

ANNUAL REPORT

2021-22



Living our best lives



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

www.mpsociety.ca



#ignitehope





Melissa Bilodeau
Board Chair
Canadian MPS Society

MESSAGE FROM THE BOARD CHAIR

This year has been another great year for the Canadian MPS Society. We kicked things off with our Annual Fundraiser, but also continued throughout to raise funds and awareness via social media and events such as landmark lighting in multiple provinces across Canada.

Thanks to the revamping of the Society's website, we continue to strive towards our mission of supporting all those affected by MPS in Canada. Also, the Financial Assistance Program has reached the incredible amount of 400 thousand dollars this year in funds given to families to help with the extra costs that we know the diagnosis brings.

Finally, I would like to thank our amazing donors, our amazing staff as well as our board of directors without whom none of this would be possible. To our members, we are here for you at every step of the journey, whether it means you are newly diagnosed or mourning the passing away of a loved one. Most importantly, I wish to thank you for showing us the true meaning of courage and determination.



Kim Angel
Executive Director
Canadian MPS Society

MESSAGE FROM THE EXECUTIVE DIRECTOR

There is no denying that the pandemic has created many changes in all our lives. Virtual became the reality as much of our lives were lived on-screen.

We also, had to adapt our approach and found innovative ways to constructively utilize the virtual world to provide supports to our members, raise awareness and funds, advocate, celebrate and grieve.

This year's annual report highlights how we capitalised on our virtual tools available such as our monthly digital newsletter, website, and social media to improve on our member resources. Our fundraising went virtual as well as our participation at national and international conferences and symposia.

Of course, our community also suffered devastating losses throughout the year. We grieved for loss of our loved ones, observed clinical trials fail to meet endpoints and struggled to adjust to the constant changes in our world.

MESSAGE FROM THE EXECUTIVE DIRECTOR (CONT.)

On the flip side, major accomplishments have been made this year that will benefit our community as we go forward: -

- In 2019, the Government of Canada committed to develop a National Strategy for Drugs for Rare Diseases, with an initial commitment of \$1 billion over two years beginning in 2022-23
- The development of a National MPS Pediatric Registry and Core Outcome Sets with our partners INFORMRARE
- Numerous pharmaceutical companies leading clinical trials that pioneer new therapies, such as gene therapy to treat MPS, are showing very promising data and results
- And we have seen the diagnosis of the first baby screened at birth for MPS in Ontario.

Like usual, the Canadian MPS community pulled together to do what we do best - Support one another, stay hopeful and celebrate the small things in life.

On behalf of the Board of Directors and staff of the Canadian MPS Society, we are exceptionally grateful to all our supporters, sponsors, staff, and volunteers who help us deliver our work year after year.

Most of all though I would like to thank the families that we serve. Their strength continues to be my personal inspiration and motivation.

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

STAFF:

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

MEDICAL ADVISORY BOARD 2021/2022

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 2021/2022

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

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

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

RETIRING MEDICAL ADVISORY BOARD MEMBERS

Immense gratitude to the following Board Members who are retiring from the Advisory Board this year, for lending their expertise, guidance and dedication to the MPS community.

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

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

FUNDRAISING + EVENTS

ANNUAL FUNDRAISER



DEC 2021-JAN 2022

\$5,135

AMOUNT RAISED

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



MPS Society Programs

The Canadian MPS Society is proud to be able to offer financial assistance to our member families. Canadian resident members are eligible to apply for assistance with respite, home renovations, medical expenses and out-of-pocket medical care costs. We connect our families through our Family Referral Directory and our National Family Conferences.

Donations from kind and caring people like you enable us to provide a myriad of individualized supports to families in Canada that are affected with MPS and related Lysosomal Storage Disorders. **Please, help us help these families.**

Scan the URL code to donate online.



