

Annual Report 2022-2023









OUR VISION

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



OUR MISSION

The Canadian Society for
Mucopolysaccharide and Related
Diseases Inc. (The Canadian MPS Society),
founded in 1984, serves all Canadians
affected by MPS and related diseases
through support, education, advocacy
and by advancing research.

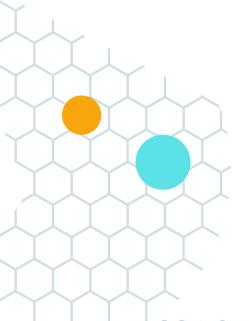


OUR VALUES

Community & Compassionate support | Health & Wellness | Justice & Equality | Education & Awarenesss | Research & Innovation | Accountability & Transparency

www.mpssociety.ca







Kim Angel Executive Director Canadian MPS Society



MESSAGE FROM THE EXECUTIVE DIRECTOR

Dear Members and Supporters,

As we reflect on the past year, I am pleased to share with you the highlights and achievements of the Canadian MPS Society. Together, we have made significant strides in our mission to support individuals and families affected by MPS (Mucopolysaccharidoses) and related disorders.

One notable accomplishment is the successful implementation of newborn screening for MPS in Ontario in 2020. This groundbreaking initiative has led to the early diagnosis of babies affected by MPS, enabling timely interventions and improved outcomes. Our cover photo features Gianna, the first baby in Canada to be positively screened for MPS IH. Marking her 2 year post bone marrow transplant "Gianna is not on any medications and doing all the things a regular toddler would do!" However, it is disheartening to note that Ontario remains the only province in Canada with MPS included in its newborn screening panel. This situation is unacceptable, and we are actively working towards advocating for the addition of MPS to the newborn screening panels across all provinces and territories in our country. Like Gianna, every child deserves the chance for early detection and intervention, regardless of their geographic location.





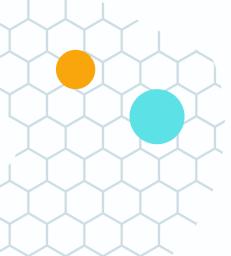
MESSAGE FROM THE EXECUTIVE DIRECTOR (CONT.)

I am also pleased to inform you that the Canadian government has made a significant investment of 1.5 billion dollars into a Rare Disease Drug Strategy. While this funding is a step in the right direction, we believe that more needs to be done. It is essential to broaden the scope of the strategy to encompass a comprehensive Rare Disease Strategy that goes beyond pharmaceutical interventions. Early detection and diagnosis, as well as adequate support systems for parents and caregivers, are equally crucial in ensuring better outcomes for individuals living with rare diseases like MPS.

In partnership with INFORMRARE, we are excited to announce the forthcoming launch of the Canadian Pediatric Longitudinal Registry. This registry will serve as a vital resource for collecting and analyzing data on MPS patients, facilitating research, and guiding future advancements in treatments and care strategies. We are confident that this collaborative effort will significantly contribute to improving the lives of those affected by MPS in Canada.

Throughout the year, we have welcomed many new members to our society, providing them with a supportive and understanding community. However, we have also experienced the heartache of losing loved ones to this relentless disease. Their memories and legacies will continue to inspire us in our ongoing fight against MPS.







MESSAGE FROM THE EXECUTIVE DIRECTOR (CONT.)

I would like to express our deep gratitude to all the individuals and organizations who have generously contributed to our fundraising efforts and helped raise awareness throughout the year. Your support is invaluable and enables us to continue our vital work in advocating for improved care, promoting research, and providing much-needed resources to our community.

Looking ahead, we remain steadfast in our commitment to serving individuals and families affected by MPS. Together, we will strive for a future where early detection, effective treatments, and comprehensive support systems are accessible to all. Your continued involvement and support are essential as we work towards realizing this vision.

Kim Angel Executive Director Canadian MPS Society







Melissa Bilodeau MPS IVA – Adult, Board Chair, Canadian MPS Society



MESSAGE FROM THE BOARD CHAIR

Another great year is behind us. It's with great pleasure we present to you this Annual Report. Allow me to first thank our amazing sponsors and donors without whom this would not be possible. We've also had many amazing fundraising and events this year such as our Annual Fundraiser Elevate Hope and our multi-event campaign on MPS Awareness Day.

