by many uncles, aunts, nephews, nieces, cousins, other family members and loved ones.

The Phaneuf Family have been members and supporters of the Canadian MPS Society for many years. We last met in person at the 2017 National Family Conference in Montreal. This year Lisa and Chelsea have joined us as volunteers. Some time ago, we asked Lisa to write about their experience and life with Nathaniel. Here are her words:

'I will start with the beginning. It was devastating and seemed like time stood still in our lives on diagnosis day. I remember curling into a ball and feeling so hopeless when they told us to go home and enjoy our son, and at least you have a healthy daughter. Then there was hope with enzyme replacement therapy. My hope was that enough of the enzyme would cross the blood brain barrier to keep Nathaniel healthy until a cure was found. We were told that a cure would come too late for Nathaniel and it has. However he has, and continues to teach us many life lessons. He has taught us to slow down and enjoy the roses, and he has led us down paths that we never would have gone. We have met a lot of wonderful MPS families who are nothing short of amazing. We are blessed, and my hope is for a cure so that no parent or family ever loses their child from MPS II.'



# Inspiration + Hope

We would like to share this beautiful letter received from the family of a newly diagnosed young man by the name of Henry. It inspired us + reminded us that whatever life deals us, there is always hope:

**Why we would like to attend the Conference: Geoff, Riki and Henry (& Carter, Gabby, Willie & Maddie who will be staying at home).**

The evening after we received the diagnosis from Henry's doctors, myself, Riki and his grandma were crowded into our little bathroom all playing imaginary lemonade stand with Henry in the tub. He pours water into a jug, and pours out cups full of lemonade and tells us to drink it (but not really) and if its good. As a family we had just been given a bag of lemons by life. And yet, Henry was only caring about making lemonade. We made a promise to simply make lemonade. Our home is a faithful one, we pray and we love. Yet the three of us all needed a five year old boy to remind us to simply make lemonade.

Time, as every parent of a child with MPS becomes incredibly aware of. It has been a week since Henry's doctor shared the diagnosis with us. Barring some abnormally expected test results, or rather un abnormal - Henry's time with us is finite. Time is finite, but somehow a doctor telling us this about our son doesn't seem right. It seems like we are in a dream, like a fog has come over us and we are simply moving from day to day. As I shared with Jill at the MPS Society, I prayed for three things after the information from his doctors. Peace, Hope and Time.

Peace came to me in a sense of calmness, and an appreciation for every moment with Henry. As his Dad I always appreciated moments before, but I want to record every breath he takes in my mind and see his life filled with curiosity and laughter, whatever length of that life is, I want it to be amazing. Somehow Henry hopping up onto the hammock and cuddling into me as we relax for three minutes before he's onto the next thing seems to mean more than it did a week ago.

Hope came to me through the MPS Society, treatments, plans, and information that seems to be evolving. I am hopeful that somehow I will gain information through this conference or support from other people that will offer more and more hope to our family.

Geoff Lucas



# 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.

*Manning Elliott LLP*

Chartered Professional Accountants Vancouver, British Columbia

## The Canadian Society For Mucopoyasacchararide & Related Diseases Inc. Statement of Financial Position as at March 31, 2019

Assets	2019	2018
Current Assets		
Cash	\$74,321	\$57,726
Investments	\$140,902	\$188,643
Accounts Recievable	\$11,504	\$964
Government Remittances Recievable	\$3,818	\$4,885
Prepaid Expenses and Deposits	\$2,386	\$3,765
	<b>\$232,841</b>	<b>\$255,983</b>
Liabilities + Net Assets		
Current Liabilities		
Accounts Payable + Accrued Liabilities	\$13,138	\$9,633
Government Remittances Payable	\$1,505	\$1,510
Deferred Revenue (Note 4)	\$45,000	\$89,172
Deposits Recieved in Advance	-	\$500
	<b>\$59,000</b>	<b>\$100,815</b>
Net Assets	<b>\$173,198</b>	<b>\$155,168</b>
	<b>\$232,841</b>	<b>\$255,983</b>



**2019 National Family Conference**

Sponsorship from caring people and organizations like yours enable the operation our programs, providing emotional and financial support to children and families in need.

[www.mpssociety.ca](http://www.mpssociety.ca)

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

## The Canadian Society For Mucopolysacchararide & Related Diseases Inc. Statement of Financial Position as at March 31, 2019

Revenue	2019	2018
Donations + Grants	\$124,406	\$99,693
MPS II Research Fund	\$89,172	-
Fundraising	\$65,150	\$43,855
Dividend Income	\$2,521	\$1,644
Miscellaneous Income	\$880	\$4,567
Membership Fees	\$160	\$1,460
Conference		
	<b>\$282,289</b>	<b>\$234,556</b>

### Expenses

Salaries	\$74,746	\$83,799
MPS II Project	\$50,130	-
Professional Fees	\$36,577	\$25,554
Fundraising	\$36,441	\$27,373
Office Miscellaneous	\$13,307	\$9,145
Research Grants	\$12,964	\$8,000
Travel	\$10,970	\$6,993
Family Assistance Program	\$7,329	\$10,612
Meetings	\$5,018	\$94,276
Computer	\$4,730	\$5,100
Advertising, Communication + Promotion	\$4,586	\$1,832
Telephone + Internet	\$3,465	\$3,323
Office Lease	\$1,560	\$1,560
Insurance	\$1,306	\$1,479
Printing + Postage	\$599	\$754
Conference	\$356	\$3,537
Membership Dues	\$175	\$50
	<b>\$264,259</b>	<b>\$283,387</b>

### Excess (Deficiency) of Revenue Over Expenses For The Year

\$18,030	(\$48,831)
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# 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.

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

Contact us / Pour nous contacter:

Address: #218-2055 Commercial Drive  
Vancouver, BC V5N 0C7

Toll Free: 1-(800)-667-1846

Phone: 1-(604) 924-5130

Email: [info@mpsociety.ca](mailto:info@mpsociety.ca)

Website: [www.mpsociety.ca](http://www.mpsociety.ca)