www.mpsociety.ca/donate



FUNDRAISING + EVENTS

DEC 2021-JAN 2022

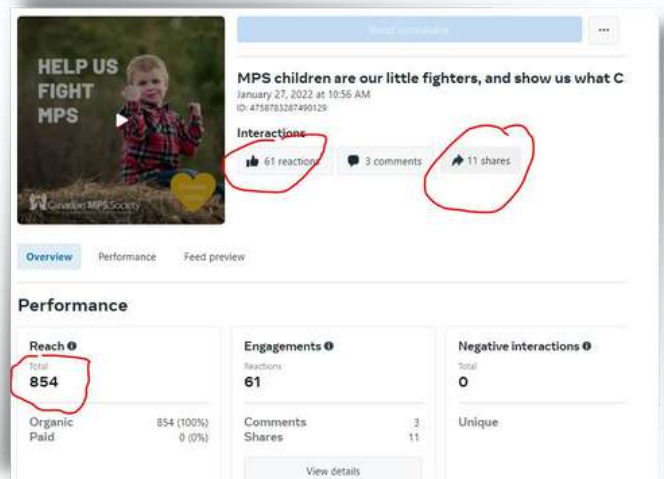
ANNUAL FUNDRAISER

x8

INCREASE IN FACEBOOK REACH



A social media campaign was also launched as part of the annual fundraiser, with posts designed to engage and raise awareness going out several times a week for the Dec-Jan period.



FUNDRAISING + EVENTS

INTERNATIONAL MPS AWARENESS DAY

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.

19

ICONIC LANDMARKS ACROSS CANADA LIT UP

in blue and yellow on and leading up to May 15, International MPS Awareness Day.



Feed preview



FUNDRAISING + EVENTS

RARE DISEASE DAY + GIVING TUESDAY



“GIANNA'S DISEASE MAY BE RARE, BUT TOGETHER WE ARE STRONG.” - CRISTINA CHIAPETTA, MOTHER



The Canadian MPS Society was proud to be part of Canada's Rare Voices 2022. This year, Gianna Rodorigo's story, the first child diagnosed with MPS I through newborn screening in Canada, was shared by Atlas Content Studio in the rare disease day special segment ('Canada's Rare Voices') in the Toronto Star.



Sponsored ads ran on Facebook and Instagram on behalf of the Canadian MPS Society. They showed up in the 'wild', on the Facebook newsfeeds of Canadians who don't already follow the Can MPS page helping to bring in new audiences for our pages.

The segment also captured the opinion of expert Dr. John Mitchell, a pediatric endocrinologist at the Montreal Children's Hospital. Cristina. Gianna's mother, said “Newborn screening saved Gianna's life... We want to see MPS I on the newborn screening panels across Canada and the world.”



FUNDRAISING + EVENTS

LANDMARK LIGHTING

The iconic sites that lit up for MPS Day included:

Alberta

City of Red Deer's City Hall
Calgary Tower

British Columbia

BC Place, Vancouver (from sunset)
Canada Place Sails of Light, Vancouver
Fitzsimmons Creek Bridge, Whistler
Vancouver City Hall
Burrard Street Bridge
Victoria Street Bridge, City of Trail
Science World at TELUS World of Science, Vancouver



Ontario

Brant Street Pier, Burlington
City Hall Cambridge sign and pedestrian bridge
Civic Centre Clock Tower, Mississauga
City Hall of Kingston
CN Tower
Fred A. Lundy Bridge, Town of Newmarket
Niagara Falls
Toronto 3D Sign
Ottawa Sign, York Street at Sussex Drive
Riverwalk Commons, Water Street, Town of Newmarket



FUNDRAISING + EVENTS

A GLOBAL CAMPAIGN - CUT TO THE CHASE



The Canadian MPS Society was proud to partner 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 rolled out a multichannel campaign “Chase the Signs” to help people identify the key MPS symptoms and to raise awareness of the urgency to reach a diagnosis.

The main messaging was - An early diagnosis means earlier treatment leading to better outcomes.

Animations, videos and social posts were distributed as part of this international campaign. People were invited to follow us on [Facebook](#), [Instagram](#) or [LinkedIn](#). share our posts and help us CUT TO THE CHASE.



FUNDRAISING + EVENTS

FACEBOOK TAKEOVER WITH

RARE **REVOLUTION** MAGAZINE

The Canadian MPS Society partnered with Rare Revolution Magazine and participated in a social media Facebook takeover on MPS Day, May 15. Rare Revolution Magazine posted social media posts and videos to their international followers throughout the day increasing our reach.

SOCIAL MEDIA CAMPAIGN RESULTS:

3.6 K

people reached

+633%

increase in Facebook visits



http://

500

visits to the website for
Canadian MPS Society



FUNDRAISING + EVENTS

FACEBOOK FUNDRAISERS

Hilary Rosen, a Canadian MPS Society member, met her goal of raising \$5K for the Canadian MPS Society, through the raffle she launched for MPS Awareness week. Hilary raised a further \$5K with a birthday fundraiser. Thank you to all who generously donated, shared the campaign and shared their stories. As a community, we are all in this together.



