

#ignite
hope

Annual Report

2023-2024



40
YEARS
STRONG
1984 - 2024





ABOUT US

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 & Awareness | Research & Innovation | Accountability & Transparency





MESSAGE FROM THE EXECUTIVE DIRECTOR

Kim Angel



As we reflect on this past year, I am filled with pride and gratitude for the remarkable achievements and the unwavering support of our MPS community. The **2023 National Family Conference** was a heartwarming and inspiring event, bringing together families, researchers, and healthcare professionals from across the country. It was a moment of connection, learning, and shared hope as we united to support each other and focus on the future of MPS care.

Our **We Care Program** has continued to be a vital source of connection, information, friendship, and support within our family community. It has become a lifeline for families, offering them a space to share their experiences, find comfort, and gain valuable insights from others who truly understand the challenges of living with MPS. This program exemplifies the strength and solidarity that define our MPS family, and I am so proud of the impact it has had.

We are also deeply grateful for the independent fundraisers organized by dedicated supporters who have gone above and beyond in their efforts to raise much-needed funds for the Society. These initiatives, alongside our successful **Annual Fund Campaign**, have allowed us to continue supporting vital programs for our families, advocating for early diagnosis, and driving research forward.

As we celebrate our successes, we also take a moment to honour the memory of those we have lost to MPS this year. Their lives and legacies inspire us to continue our work with renewed determination. To their families, please know that our hearts are with you, and your loved ones will always be remembered within our community.



Amidst the challenges we face, there is also a renewed sense of hope as new research and treatments are being developed for MPS patients. Advances in gene therapy, enzyme replacement therapies, and other innovative treatments are bringing us closer to better outcomes and improved quality of life for those affected by MPS. We were thrilled to be able to share at the National Family Conference, in Calgary, that Alberta is including MPS I in their newborn screening program. We remain committed to ensuring all these life-changing developments are accessible to all who need them.

Looking ahead, we are filled with anticipation for the **2025 National Family Conference** and the **Canadian MPS Society's 40th Anniversary Celebration**. It will be an incredible milestone, and we will come together to reflect on the progress made over the past four decades and continue our mission of providing support, advocacy, and hope to families across the country.

I would like to take this opportunity to honour **Sheila Lee**, the founder of the Canadian MPS Society. Sheila's courage, vision, and bravery in establishing this organization 40 years ago have touched the lives of countless Canadian families affected by MPS. Her determination has created a legacy of support, education, and advocacy that continues to guide us today. We thank Sheila for her extraordinary work, and we carry her spirit forward in all we do.

To our **donors, supporters, volunteers, Board members, and staff**, thank you for your commitment and dedication to our MPS families. Your generosity and hard work ensure that we can continue providing essential resources, advocacy, and hope to those who need it most.

It has been an incredible honour to be part of this outstanding organization and to get to know the amazing families, researchers, and partners who make up our community.

Together, we are making a difference, and I am proud to be on this journey with all of you.

With deep gratitude and hope for the future,



KIM ANGEL
EXECUTIVE DIRECTOR, CANADIAN MPS SOCIETY



MESSAGE FROM THE BOARD CHAIR

Melissa Bilodeau
MPS IVA – Adult



As much as I wish we lived in a world where children do not get sick and families do not have to go through such tremendous challenges as they do living with MPS, it is not in the reality we live in. Yet, throughout all this, we have something to celebrate: the 40th anniversary of the Canadian MPS Society. This anniversary demonstrates that as a community, we are able to rise up and stand together. Even in the simplest of acts such as a parent reaching out and helping another reflects our communal strength and courage and that is something to be celebrated.

This year again, we helped connect families to one another, we supported the members via our Family Assistance Program and we have contributed to research via the Student Research Grants Program. We have also started a new initiative aimed at helping out directly affected pursuing their studies.

I do hope for a future where no one has to grow up with MPS and receive a cure but as long as people continue to do so, I hope for a Canadian MPS Society that supports them, that helps them reach their full potential and live a fulfilling life.

As such, we are happy to bring you this Annual Report. I wish to thank our amazing staff and board without whom none of this would be possible. Their dedication and hard work is not something that words can fully convey but I hope that in the lives they have touched, they find the best of recognition.