Thanks to their generosity, we were able to meet our objectives of helping raise awareness and our members. Amongst those, the Family Assistance Program was able to help many families struggling with the challenges brought on by MPS and the Student Research Funding.

Going through MPS can be a challenging journey but I think we can all agree that together, we can help create a better future for families and individuals affected by MPS and forge a path towards living our best life. - MELISSA







MEET OUR TEAM

BOARD OF DIRECTORS EXECUTIVE:

Mélissa Bilodeau, Chair Montreal, Quebec MPS IVA – Adult

Terry Byrne, Treasurer Guelph, Ontario MPS I Parent Marilyn Marchment, Vice-Chair Vancouver, BC Communications Consultant

Julie Lariviere, Secretary Rockland, Ontario MPS I Parent

DIRECTORS AT LARGE:

Ruben Krishnamurthy
Ontario Mannosidosis Parent

Mojan Zehtabchi Toronto, Ontario Naturopathic Doctor Angie Lombardo, Laval, Quebec MPS I Parent

Alexandra Wyatt Montreal, Quebec

STAFF:

Kim Angel, Executive Director, kimangel@mpssociety.ca Jocelyn Chee, Program Assistant, jocelyn@mpssociety.ca







MEDICAL ADVISORY BOARD 2022/2023

MEDICAL ADVISORY BOARD CHAIR

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

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, MB

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 – Assistant Professor – Department of Paediatrics, Research Institute University of Toronto, ON

Sarah Dyack MD, FRCPC, FCCMG Division of Medical Genetics, Associate Professor Dalhousie University, Department of Pediatrics, Div. of Internal Medicine Halifax, NS





MEDICAL ADVISORY BOARD 2022/2023

MEDICAL ADVISORY BOARD MEMBERS (CONT.)

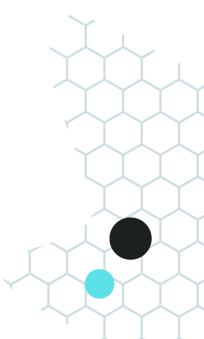
Aneal Khan, MD Inherited Metabolic Clinic, Alberta Children's Hospital Calgary, AB

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

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

Pranesh Chakraborty MD, FRCPC, FCCMG Metabolic Physician, CHEO Medical Director, Newborn Screening Ottawa, ON









ANNUAL FUNDRAISER: ELEVATE HOPE

This year we challenged ourselves to create an engaging campaign while increasing fundraising from the previous year. We chose a theme Elevate Hope – imaged by a Hot Air Balloon being elevated by other aerostats, such as single heart balloons, party clusters of balloons and even blimps towards our target amount. The type of aerostats was determined by the value of the donations. A digital web image of the hot air balloon rising was created to recognize donors.

We implemented various tactics to get people involved and donating more, such as identifying our strongest supporters and requesting their help in peer-to-peer fundraising, and adding value statements on our donation pages to encourage larger donations. We also created some fun shareable digital assets to help our supporters fundraise among their own networks. and let people know how they could influence the hor air balloon trajectory on our web image through their donations.

A direct mail campaign was also launched in December to raise funds for the society. The flyer was distributed to all our stakeholders.







ANNUAL FUNDRAISER: ELEVATE HOPE











We kept our supporters engaged by providing some shareable fun animated email headers and posts.

One of our most popular tactics was our "Balloon String Challenge," which really resonated with people and got them fired up about fundraising with many strings created, demonstrating our donors' enthusiasm for our cause. We also saw an increase in the number of donors, highlighting the impact and importance of our mission.



ANNUAL FUNDRAISER: ELEVATE HOPE





The results of our fundraising campaign were outstanding. We are thrilled to report we met and exceeded our \$10k goal by approximately 20%, an achievement that is commendable given the current economic situation. The success of the fundraiser can be attributed to the effectiveness of these tactics, resonating with our supporters, and compelling them to give, regardless of the amount.

We extend our heartfelt appreciation to everyone who supported us and made this fundraising campaign a tremendous success.





INTERNATIONAL MPS AWARENESS DAY - 15 MAY

A multi - event campaign was organised in May for International MPS Awareness Day to spread the word about MPS and how to recognise the signs. Iconic sites lit up during the week before, and on MPS Day including: Calgary Tower, Vancouver City Hall and BC Place, Vancouver, CN Tower, 3D Toronto sign, Montreal Tower and Niagara Falls.