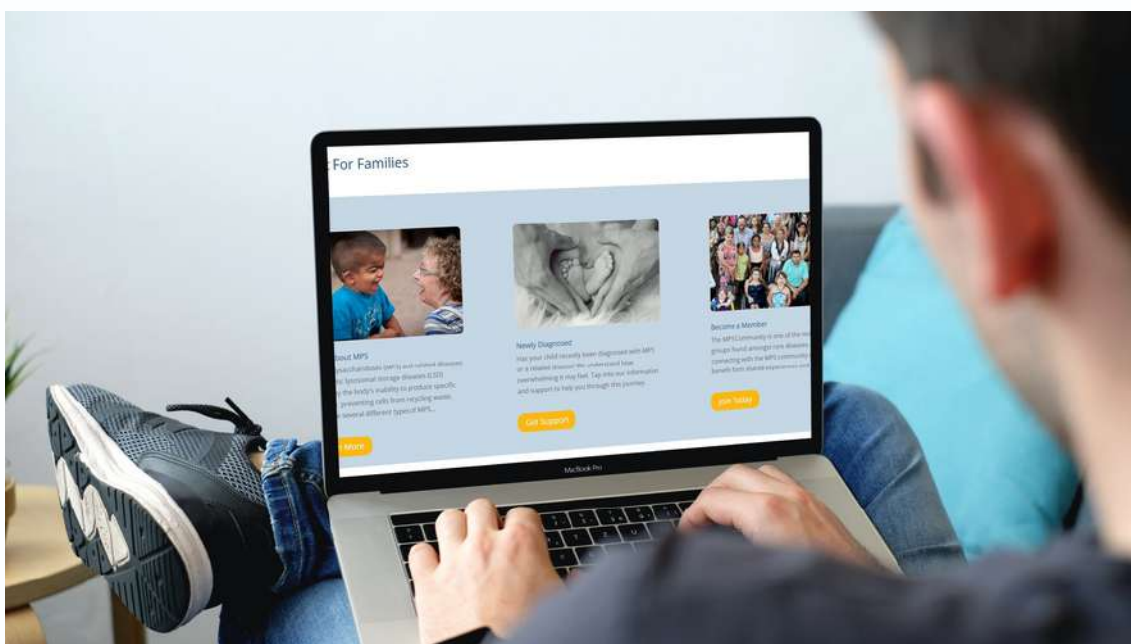
IMPROVING OPERATIONS

A NEW WEBSITE FOR THE CANADIAN MPS SOCIETY



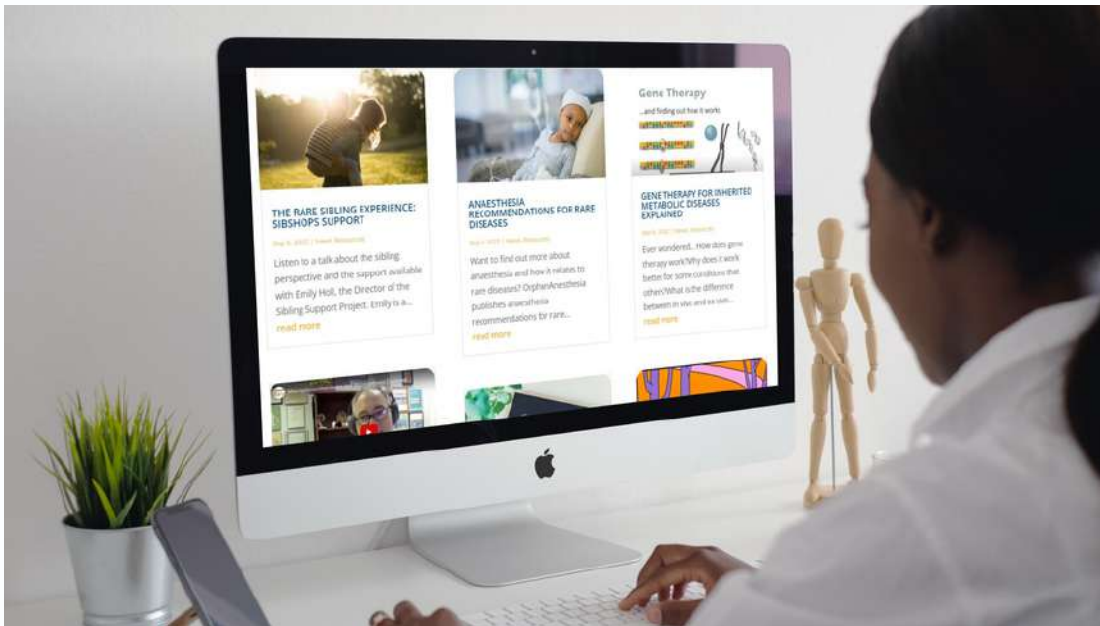
There was a need to develop a new website as due to technical difficulties we were no longer able to update the old one. We took this as an opportunity to refresh the whole layout. While much of the work was done in this fiscal year with a soft launch, the official announcement went out in May 2022.