Melissa Bilodeau



MEET OUR TEAM

BOARD OF DIRECTORS 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, Ontario
MPS I Parent

DIRECTORS AT LARGE:

Ruben Krishnamurthy
Ontario Mannosidosis Parent

Alexandra Wyatt
Montreal, Quebec

Mojan Zehtabchi
Toronto, Ontario Naturopathic Doctor

Meghan Henry
Langley, BC MPS IVA Parent

Angie Lombardo,
Laval, Quebec MPS I Parent

Stephanie Aubin
Sherbrooke, Quebec MPS II Parent

STAFF:

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





MEDICAL ADVISORY BOARD 2023/2024

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 2023/2024

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

Kim L. McBride MD Head, Department of Medical Genetics, Cumming School of Medicine (CSM), University of Calgary and Section Chief, Medical Genetics, Department of Pediatrics at Alberta Health Services Department of Neuropsychology Hospital for Sick Children Toronto, ON

Pranesh Chakraborty MD, FRCPC, FCCMG

Metabolic Physician, CHEO Medical Director, Newborn Screening Ottawa, ON

Philippe Campeau, MD, FRCPC, FCCMG Geneticist, Department of Pediatrics, University of Montreal and Sainte-Justine Hospital. Montreal, QC



2023 NATIONAL FAMILY CONFERENCE

UNITING MPS FAMILIES WITH HOPE

The Canadian MPS Society's 2023 National Family Conference in Calgary brought together over 170 attendees, including MPS families, presenters, and volunteers from across Canada. This two-day event embodied our core values of Community & Compassionate Support, Health & Wellness, and Education & Awareness.

Key highlights included:

- Informative sessions on cutting-edge research and treatments by medical experts, aligning with our Research & Innovation value
- Practical presentations on anesthesia risks and transition planning
- Inspiring talks by MPS parents Mark Dant, Bob Stevens, and Geoff Lucas on advocacy and awareness





2023 NATIONAL FAMILY CONFERENCE

The children enjoyed specialized programming, including music therapy and a field trip to the Studio Bell National Music Centre. The Born to Shine Banquet featured a performance of the children's self-penned song "We are Born to Shine" and the Rare Stars Awards ceremony.

The 2023 award recipients were:

- Geoff Lucas (MPS III Parent) : For providing guidance to families navigating new diagnoses
- Cristina Chiappetta (MPS I Parent): For championing early detection and diagnosis advocacy
- Arielle Serviss MPS I: For her determination in outdoor and athletic pursuits
- Dr. Serge Melancon: Lifetime Achievement Award for dedication to the MPS Community



29

CHILDREN WITH MPS AND
THEIR SIBLINGS ATTENDED
THE CONFERENCE

73

AFFECTED MPS FAMILY
MEMBERS ATTENDED THE
CONFERENCE



2023 NATIONAL FAMILY CONFERENCE

UNITING MPS FAMILIES WITH SUPPORT

The impact of the conference on MPS families was profound and far-reaching. For many, it provided a rare opportunity to connect with others who truly understand their daily challenges and triumphs. Families left with renewed hope, armed with the latest information on treatments and research. The shared experiences and knowledge gained at the conference empowered parents to become better advocates for their children.

And importantly, the connections formed during these three days created a support network that extends far beyond the conference, offering ongoing emotional support and practical advice throughout the year. For children with MPS, the conference offered a chance to feel less isolated and to form friendships with peers who share similar experiences.

This year's conference was made possible through the generous support of our sponsors: Biomarin, Takeda, Regenxbio, Sanofi, Ultragenyx, Denali, Homology Medicines, JCR Pharmaceuticals, and SickKids Foundation to whom we are grateful.

"WE LEFT FEELING UPLIFTED AND EQUIPPED WITH NEW CONNECTIONS, INSIGHTS, AND ENCOURAGEMENT TO KEEP ADVOCATING FOR OUR CHILDREN."



FUNDRAISING + EVENTS

ANNUAL FUNDRAISER: *IGNITE A STAR*

GIVING TUESDAY Nov 28

mpsociety.ca/donate



AMOUNT RAISED

\$8,000

DEC 2023 - JAN 2024

While we aimed for the stars with our \$10,000 goal, we are immensely grateful to have raised \$8,000. This will fuel our programs and services, providing crucial support to families affected by mucopolysaccharidoses.

Though we fell slightly short of our target, the outpouring of support from our community was truly inspiring. We extend our heartfelt thanks to all who contributed, shared, and supported this campaign. Your generosity has ignited hope for MPS families, proving that together, we can reach for the stars and make a difference in the lives of those we serve.