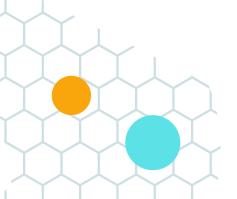














INTERNATIONAL MPS AWARENESS DAY

THE 7 DAYS OF MPS - CANADIAN CAMPAIGN

The MPS disease encompasses seven distinct types, with each type originating from a deficiency in a specific enzyme responsible for mucopolysaccharide breakdown. The manifestation and severity of symptoms vary depending on the particular MPS type.

In anticipation of MPS Awareness Day on May 15, we dedicated the week leading up to it to highlight a different MPS type and educate our audience about recognizing its symptoms. Through our daily presence on social media platforms such as Facebook, Instagram, and LinkedIn, we successfully engaged a wider audience, resulting in a remarkable 500% increase in Facebook reach. Our hope is that this heightened visibility allowed us to spread awareness and foster understanding of MPS among a broader community.

















A GLOBAL CAMPAIGN - CUT TO THE CHASE









The Canadian MPS Society was delighted to collaborate with over 40 global organizations to raise awareness for MPS around the world. Together with our industry partners and within the International MPS network (IMPSN) we refreshed last years multichannel campaign "Chase the Signs".

This campaign aimed to empower individuals in recognizing the key symptoms of MPS while emphasizing the critical importance of expediting the diagnostic process.

To amplify the reach and impact of the campaign, engaging videos, and informative social media posts were widely shared through platforms such as Facebook, Instagram, and LinkedIn. We encouraged active participation by urging individuals to share our posts and join us in our collective pursuit to expedite diagnosis, hence the rallying cry, "CUT TO THE CHASE."





INDEPENDENT FUNDRAISERS



Pharmacie Chabot & Vermette in Laval, Quebec, offered to fundraise for the Society and had a wonderful idea of changing employees' car tires in exchange for donations.

For MPS Awareness Day, May 15, they held an incredible BBQ for their customers, complete with a dunking tank, a raffle, and pharmacists on site to answer questions and bring awareness of MPS. They raised over \$3700 during their event and their manager amazingly doubled the amount making a grand total of over \$7000 for the Canadian MPS Society!













INDEPENDENT FUNDRAISERS

Hillary Rosen, grandmother to Hayley (MPS I) also launched her annual raffle for MPS raising another \$7000. Every year, Hillary has raised thousands of dollars and equally as important - she has raised awareness of MPS and related LSDs.





These efforts from independent fundraisers not only helped raise essential funds but also raised awareness of MPS, and we are extremely grateful to have amazing people in our MPS Community!!

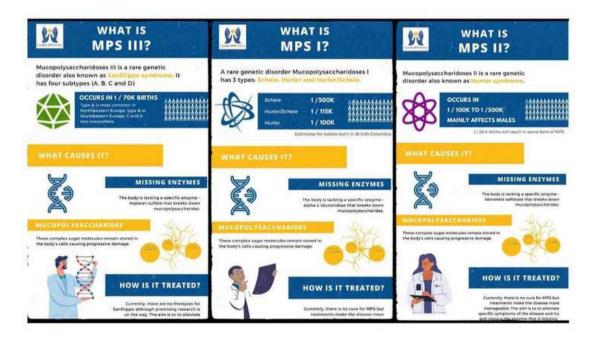






NEW RESOURCES

INFOGRAPHICS



To facilitate a greater understanding and awareness of MPS, we created a series of infographics that provided an overview of the 7 different subtypes of MPS, their respective symptoms, and the available treatment options.

Our aim is to present complex information in an engaging and accessible manner, catering to a wider audience, including patients, caregivers, healthcare professionals, and the general public. We hope that this approach will not only aid in comprehension but also spark interest and curiosity, increasing awareness and understanding of the disease and its management.





NEW PUBLICATIONS

FUNDRAISING HANDBOOK AND DONOR PACKAGE



We are delighted to announce the successful development of a Fundraising Handbook, which serves as a valuable resource for our third-party fundraisers. The toolkit provides comprehensive guidance, ideas and tips for organizing successful fundraising campaigns on our behalf.