The new simplified, refreshed architecture is intended to be more intuitive, user friendly, with improved navigation so visitors can find the information they are looking for quicker.

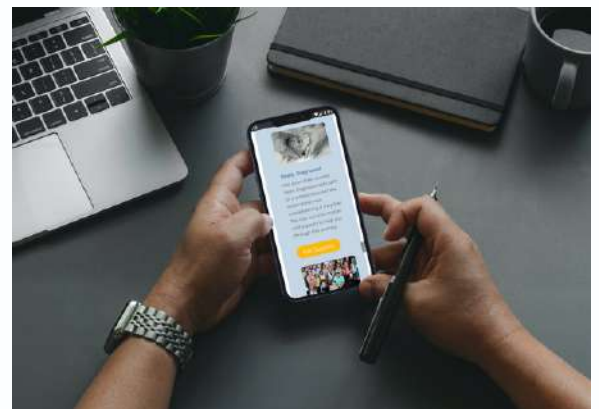


IMPROVING OPERATIONS

A NEW WEBSITE FOR THE CANADIAN MPS SOCIETY



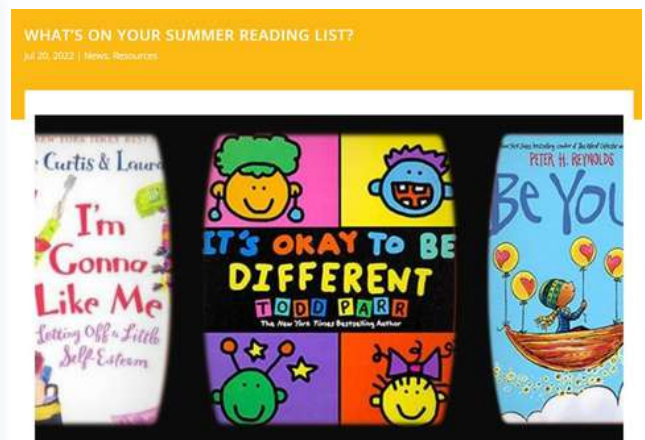
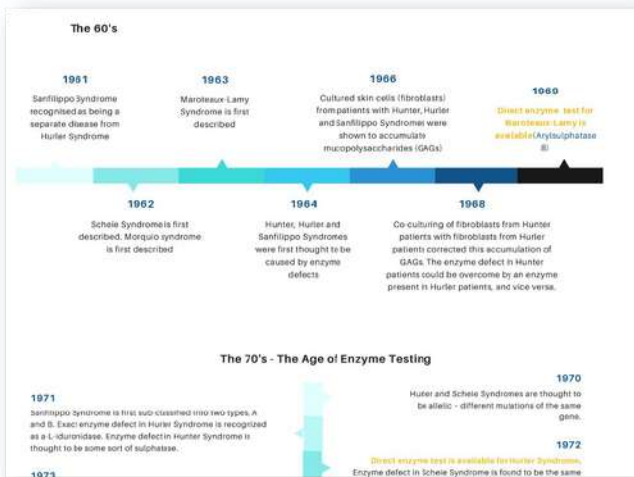
The new website has been designed to be viewable on a desktop, tablet or smartphone.



IMPROVING OPERATIONS

A NEW WEBSITE FOR THE CANADIAN MPS SOCIETY

We continue to add more resources and develop more educational resources to benefit members.



