



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

## 2020-21 Annual Report



## Vision

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

## 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.

## Values

- ♥ Community & Compassionate support
- ♥ Health & Wellness
- ♥ Justice & Equality
- ♥ Education & Awareness
- ♥ Research & Innovation
- ♥ Accountability & Transparency



## Message From The Board Chair



**Melissa Bilodeau**  
Board Chair Canadian  
MPS Society

Dear members/Cher membres,

Another year gone by and another one shaped by the COVID-19 pandemic. The Society has remained there for you and has put in place measures to financially assist our members as reflected in the financial statements. We have been able to do so because of the pro-activeness of our employees and the support given from the federal government through the Emergency Community Support Funds.

Even though things have been different, the Society has been striving to become better and adapt to change. We hope to be able to bring more in-person events soon.

*Une autre année passée et une autre façonnée par la pandémie de COVID-19. La Société est restée là pour vous et a mis en place des mesures pour aider financièrement nos membres comme en témoignent les états financiers. Nous avons été en mesure de le faire grâce à la proactivité de nos employés et au soutien apporté par le gouvernement fédéral par le biais des fonds d'urgence de soutien communautaire.*

*Même si les choses ont été différentes, la Société s'est efforcée de s'améliorer et de s'adapter au changement. Nous espérons pouvoir organiser bientôt d'autres événements en personne.*



## Message From The Executive Director



**Kim Angel**  
Executive Director  
Canadian MPS Society

In life, we all face difficulties, challenges and setbacks but resilience is what determines whether we fight through it and grow, or whether we cave in and let those challenges defeat us.

The past year has been an exercise in resilience in the face of adversity. The pandemic has created a new world of elevated fears and stresses, isolation and grief. I often find myself making parallels between the pandemic and the reality of the MPS diagnosis and ongoing management. Both an MPS diagnosis and a global pandemic come with feelings of isolation, devastation and frustration, but in these moments of adversity, we define our character and values. Every single one of the individuals and families that I am fortunate to work with at the Canadian MPS Society are those who inspire me to face my own hardships with courage and strength. The members of this organization have taught me how to lead with determination and fortitude, as I watch them do the same and more in their own lives. Being a part of the Canadian MPS Society has taught me the true values of empowerment and resilience, and for that I am eternally grateful.

I am more grateful than ever for the incredible team of staff members who consistently provide exceptional service, and who have demonstrated outstanding commitment, flexibility and perseverance during the pandemic. Our volunteers have also shown amazing dedication, continuing to give extraordinary amounts of their time and energy to support our work. Our volunteer Board of Directors has done exceptional work in providing governance and support to the Society, particularly this past year as we responded to the pandemic. I thank each and every staff member, volunteer and Board member for their tireless efforts, now and always.

Finally, many thanks to you, our friends, donors, partners and funders. You sustain the work we do and ensure that we can continue supporting our community members who need us most.

I hope you and your loved ones are staying safe and well, and we look forward to seeing you again in person as soon as we are able to.

A handwritten signature in black ink, appearing to read 'Kim Angel'.

# Medical Advisory Board

## Lorne Clarke, MD, CM, FRCPC

Director, Provincial Medical Genetics Programme

Department of Medical Genetics

BC Children's Hospital

**Vancouver, BC**

## Pranesh Chakraborty

Metabolic Physician, CHEO

Medical Director, Newborn Screening Ontario

Newborn Screening Ontario

**Ottawa, Ontario**

## Serge Melancon

*MD*

Biochemical Genetics Unit

Montreal Children's Hospital

**Montreal, QC**

## John Mitchell

*MD*

Biochemical Genetics Unit

Montreal Children's Hospital

**Montreal, QC**

## Eva Mamak,

*PhD*

Department of Neuropsychology

Hospital for Sick Children

**Toronto, ON**

# Medical Advisory Board

## 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**

## J.T.R. Clarke

*MD, Ph.D. (Retired)*

The Hospital for Sick Children  
(formerly)  
**Toronto, ON**

## Aneal Khan

*MD*

Inherited Metabolic Clinic Alberta  
Children's Hospital  
**Calgary, AB**

## 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 University of Toronto,  
Assistant Professor – Department of  
Paediatrics University of Toronto  
**Toronto, ON**