We have also created a donation package – Changing Lives, One Donation at a Time. Our supporters now have access to a range of resources that they can use to raise funds on our behalf. This helps us to build stronger relationships with our supporters, as we are now able to provide them with more personalized support and guidance and assist them to successfully execute effective campaigns that align with our organization's goals.





SUPPORTING CONNECTIONS

In our mission to provide a supportive community for members facing challenging situations in life, we introduced We Care - a Gathering for Parents and Caregivers, a virtual monthly event, led by Angie Lombardo, Board member and MPS I parent.

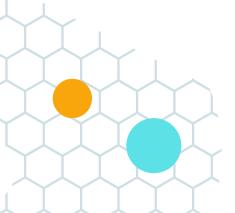
Our primary objective has been to establish a network of parents and caregivers who have gone through similar experiences. By fostering an environment of openness and trust, we encourage participants to share their advice, tips, and personal stories. This opportunity allows our members connect with each other, gain valuable support, companionship, and insights, all within a relaxed and confidential setting.

We are proud to offer these sessions free of charge and in an online format, ensuring accessibility and convenience for our members. By continuously providing opportunities for connection and support, we aim to make a positive and lasting impact on the lives of MPS parents and caregivers.











FINANCIAL ASSISTANCE PROGRAM

The Canadian MPS Society provides financial support to help families manage the extraneous costs associated with MPS and related diseases, such as travel to treatment facilities, medical aides and wheelchair accessible home remodelling. We make sure families know that we're there for them through grants that help them focus on their children rather than on financial hardships.

From the beginning of this program, over \$400,000 in financial assistance has been distributed to over 500 families.

YOUR DONATIONS AT WORK

This year grants were given for assistance in the following categories:



HOME ADAPTATIONS



MOBILITY AIDS



PHYSICAL THERAPY

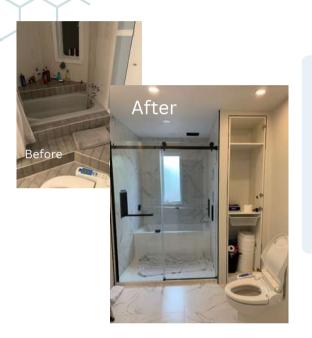


RESPITE





FINANCIAL ASSISTANCE PROGRAM



This renovation will have a huge impact on our family once completed as now Matteo will be 100% independent when showering/bathing and as a bonus its right across the hall from his bedroom making it even more convenient for the days he's not feeling himself or struggling with pain in his lower extremities. Thank you Can MPS! - Angie Lombardo

Canadian MPS Society has been an incredible support to my family since my daughters diagnosis. In recent months, we have unfortunately been experiencing the health declines and behaviour challenges that Sanfilippo Syndrome brings and desperately needed to modify our home to accommodate these changes and keep my girl safe. As a single parent, it is an enormous struggle to provide everyday necessities for my daughters on my own and it felt impossible to ever afford the modifications needed to our home. Gratefully, the financial assistance program was able to provide us funding to help cover some of the cost of our much needed renovations. Our biggest thanks for the continued support and assistance and for lessening some of the financial burden that comes with this journey. - Rebecca Cousineau





FINANCIAL ASSISTANCE PROGRAM



"The Canadian MPS Society has been instrumental in helping us provide supports for our daughter Maya (MPS1).

Recently we were gifted financial support from this program for a desk chair for Maya that provides good lumbar support, is on wheels for convenient mobility, has armrests and has height adjustability. As an 18 year old she spends a lot of her time sitting at her desk doing school work and is about to embark on a university journey so this chair will help keep her comfortable while pursuing her education.

Accessibility equipment is very expensive and unaffordable for most families. We are extremely grateful for the Financial Assistance Program that the Canadian MPS Society offers to its members!

With our deepest appreciation, Lisa, Jeffrey & Maya"





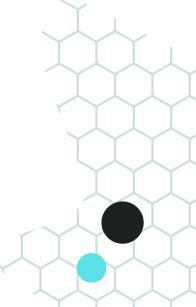
STUDENT RESEARCH FUNDING

Thanks to the generous support of the Gentle Family Research Fund, the Canadian MPS Society awarded a Summer Studentship grant of \$4000 to Yeniay Erdem, at the Research Institute McGill University Health Centre. Yeniay's research project, titled "Dihydroceramide and Ceramide Profiling in MPS Diseases," holds great potential for advancing our understanding of MPS and its underlying mechanisms.