NEW COMPASS PROGRAM



Since the Covid-19 pandemic, it has been evident through requests for assistance to the Society that it is a strategic imperative to have formal mental and emotional support for parents and caregivers of MPS and related diseases children and adults. These supports need to be in place from first point of contact with the Canadian MPS Society to post bereavement. As a result, the Canadian MPS Society and our parent/caregiver advisors are currently developing the Compass program.

The Compass program will provide tailored and timely (proactive and real-time) access to peer support, self-help and care, spiritual, and formal mental health services reflective of an individuals' current place on the disease continuum, from pre-diagnosis to post-bereavement.

Program Goal

All Canadians affected by MPS and related Lysosomal Storage Disorders (LSD) feel equipped and supported for their MPS journey.

Objectives

Provide access to tools, information and support to improve the physical, mental, spiritual and emotional health of all Canadians affected by MPS and related LSD by December 2024.

Create a community where shared experiences and empathy can help improve the physical, mental, spiritual and emotional health of all Canadians affected by MPS and related LSD by December 2024.

COMPASS PROGRAM ADVISORY COMMITTEE

An Advisory Committee for the Compass program was established, comprising 19 members of The Canadian MPS Society, from across Canada and who reflect the entire MPS journey.

To date, the advisory group has developed program guiding principles and values, identified desirable tools and supports, and defined key stages in the caregiver journey where support is desired.

The project team has aligned the journey with tools and supports that the Compass program may provide.

- Pre-diagnosis (e.g. create digital pathways to information)
- Diagnosis (e.g. tips on how to tell family, coping with diagnosis grief, connect to mentor)
- Day-to-Day Living (e.g. foods, exercise, connection, helpful equipment, what to expect at specific ages)
- Surgeries (e.g. what to expect with specific surgeries, mentor, tips to handle stress, MPS-outreach, meal support, accommodation support)
- Puberty/Maturity (e.g. what to expect, equipment considerations, coping skills)
- Adulthood (e.g. community connection, coping skills)
- Disease Progression (e.g. crisis support, house cleaning, family/couple counselling)
- End of Life (e.g. list of legal considerations, spiritual support, crisis outreach, stress management)
- Post Bereavement (e.g. celebration of life, continued community outreach, memorializing, anniversaries, grief)

The next stage will be the development of content (including a web portal), tools, programs and partnerships.

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:



RESPITE



MOBILITY APPLIANCES



PHYSICAL THERAPY



UNINSURED MEDICAL EXPENSES



FINANCIAL ASSISTANCE PROGRAM



The transition to the adult world is often marked by great changes. Loïc could not escape it. After having lived for 9 years at the Montreal Children's Hospital, he had to move at the age of 18 to the Camille-Lefebvre Pavilion, a long-term care center. This move entailed several expenses to readapt his environment to his special needs.

Your financial assistance allowed us to buy him an electric table so that he could use it to do his homework for his college studies in computer science. You also helped us adapt his iPad stand, which could no longer be attached to the base of his new bed. Loïc's iPad is a precious and indispensable tool for a 19-year-old paraplegic young man. Without its support, he could no longer have access to his virtual world and his friends overseas.

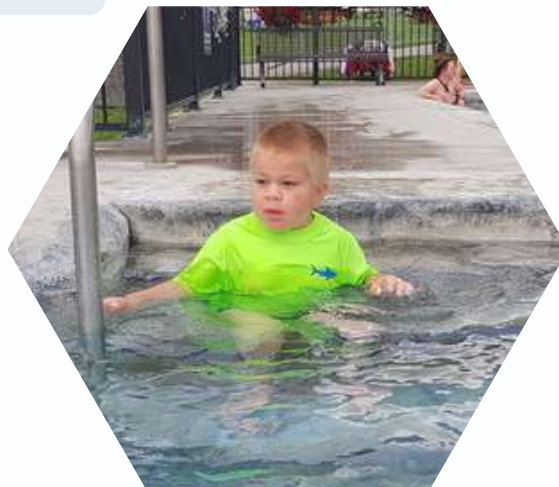
How lucky to have you in our life! Without your financial support, we could not have adapted everything! Thanks! ~ Anik Pilon



FINANCIAL ASSISTANCE PROGRAM



“Our family very much appreciated your organization with HUGE support of our son Misha. Thank you so much for the financial support, our family was able to enjoy an amazing vacation this summer in BC and Toronto. It's been great!!!
~ Aleksandr Bursov”