## Sarah Dyack

*MD, FRCPC, FCCMG*

Division of Medical Genetics, Associate  
Professor Dalhousie University,  
Department of Pediatrics, Division of  
Internal Medicine  
**Halifax, NS**

## Directors, Medical Advisory Board & Staff

### Board of Directors

Melissa 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

Ruben Krishnamurthy  
Ontario  
Mannidosis - Parent

Mojan Zehtabchi  
Toronto, Ontario  
Naturopathic Doctor

### Staff

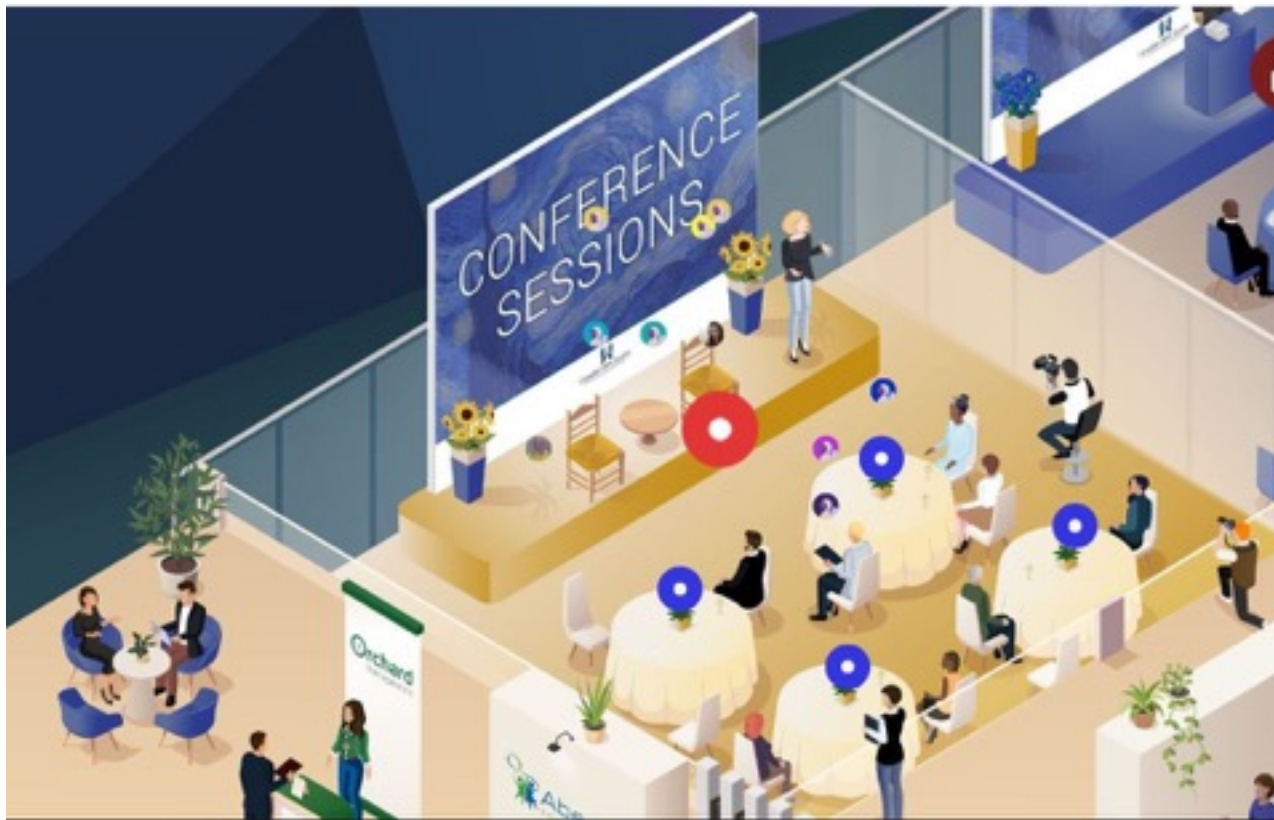
Kim Angel  
*Executive Director*  
[kimangel@mpsociety.ca](mailto:kimangel@mpsociety.ca)