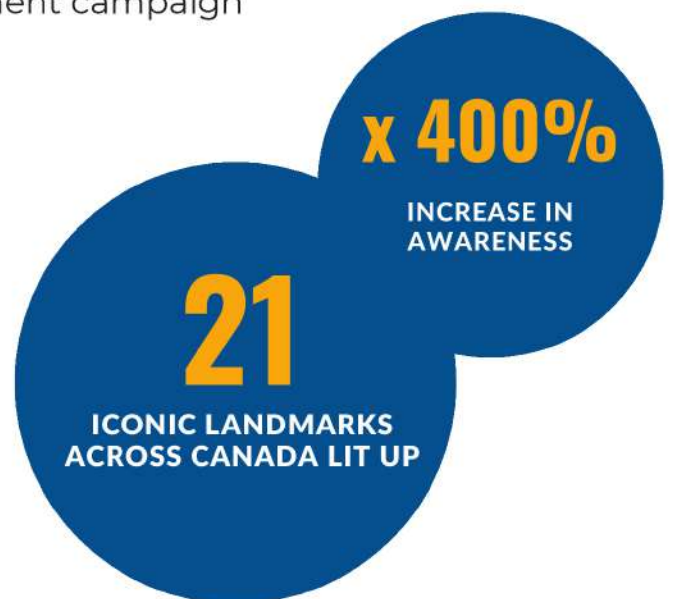
INTERNATIONAL MPS AWARENESS DAY - 15 MAY

GLOBAL AWARENESS INITIATIVE: "IT'S ABOUT TIME"

In collaboration with over 40 global organizations, we participated in a groundbreaking multichannel campaign, "It's About Time," to raise awareness about Mucopolysaccharidosis (MPS) diseases worldwide. This initiative, developed in partnership with industry leaders and the International MPS Network (IMPSN), aimed to advocate for improved access to treatment and support for affected individuals and families. The campaign emphasised the critical role of time in early diagnosis and treatment access, highlighting that every moment counts in improving outcomes for MPS patients.

National Engagement:

- 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.
- Social media outreach and engagement campaign





COMMUNITY SPOTLIGHT ST. AUGUSTINE SCHOOL, HUMBOLDT, SK

The school in Humboldt, SK rallied around their classmate Henry, who lives with MPS III Sanfilippo syndrome, helping to create inspiring videos for "It's About Time to Shine a Light: Fight and Unite for MPS."

Thanks to the dedicated efforts of our MPS community in sharing these videos, one of them has reached a milestone of over 6,500 views! - a new record for CanMPS.

This outstanding achievement showcases the power of community and the impact we can make when we unite for a cause. The students, teachers, and families of St. Augustine School have not only supported Henry but have also significantly boosted MPS awareness across the country. They can stand proud!





FUNDRAISING + EVENTS

This year we had a number of grassroots initiatives which are vital to our ongoing work, combining fundraising with community engagement and public awareness.

On August 29, 2023, the Canadian MPS Society marked a significant milestone with the 20th anniversary celebration of the **MPS CUP 20th Anniversary Gala**. This event not only commemorated two decades of community support but also launched an exciting new fund for our members. Donations from this event established the Canadian MPS Society Education and Learning Fund (ELF).

There were around 100 generous donors in attendance at the Seymour Golf & Country Club, North Vancouver, BC. Dr. Lorne Clarke was there to inform guests on the progress of MPS research and care in the past 20 years, and what's yet to come, Jansen Harkins – the event's organizer – gave his personal perspective on living with a sibling, Nicklas affected by MPS. The event's crowning achievement was the introduction of our pilot Education and Learning Fund Scholarship Program for young adults affected by MPS, which received enthusiastic support



Emcee Mike Killeen & his wife, Jill



Dr. Lorne Clarke presents the History Of MPS & What's To Come

\$35,000
TOTAL AMOUNT RAISED
AT THE MPS CUP 20TH
ANNIVERSARY GALA



Jansen With Martin Jones and wife, Alex



MPS Cup Volunteers!