FINANCIAL ASSISTANCE PROGRAM

“Our little Anaïs was diagnosed on November 18, 2019, with Morquio syndrome. She was just 5 years old. This date will always be remembered as a mom. It was like a happy and sad feeling at the same time. We have been looking for help for years without consideration from our Quebec health system. The diagnosis was the event that finally opened the doors to help and listening from health professionals. For our part, we have applied for funding for the program "direct financial support through the COVID-19 Extended / Emergency Financial Assistance Program (CFAP)." This help has greatly helped us to defray the costs of accommodation and hotel for our visits to hospitals in Montreal. We live a 6-hour drive from Montreal and the Manoir Ronald Mc Donald was closed during our visits due to Covid isolation. No need to say that a week without pay, 1200 km by car to get to Montreal, the hotel costs for 4 nights and the restaurant costs are exorbitant for our family. Thank you to the Canadian Society for MPS for this financial assistance which had greatly helped us. - MÉLISSA POTVIN”



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 \$35,000 +

Takeda Pharmaceuticals
Sanofi
BioMarin Pharmaceutical Canada Inc.

DONATIONS OF \$20,000 +

Benevity Community Impact Fund
Gentle, Cassidy

DONATIONS OF \$10,000 +

Abeona Therapeutics
Crowley Heating & Air Conditioning

DONATIONS OF \$4000-\$9,999

Orchard Therapeutics
Paypal
REGENXBIO Inc.
Rosen, H
Ultragenyx

DONATIONS OF \$1000-\$3,999

Azafaros
BioTalent Canada
Innomar
Limestone District School Board
Maize Siding & Eavestroughing Inc.
Mode Choc
Scotiabank Race Roster
Roth, Grace
The Calgary Foundation
Trott, N

DONATIONS OF \$500-\$999

Boland, B & G
Canada Helps
CHIMP
Dalfino, Alessandro
Di Ilio, R & L
Linton, E & R
United Way - Greater Toronto



THANK YOU TO OUR DONORS



DONATIONS OF \$0-\$499

Angel, Kim
Bankert, Ralph & Cathy
Beehan, James
Blanchard, Natalie
Bley, Annette
Boland, S
Bowden, Gregory
Bracewell, Jane
Burns, Nicole
Burt, Michelle
Byrne, J & T
Byrne, T
Carter, L
Chartier, B & C
Colaianne, Donna
CUPW Hamilton
Farnand, Debbie
Friel, Karen
Fuchihara, Ken & Sue
Fudge, Brenda & Gary
Gambrill, B & R
Gunton, J
Haggerty, Braden
Halliday, Carolyn
Hamberger, Hans
Haney, Mary Ann
Hans-Pouliot, Jeremie
Harkins, K
Holmwood, Marlene

Husberg, P
Kaweski, V & F
Knox, Elizabeth & Derek
Lanese, S & N
Lariviere, Julie
Lariviere, Sophie
Lee, Kaitlyn
Lee, Kam
Lee, Katie
Matyas, Andrew
McAlear, Laura
Miller, Dianne
Montalban, Mary-Jo
Novenski, Beverly
Ogg, Sharon
Olson, Anna
Palmer, Robert
Peckford, Margaret
Perry, R & E
Potter, Gina
Power, Paul
Preece, Cathy
Prescott, Russell
Provincial Employees
Community Service Fund

Rae, Ian & Lesley
Reeds, Lynda
Regimbald, Mathieu
Ross, Michael
Rusak, Carol
Scardamaglia, Devan
Shields, Alice
Shiels, D
Simpson, S
Sinclair, Benjamin
Snow, M
Stoll, J
Thermolec Ltd.
Tucker, Linda
Tuff, David
United Way - Greater
Moncton
Walters, S
Wednesday Friday Curling
Club
Wharton, J & K
Wong, Dominic
Anonymous Donor

FINANCIAL STATEMENTS

THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF FINANCIAL POSITION
AS AT MARCH 31, 2022

	2022	2021
ASSETS		
CURRENT		
Cash	\$ 180,031	\$ 240,245
Accounts receivable	-	84,578
Government remittances receivable	11,864	9,970
Prepaid expenses and deposits	2,230	15,251
	\$ 194,125	\$ 350,044
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	\$ 19,580	\$ 23,294
Government remittances payable	5,582	8,534
Deferred revenue (Note 3)	-	155,462
	25,162	187,290
CANADA EMERGENCY BUSINESS ACCOUNT LOAN (Note 5)	40,000	40,000
	65,162	227,290
NET ASSETS	128,963	122,754
	\$ 194,125	\$ 350,044
NET ASSETS, BEGINNING OF YEAR	\$ 122,754	\$ 144,715
EXCESS (DEFICIENCY) OF REVENUE OVER EXPENSES FOR THE YEAR	6,209	(21,961)
NET ASSETS, END OF YEAR	\$ 128,963	\$ 122,754