Priyadarshini Ramakrishnan  
*Special Projects/Research Assistant*  
[priya@mpsociety.ca](mailto:priya@mpsociety.ca)

Alexandra Wyatt  
*Special Projects & Initiatives Coordinator*  
(Employed Jan 2021 - Sept 2021)  
[alexandra@mpsociety.ca](mailto:alexandra@mpsociety.ca)



## Fundraising & Events 2020-21



The Canadian MPS Society offered all affected individuals & families, healthcare providers and industry partners, the opportunity to participate in this conference. Despite the virtual nature of this conference, we were still able to see and feel the magic of the meaningful connections and friendships that were formed from this event.



### 2021 VIRTUAL National Family Conference

The Canadian MPS Society's Virtual National Family Conference was an opportunity for all members of the MPS community in Canada, and around the world to come together for three days of educational and networking events.

Our team carefully curated three days of informative sessions covering topics in MPS health policy, Canadian research updates and disease management for all aspects of the disorder.





## Vision

The Canadian MPS Society's National Family Conference is a pivotal opportunity for families to learn about the rapidly changing discoveries about their child's disease and health in terms that are easily understandable. Our vision for the 2021 National Family Conference was to execute and deliver meaningful educational and networking sessions to our member-base. We want to ensure that families. We want to equip our members with the most up to date information, along with meaningful life-long connections. Mutual support and kindness are the pillars of our small community, and this conference gives existing and new members the chance to feel unified in the fight against this disease.



## 2021 National Family Conference

Thank you for attending!

We hope you enjoyed the conference, keep an eye out for your National Family Conference SWAG packages that will be arriving shortly!



Don't forget to visit our **online** NFC event store!



## Fundraising & Events 2020-21

### 2021 VIRTUAL Gala Fundraising Event

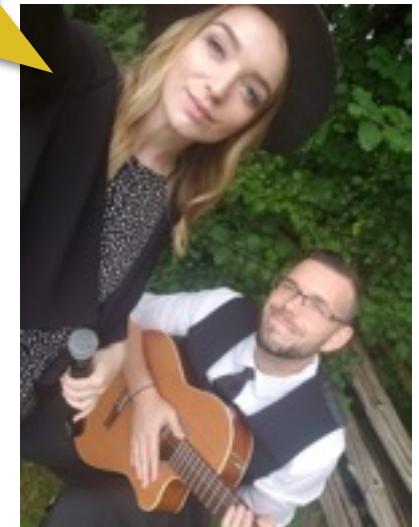
On October 2nd, 2021, guests from across Canada will join together virtually to raise funds and awareness at the Canadian MPS Society's Annual Fundraising Gala!

With valuable resources, educational presentations, and inspirational experiences to support the courageous children and families affected by MPS and related diseases across Canada, we hope to raise much needed funds to support MPS families across Canada.

**A big THANK YOU to all our Conference Sponsors, Presenters and Volunteers - we are looking forward to celebrating with all of you!**



We will be presenting our  
**RARE Star Awards** also!



**Amazing Performances by: Shawn Bush & Em Lanther**

**We hope to see you at our Gala...**

**A RARE  
& Starry Night**

**October 2nd, 2021**



# COVID-19 Relief Packages

## COVID-19 Extended/Emergency Member Support & Assistance Project

The COVID-19 Extended/ Emergency Member Support and Assistance Project was developed to provide assistance to our members in the following ways.

- \* Delivery of PPE and care kits to our members;
- \* An online education and connection series;
- \* An online COVID-19 resource guide;
- \* Direct financial support through the COVID-19 Extended/Emergency Financial Assistance Program (CFAP).