FUNDRAISING + EVENTS

MPS CUP 20TH ANNIVERSARY GALA

We are so grateful for all the support from the guests in attendance. We would like to particularly thank the event's gold sponsors Takeda, Ultragenyx and KO Sports, and its silver sponsors Babych Group Realty Vancouver, Speedbolt Printing and Mex Y Can USA. We'd also like to extend our gratitude to the donors of live auction items: Jansen Harkins, Martin Jones, Seymour Golf & Country Club, Annex Hotels Toronto, and Chris & Cindy Bouchard, who donated a week's stay at their stunning boutique hotel Villa Amor Del Mar.



Kirsten Harkins and MPS Society Board Member, Meghan Henry



Kim Angel & Kristina Gentes From Takeda



Nicklas With Law School Buddies

Above all, we want to express our deep appreciation to the Harkins family, whose profound contributions have left a lasting impact on the MPS community and the educational aspirations of young adults and children affected by MPS and related diseases.

The MPS CUP 20th Anniversary Celebration raised close to \$35,000 for The Canadian MPS Society and the launch of the **Education and Learning Fund** marks a new chapter in our support for individuals affected by MPS.



FUNDRAISING + EVENTS

PARTNERSHIP WITH MOSAIC HOME SERVICES LTD.

In a remarkable display of corporate social responsibility, Mosaic Home Services Ltd chose the Canadian MPS Society for their September Charity Day, resulting in a significant boost to our outreach capabilities.

With active participation from Mosaic's staff and customers over \$3,000 was raised

We extend our heartfelt gratitude to Mosaic Home Services Ltd. for selecting us as their Charity Day recipient, Mosaic's dedicated staff for their enthusiastic participation and their customers who generously contributed to the cause.

\$3K

**AMOUNT RAISED BY
MOSAIC CUSTOMERS
FOR THE CANADIAN
MPS SOCIETY**





FUNDRAISING + EVENTS

TCS TORONTO WATERFRONT MARATHON CHARITY CHALLENGE

In October 2023, the Canadian MPS Society witnessed an inspiring display of dedication and community spirit through participation in the TCS Toronto Waterfront Marathon Charity Challenge. Terry Byrne (Board Member), braved the elements with his 4 team members in Millet, Alberta and Toronto, Ontario to raise funds and awareness for our cause. Team MPS Shooting Stars raised over \$7,600.

This event not only raised significant funds but also increased visibility for MPS.

We extend our heartfelt gratitude to Terry, Judy, Diana, and Lucy for their exceptional efforts. Their willingness to "go the extra mile" serves as an inspiration to all and reinforces the strength of our community in facing the challenges of MPS together.



Terry Byrne



Judy Byrne & friend Lucy



TCS Toronto Waterfront Marathon



Diana Bruun

\$7,800

AMOUNT RAISED BY
TEAM MPS SHOOTING
STARS



FUNDRAISING + EVENTS

PHARMACIE CHABOT & VERMETTE IN LAVAL, QUEBEC

On International MPS Awareness Day, May 15th, Pharmacie Chabot & Vermette in Laval, Quebec, hosted a highly successful barbecue fundraiser for the second year running. This event not only raised substantial funds for the Canadian MPS Society but also greatly increased public awareness of MPS. MoTransMed, a local delivery company, demonstrated outstanding corporate citizenship by donating all food, equipment, and staff for the barbecue. Pharmacy staff showed tremendous dedication, with one team member baking and selling 120 MPS awareness cupcakes. The event also brought together MPS families with the local community.



Pharmacie Chabot & Vermette pledged to match and double the funds raised from the barbecue, combining them with proceeds from additional fundraising initiatives including an employee gift card raffle and a planned bowling event.



FUNDRAISING + EVENTS

PHARMACIE CHABOT & VERMETTE IN LAVAL, QUEBEC



Board Member, Angie Lombardo with the Pharmacie team



MPS parents enjoy reconnecting!

We extend our heartfelt gratitude to Pharmacie Chabot & Vermette, MoTransMed, and all participants for their generous support and dedication to our cause. Such collaborative efforts are vital to our ongoing work in supporting individuals and families affected by MPS. We look forward to fostering more such partnerships in the future.