We are proud to be able to support promising researchers like Yeniay, as they work towards unraveling the complexities of MPS, ultimately leading to improved treatments and enhanced quality of life for affected individuals.











THANK YOU TO OUR DONORS

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.

DONATIONS OF \$50,000 +

Biomarin Phrmaceutical Canada Inc. Sanofi (Genzyme) Takeda Canada Inc.

DONATIONS OF \$5000-\$9,999

Pharmacie Chabot & Vermette Rosen, Hillary

DONATIONS OF \$500-\$999

Benga, Amad
Byrne, J & T
Crossfit Rush
D'Odorico, Chris
Hans-Pouliot, Jeremie
Lacroix, E
Parker, Lloyd & Joanne
Parlement des Eleves Escrh
Roth, Grace
Teck Resources
United Way - Greater Toronto

DONATIONS OF \$20,000 +

Cassidy Gentle and Google matched donations

DONATIONS OF \$1000-\$4,999

Canadian Online Rare Disease Research Partners The Calgary Foundation Trott, N Young, R & S







THANK YOU TO OUR DONORS **DONATIONS OF \$0-\$499**

Amirault, Robert Angel, Kim Baird, James Bankert, Ralph & Cathy Bholat, Mehnaaz Bley, Annette Boland, B Boland, S Boucher, Annie Brager, L & Ray, I

Brennan, Robert Canada Helps

Choudhry, Mohammad Christensen, Suzannah

Cleland, Mary Collins, M & K

Delugt, Cheryl

Desigardins Aublet, Louise

Di Ilio. R & L

Eisenbach. Sarah

Farnand. Deborah

Elizabeth

Flamez, Marie Josee

for AR

Foster, Sarah

Fournier, Michelle

Fraser, Bruce

Fry, Vivian

George, Barbara

Goldie, Mark

Gonyea, Jeff & Julie

Gordon, B

Haggerty, Braden

Hammond, Richard

Harkins, K

Hawton, R. Aubrey

Hebert, Viviane

Howard, Judith

Husberg, P

Jacobs, Cameron

Johnson, Melody

Kaweski, V & F

Knox, Elizabeth & Derek

Lacroix, Andre

Lapalme, Kristina

Lariviere, Julie

Lariviere, Sophie

Le Clerc. R & J

Leila & Paul Boland

Lynch, Guri-Ann

MacEachern, Catriona

Madani. Arash

Martin, Wayne & Marilyn

Matyas, Andrew

Murphy, Cathy

Nelis. J

Nellis. M.

Perry, Betty Anne

Perta, Floretta

Provincial Employees

Community Service Fund

Rabak, Marie

Reeds, Lynda

Roth, Dan & Lori

Saccomano, R & D

Serviss, Tom

Sharman, Asheer

Silveri. E

Snow, M

Spina, Sandra

Steinberg, C

Taylor, A

Thermolec Ltd.

Thivierge, Marie-Josee

United Way - Lower

Mainland

United Way - Victoria

Virginillio, Nancy

Walters, Sandra

Ward, Jessica

Wharton, J & K



THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC. STATEMENT OF FINANCIAL POSITION AS AT MARCH 31, 2023

	2023	2022
ASSETS		
CURRENT		
Cash	\$ 222,922	\$ 180,031
Accounts receivable	4,453	-
Government remittances receivable	13,360	11,864
Prepaid expenses and deposits	9,820	2,230
	\$ 250,555	\$ 194,125
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	\$ 60,382	\$ 19,580
Deferred contributions (Note 3)	35,000	-
Government remittances payable	6,090	5,582
Canada Emergency Business Account loan (Note 5)	40,000	74
	141,472	25,162
CANADA EMERGENCY BUSINESS ACCOUNT LOAN (Note 5)		40,000
	141,472	65,162
NET ASSETS	109,083	128,963
	\$ 250,555	\$ 194,125





THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC. STATEMENT OF OPERATIONS AND CHANGES IN NET ASSETS FOR THE YEAR ENDED MARCH 31, 2023