FINANCIAL STATEMENTS

THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF OPERATIONS
FOR THE YEAR ENDED MARCH 31, 2022

	2022	2021
REVENUE		
Donations and grants	\$ 219,168	\$ 72,459
Conference	50,699	-
Fundraising	7,371	13,523
Other	1,152	-
Membership fees	37	100
MPS II Research Fund	-	89
	278,427	86,171
EXPENSES		
Meetings	113,063	6,920
Salaries and contract fees	88,266	81,282
Office and miscellaneous	57,162	41,486
Fundraising	37,858	2,072
Professional fees	38,117	40,100
Research grants	14,000	10,000
Computer	9,066	12,672
Family Assistance Program	8,394	8,732
Telephone and internet	2,433	2,615
Travel	2,390	1,018
Advertising, communication and promotion	1,604	2,394
Insurance	1,562	1,479
Office lease	1,560	1,560
Conference	1,138	2,819
Printing and postage	660	601
Membership dues	200	50
	377,473	215,800
DEFICIENCY OF REVENUE OVER EXPENSES FROM OPERATIONS	(99,046)	(129,629)
OTHER INCOME		
ECSF funding	60,462	37,038
Special projects	30,476	16,635
Canada Emergency Wage Subsidy (Note 4)	6,497	26,621
Canada Summer Jobs Subsidy (Note 4)	4,766	-
Consultation fees	2,005	-
Private summer student reimbursement	1,049	7,374
Canada Emergency Business Account forgivable portion (Note 5)	-	20,000
	105,255	107,668
EXCESS (DEFICIENCY) OF REVENUE OVER EXPENSES FOR THE YEAR	\$ 6,209	\$ (21,961)

FINANCIAL STATEMENTS

THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED MARCH 31, 2022

	2022	2021
OPERATING ACTIVITIES		
Excess (deficiency) of revenue over expenses for the year	\$ 6,209	\$ (21,961)
Item not affecting cash:		
Canada Emergency Business Account forgivable portion	-	(20,000)
	6,209	(41,961)
Changes in non-cash working capital:		
Accounts receivable	84,578	(55,916)
Government remittances receivable	(1,894)	694
Prepaid expenses and deposits	13,021	(728)
Accounts payable and accrued liabilities	(3,714)	2,989
Deferred revenue	(155,462)	110,462
Government remittances payable	(2,952)	3,295
	(66,423)	60,796
	(60,214)	18,835
FINANCING ACTIVITY		
Canada Emergency Business Account loan	-	60,000
(DECREASE) INCREASE IN CASH FLOW	(60,214)	78,835
CASH, BEGINNING OF YEAR	240,245	161,410
CASH, END OF YEAR	\$ 180,031	\$ 240,245

FINANCIAL STATEMENTS

THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
NOTES TO FINANCIAL STATEMENTS
FOR THE YEAR ENDED MARCH 31, 2022

3. DEFERRED REVENUE

	2022	2021
Balance, beginning of year	\$ 155,462	\$ 45,000
Add: contributions received during the year	-	147,500
Less: amounts recognized as revenue during the year	(155,462)	(37,038)
	\$ -	\$ 155,462

4. WAGE SUBSIDIES

In response to the COVID-19 health pandemic, the Society took advantage of programs providing relief. As at March 31, 2022, the Society received the Canadian emergency wage subsidy and the Canada summer jobs subsidy from the federal government for an amount totaling \$6,497 (2020 - \$26,621) and \$4,766 (2020 - \$Nil) respectively. The amounts have been included as other income in the statement of operations.

5. 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.

WHAT'S NEXT

NEW YEAR, NEW GOALS



NATIONAL FAMILY CONFERENCE

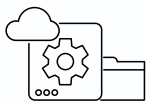


Since 1984, The Canadian MPS Society has been providing support and education to families across Canada devastated by Mucopolysaccharide (MPS) and related diseases. Our bi-annual conferences are extremely important to our members as they represent an opportunity – sometimes the only opportunity – for affected individuals to meet each other, and for parents to meet with other parents whose children are affected by the same disease. The information-sharing at our conferences between families and professionals alike is instrumental in providing opportunities for those affected to achieve the best quality of life possible.