SUMMER STUDENT PROGRAM FUNDED BY THE GENTLE FAMILY RESEARCH FUND

KEY RESEARCH HIGHLIGHTS

1. Quantifying Pro-Inflammatory Fats in MPS Patients

Researcher: Hanine Bahsoun

Achievements:

- Established a methodology to quantify 1-deoxysphinganine and 1-deoxysphingosine in MPS patients' bloodstream
- Successfully validated the method's reliability in recovering and quantifying fats from blood samples
- Laid groundwork for larger studies to enhance understanding of MPS and related rare diseases

2. Sphingolipid Extraction for Pain Management in MPS

Researcher: Samaan Abiad

Achievements:

- Developed a simplified method to extract and measure sphingolipids from dried blood spot samples
- Created a potential clinical lab adoption tool due to its speed and low error margin
- Contributed to ongoing clinical trials assessing TNF-alpha inhibitors for inflammation and pain in MPS.

3. Verified Interest to Participate in Research

Researcher: Christine Fodor

Achievements

- Developed a project proposal and survey to be used for the development of an online registry of MPS patients which will increase patient access to research and clinical trials for MPS.



SUMMER STUDENT PROGRAM FUNDED BY THE GENTLE FAMILY RESEARCH FUND

The summer student program has not only contributed significantly to ongoing MPS research but also cultivated emerging talent in the field. As we look forward to the potential long-term impacts of these studies, we remain committed to supporting innovative research initiatives that bring us closer to improving the lives of those affected by MPS.

We extend our heartfelt gratitude to the Gentle Family Research Fund for their invaluable support in making these research positions possible. Their commitment to fostering the next generation of MPS researchers is instrumental in advancing our mission.

The full report presented to Cassidy Gentle and the Gentle Family that highlights the impact to MPS research their funding has enabled, can be found at www.mpsociety.ca/research-grants/





CANADIAN PEDIATRIC MPS REGISTRY LAUNCH

A major milestone was achieved this year with the launch of the Canadian Pediatric MPS Registry at the 2024 Garrod Symposium, made possible through our strategic partnership with Inform Rare.

This registry marks a critical advancement in our understanding and support of individuals with MPS disorders. By consolidating data from across Canada, it will provide essential insights into the prevalence of MPS in pediatric patients, and disease progression patterns.



Key Features:

- Hosted on the National Organization for Rare Disorders IAMRARE 2.0 platform
- Available in both English and French
- Patient-powered database collecting vital information
- Visit <https://www.mpsregistry.ca/> to learn more and join!

The registry will serve as a cornerstone for future research and therapeutic developments, enabling researchers to enhance understanding of MPS disease progression and patient impact, evaluate current treatments and develop new therapies and improve standards of care and patient outcomes. This initiative underscores our unwavering commitment to improving the lives of those affected by MPS. We extend our deepest gratitude to Inform Rare for their collaboration in this groundbreaking project.

BY JOINING THE CANADIAN MPS REGISTRY, YOU'RE NOT JUST SHARING YOUR DATA - YOU'RE DRIVING MPS RESEARCH FORWARD AND HELPING CREATE A BRIGHTER FUTURE FOR ALL THOSE LIVING WITH MPS.



NEW EDUCATION AND LEARNING GRANT (ELF)

In April 2024, we were proud to launch the Canadian MPS Society **Education and Learning Fund (ELF) Scholarship Program**, an initiative made possible through the generous support of the Harkins Family and donors from the 20th Anniversary of the MPS Cup.

Program Highlights:

- Purpose: To support and empower individuals affected by MPS or related LSDs in their educational and developmental pursuits
- Scope: Covers a wide range of learning opportunities, including post-secondary education, life skills acquisition, arts training, certification programs, and career advancement
- Funding: Awards can be applied to various expenses such as tuition fees, course materials, travel, memberships, and other related costs
- Members in good standing with the Canadian MPS Society directly affected by MPS or related LSDs, - age 16 and above and residing in Canada are eligible.

The ELF Scholarship Program embodies our commitment to recognizing the diverse abilities and needs of our membership. By providing financial support for a broad spectrum of educational and developmental activities, we aim to empower our members to pursue growth opportunities and live their best lives.

We extend our heartfelt gratitude to the Harkins Family and all donors who have made this initiative possible. Their generosity will have a lasting impact on the lives of individuals affected by MPS and related LSDs, opening doors to new opportunities for personal and professional development.



ENHANCING SUPPORT

In line with our mission to provide a supportive community for members facing challenging situations, we are proud to report on the success of our initiative, "We Care - A Gathering for Parents and Caregivers." This virtual monthly event, led by Board member and MPS I parent Angie Lombardo, alongside MPS III parent Geoff Lucas, has become a cornerstone of our support services.