<u> </u>		2023		2022
REVENUE				
Donations and grants	S	175,140	\$	219,168
Fundraising	4	5.841	φ	7.371
Other		1,708		1,152
Membership fees		50		37
Conference		-		50,699
		182,739		278,427
EXPENSES		102,100		210,121
Salaries and contract fees		94,591		88,266
Professional fees		55,886		38,117
Computer		11,078		9.066
Office and miscellaneous		9,598		57,162
Family Assistance Program		8,745		8,394
Travel		8,627		2,390
Research grants		4,000		14,000
Fundraising		2,936		37,858
Telephone and internet		2,198		2.433
Advertising, communication and promotion		2,195		1,604
Office lease		1,560		1,560
Insurance		1,422		1,562
Printing and postage		473		660
Membership dues		470		200
Meetings				113,063
Conference		•		1,138
		203,779		377,473
DEFICIENCY OF REVENUE OVER EXPENSES FROM				
OPERATIONS		(21,040)		(99,046
OTHER INCOME		20202		0.000
Consultation fees		1,160		2,005
Special projects		•		30,476
Canada Emergency Wage Subsidy		•		6,497
Canada summer jobs subsidy				4,766
ECSF funding				60,462
Private summer student reimbursement		375		1,049
		1,160		105,255
(DEFICIENCY) EXCESS OF REVENUE OVER EXPENSES FOR THE YEAR		(19,880)		6,209
NET ASSETS, BEGINNING OF YEAR	\$	128,963	\$	122,754
NET ASSETS, END OF YEAR	\$	109,083	\$	128,963



THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC. STATEMENT OF CASH FLOWS FOR THE YEAR ENDED MARCH 31, 2023

		2023		2022	
OPERATING ACTIVITIES (Deficiency) excess of revenue over expenses for the year	\$	(19,880)	\$	6,209	
Changes in non-cash working capital:					
Accounts receivable		(4,453)		84,578	
Government remittances receivable		(1,496)		(1,894)	
Prepaid expenses and deposits		(7,590)		13,021	
Accounts payable and accrued liabilities		40,802		(3,714)	
Government remittances payable		508		(2,952)	
Deferred contributions		35,000		(155,462)	
		62,771		(66,423)	
INCREASE (DECREASE) IN CASH FLOW		42,891		(60,214)	
CASH, BEGINNING OF YEAR		180,031		240,245	
CASH, END OF YEAR	\$	222,922	\$	180,031	





THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC. NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED MARCH 31, 2023

3. DEFERRED CONTRIBUTIONS

Deferred contributions represent unspent restricted funding designated for future expenditures and are deferred in accordance with the accounting policy disclosed in Note 1(b). The changes in the deferred contributions balance for the year are as follows:

	2023	2022
Balance, beginning of year Contributions received during the year Contributions recognized as revenue during the year	\$ 35,000	\$ 155,462 (155,462
Balance, end of year	\$ 35,000	\$ - (100,402
Deferred contributions are comprised of:	2023	2022
BioMarin Pharmaceutical Inc.	\$ 25,000	\$ - 2
Sanofi-Aventis Canada Inc. Ultragenyx Pharmaceutical Inc	5,000 5,000	

4. WAGE SUBSIDIES

In response to the COVID-19 health pandemic, the Society took advantage of programs providing relief. As at March 31, 2023, the Society received the Canadian emergency wage subsidy and the Canada summer jobs subsidy from the federal government for an amount totaling \$Nil (2022 - \$6,497) and \$Nil (2022 - \$4,766) respectively. The amounts have been included as other income in the statement of operations.

CANADA EMERGENCY BUSINESS ACCOUNT LOAN

In fiscal 2021, the Society received a \$60,000 loan under the Canada Emergency Business Account ("CEBA") program from TD Canada Trust. This is an interest-free loan to cover payroll and/or operating costs. Repaying the balance of the loan on or before December 31, 2023 will result in a loan forgiveness of 25% (up to \$20,000). The Society intends to fulfil all facets of the loan arrangement and qualify for the forgiveness.





THANK YOU

218-2055 Commercial Dr., Vancouver, BC V5N 0C7

(604) 924-5130



mpssociety.co



info@mpssociety.ca