We're delighted to announce that planning for the 2023 in-person National Family Conference is underway.

Save the date: July 21 - 23, 2023

Location: Calgary, Alberta



CANADIAN PEDIATRIC MPS REGISTRY

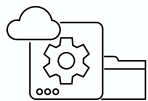


A patient-oriented longitudinal registry designed to support innovative observational and intervention research that will ultimately improve care and outcomes for patients with MPS is currently in development with INFORMRARE - www.informrare.ca. The registry is anticipated to launch in early 2023.

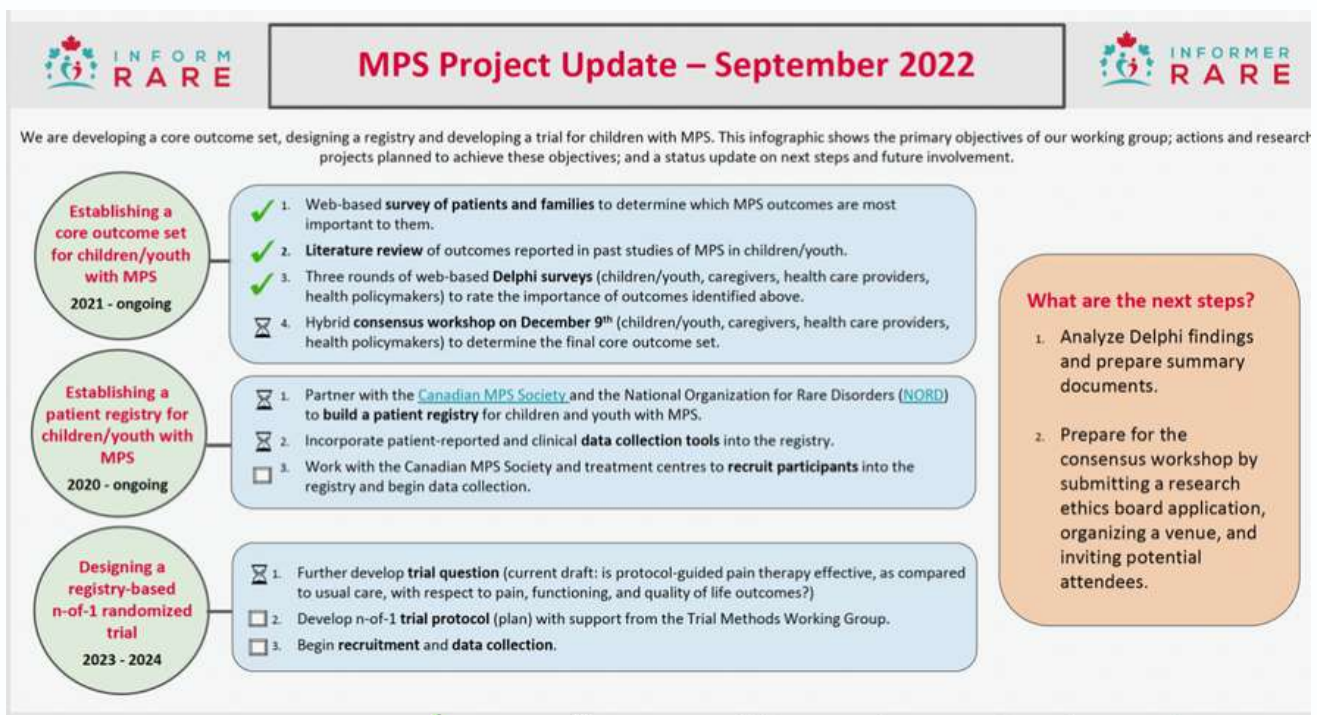
For eligible participants (children aged 18 years or younger receiving care in Canada for MPS) and with informed consent, the registry will collect and store patient, caregiver, and clinician reported data informed by core outcome sets for MPS. Participants will own their own registry data and have the option to share their data with researchers meeting prescribed criteria.



WHAT'S NEXT



CANADIAN PEDIATRIC MPS REGISTRY



#ignite
hope



 *Alone we are rare but
together we are strong.*

CONTACT US!

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