These sessions are held monthly and free of charge to all participants in a confidential and relaxed environment. We were able to introduce specialised sessions for targeted groups (e.g., fathers-only meetings) and some issues discussed were future of their children affected by MPS, concerns regarding friendships and bullying, struggles regarding family planning and relationships, how to cope once child starts understanding they are different, self care and mental health for kids and parents..

By maintaining these regular online sessions, we have ensured accessibility and convenience for our members, regardless of their location or circumstances. The introduction of specialized sessions this year has allowed us to address the unique needs of specific groups within our community, further enhancing the impact of the program.

Through "We Care," we continue to make a positive and lasting impact on the lives of MPS parents and caregivers, reinforcing our commitment to supporting every aspect of life with MPS.





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.

This year our Financial Assistance Program budget was fully utilized. This underscores the importance of fundraising to sustain this vital program.

YOUR DONATIONS AT WORK

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



RESPITE



TRAVEL



MOBILITY

\$11,000

**AMOUNT DISTRIBUTED
FOR FINANCIAL
ASSISTANCE**



FINANCIAL ASSISTANCE PROGRAM

“We received a Wonderfold Wagon for Emmett, through the Financial Assistance funding. This was so helpful as these wagons are so expensive and we were looking for a safe alternative to our stroller (which Emmett was outgrowing- especially with a coat on) to walk my daughter to and from school.

Emmett loves to wait on the playground for his big sister and it was such a great way to keep him safe on the walk as it has seat belts, and could fit my daughter as well. Thank you!!”

- Steph, mother of Emmett (MPS IIIA)





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 +



DONATIONS OF \$19,000 +



DONATIONS OF \$5,000-\$9,999

BC Childrens Hospital Foundation
Denali Therapeutics
Homology Medicines, Inc.
JCR Pharmaceuticals Co., Ltd.
Rosen, Hilary
Team MPS Shooting Stars - TCS
Toronto Waterfront Marathon Charity
Challenge
Ultragenyx Pharmaceutical Inc.
Marc Chabot & Daniel Vermette
Pharmaciens Inc.

DONATIONS OF \$1000-\$4,999

Castle, Heidi
Clarke, L
KO Sports Inc.
Lacroix, E
Mode Choc
Mosaic Home Services
The Calgary Foundation
Young, Dr. Robert

DONATIONS OF \$500-\$999

Amson, Kelly
Benga, Amad
Byrne, Terry
Canada Helps
Chimp
Delugt, Cheryl
Di Ilio, R & L

Hager, J
Harkins, K
Linton, E & R
Nellis, M
Perta, Floretta
Roth, Dan & Lori
Roth, Grace
Rusak, Carol
United Way - Niagara





THANK YOU TO OUR DONORS

DONATIONS OF \$0-\$499

Acheson, Janet
Angel, Sharon
Angel, Kim
Barone, Frank
Bhat, Manjunath
Bocti, Charles
Boland, Stephen
Boudreault, Lyn
Bouhadjar, Meriem
Brager, L & R
Brager, Ray
Bruce, Fraser
Buher, Anne
Byrne, J
Byrne, J & T
Chan, Alicia
Collins, Kharis
Delugt, Mark
Desjardins, Louise
Dewarle, Patrick
Dhaliwall, Randal
D'odorico, Chris
Fumerton, Linda
Garden, Emma
Gim, Akash
Gordon, B
Gunton, J
Hammond, Richard
Hans-Pouliot, Jeremie
Harris, Donna
Hebert, Viviane
Henry, Meghan
Hicks, Arlene
Humber, Alan & Sandra
Huntingford, Margaret
Johnson, Melody
Kaelber, Rhonda
Kaweski, V & F
Knox, Elizabeth & Derek
Kumar, Sameer
Lanese, S & N
Lariviere, Sophie
Lariviere, Julie
Lauder, Sandra
Lee, C
Lehman, Anna
Lewis, Violet
Lombardo, Angie
Maceachern, Catriona
Maltby, J
Marchment, Marilyn
Matyas, Andrew
McCabe, Stephanie
McClean, P
Melancon, Serge
Moen, Dawn
Nickel, Krista
Parker, Lloyd & Joanne
Pataki, Janos
Perry, R & E
Petan, Nic
Pickering, L
Poirier, Annik
Price, Charles
Provincial Employees
Community Service Fund
Rabak, Marie
Rae, Ian & Lesley
Reeds, Lynda
Santos, Margaret
Samms, Kharis
Sharman, Asheer
Shaughnessy, Theresa
Silveri, E
Skiba, S
Smith, Tracy
Snow, M
Stevenson-Moore, Peter
Stiles, Edythe
Stratkauskas, Edward
Taylor, Anne
Tayyaba, Marriam
Thermolec Ltd.
United Way - Greater
Toronto
United Way - Lower
Mainland
Walters, Sandra
Watts, Suzanne



FINANCIAL STATEMENTS

**THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF FINANCIAL POSITION
AS AT MARCH 31, 2024**

	2024	2023
ASSETS		
CURRENT		
Cash	\$ 81,501	\$ 222,922
Accounts receivable	55,264	4,453
Sales taxes receivable	14,546	13,360
Prepaid expenses and deposits	2,287	9,820
	\$ 153,598	\$ 250,555
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	\$ 75,336	\$ 60,382
Government remittances payable	-	6,090
Deferred contributions (Note 3)	16,529	35,000
Canada Emergency Business Account loan (Note 4)	-	40,000
	91,865	141,472
NET ASSETS	61,733	109,083
	\$ 153,598	\$ 250,555



FINANCIAL STATEMENTS

**THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF OPERATIONS AND CHANGES IN NET ASSETS
FOR THE YEAR ENDED MARCH 31, 2024**

	2024	2023
REVENUE		
Donations and grants	\$ 131,067	\$ 175,140
Conference	113,130	-
Fundraising	51,775	5,841
Membership fees	350	50
Other	-	1,708
	296,322	182,739
EXPENSES		
Meetings	118,791	-
Salaries and contract fees	90,055	94,591
Professional fees	63,545	55,886
Fundraising	14,764	2,936
Office and miscellaneous	13,333	9,598
Research grants	12,000	4,000
Family Assistance Program	11,354	8,745
Computer	6,785	11,078
Travel	4,022	8,627
Telephone and internet	3,251	2,198
Office lease	1,560	1,560
Insurance	1,469	1,422
Printing and postage	1,310	473
Advertising, communication and promotion	1,033	2,195
Membership dues	400	470
	343,672	203,779
DEFICIENCY OF REVENUE OVER EXPENSES FROM OPERATIONS	(47,350)	(21,040)
OTHER INCOME		
Consultation fees	-	1,160
DEFICIENCY OF REVENUE OVER EXPENSES FOR THE YEAR	(47,350)	(19,880)
NET ASSETS, BEGINNING OF YEAR	\$ 109,083	\$ 128,963
NET ASSETS, END OF THE YEAR	\$ 61,733	\$ 109,083



FINANCIAL STATEMENTS

**THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED MARCH 31, 2024**

	2024	2023
OPERATING ACTIVITIES		
Deficiency of revenue over expenses for the year	\$ (47,350)	\$ (19,880)
Changes in non-cash working capital:		
Accounts receivable	(50,811)	(4,453)
Sales taxes receivable	(1,186)	(1,496)
Prepaid expenses and deposits	7,533	(7,590)
Accounts payable and accrued liabilities	14,954	40,802
Government remittances payable	(6,090)	508
Deferred contributions	(18,471)	35,000
	(54,071)	62,771
	(101,421)	42,891
FINANCING ACTIVITY		
Repayment of Canada Emergency Business loan	(40,000)	-
(DECREASE) INCREASE IN CASH DURING THE YEAR	(141,421)	42,891
CASH, BEGINNING OF YEAR	222,922	180,031
CASH, END OF YEAR	\$ 81,501	\$ 222,922

**THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
NOTES TO FINANCIAL STATEMENTS
FOR THE YEAR ENDED MARCH 31, 2024**

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:

	2024	2023
Balance, beginning of year	\$ 35,000	\$ -
Contributions received during the year	16,529	35,000
Contributions recognized as revenue during the year	(35,000)	-
Balance, end of year	\$ 16,529	\$ 35,000

4. 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 January 18, 2024 will result in a loan forgiveness of 25% (up to \$20,000). The Society has repaid the loan and fulfilled all facets of the loan arrangement and qualified for the forgiveness.



THANK YOU

 *Living our best lives*



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

(604) 924-5130



mpsociety.ca



info@mpsociety.ca



 @CanadianMPSSociety

 @canadian.mps.society

 @canadianmpssociety