We were able to provide **over \$20,000 of direct financial assistance** to our affected members



# COVID-19 Online Resource Guide

We also launched a **COVID-19 Online Resource Guide**. This comprehensive online resource guide has timely information on medical care, COVID-19 & MPS, care for MPS affected individuals, federal & provincial financial supports available to families, mental health and counselling resources and at home educational, recreational, physical & emotional well being resources for children.

**As a part of “The Canadian MPS Society COVID-19 Emergency Member Support Program”,** we organized ‘Townhall Tuesdays’, a series of virtual member support session. We invited experts from rare disease medicine and mental health to facilitate the sessions. We have conducted four online interactive sessions to provide appropriate medical information on COVID-19 and much more.





## Rare Disease Day

This year Canadian MPS Society raised awareness on newborn screening for MPS #NBS4MPS. This Rare Disease Day saw our members sharing their journey and life with the world and raising voice for newborn screening for

### MPS. Canada's Rare Voice

The **Canadian MPS Society** was featured as part of **Canada's Rare Voices** alongside the Canadian Organization for Rare Disorders, the Canadian Association of Pompe, the Canadian Fabry Association, and the National Gaucher Foundation of Canada, among many others, via the [TheStar.com](https://www.thestar.com).



**Give the Gift of Hope**  
Your donations directly support children like Arielle Cameron - Serviss.

**Donate Today**

[www.mppsociety.ca/donate](http://www.mppsociety.ca/donate)







# Rare Disease Day

Matteo's diagnostic journey with MPS-1H was shared by Atlas Content Studio in the rare disease day special segment ('Canada's Rare Voices') in Toronto Star.

Matteo's mother Angie, shared their experience on how early diagnosis played crucial role in Matteo's treatment in the article 'Time is everything for rare, progressive diseases'. The segment also captured the opinion and views of experts including Dr. Pranesh Chakraborty, Children's Hospital of Eastern Ontario (CHEO)



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

Funds raised through donations and special events help fund research that provides **hope for a brighter future** for all children born with lysosomal diseases.

**Matteo**  
MPS IH Age 11



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



## MPS Awareness Efforts

### Rare Colors

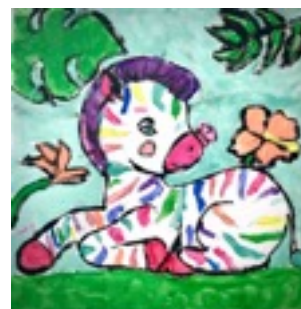
We organized "Rare Colors", a creative & interactive rare disease & MPS awareness event showcasing our rare MPS talents.



Anais Potvin



Dedicated to our beauty  
Danika, MPS III-A Rebecca



Flavie Potvin 11y/o  
Big sister Anais

### Anisa's Voice

Atlas Content Studio shared Anisa Elder's voice on social media platform of Patient Voice. Her enthusiasm and joyful spirit definitely inspired us all.



### A Story in Progress

"When I encounter difficulties, I sometimes struggle, but it is this experience that makes me stronger; that makes me unique; that makes me valuable."

Our Chair, Mélissa Bilodeau, shared her inspiring journey with MPS IVA on the Rare Disease Day global platform.

<https://www.rarediseaseday.org/stories/7095>



# International MPS Awareness Day

The Canadian MPS Society organized a number of events through the month of May, to raise awareness and honour those living with this condition. Many thanks to all of our families who participated in this campaign to help raise awareness of MPS.

## Landmark Lighting

The MPS colours were shining bright across Canada on International MPS Awareness Day! The following Canadian monuments were lit up in celebration!

### British Columbia:

Bastion, Nanaimo, BC Place, Bloedel Conservatory, Canada Place Sails of Light, Fitzsimmons Covered Bridge, Port Moody, Science World at TELUS World of Science, Vancouver Convention Centre's District Markers & Olympic Cauldron & Victoria Street Bridge





## Landmark Lighting

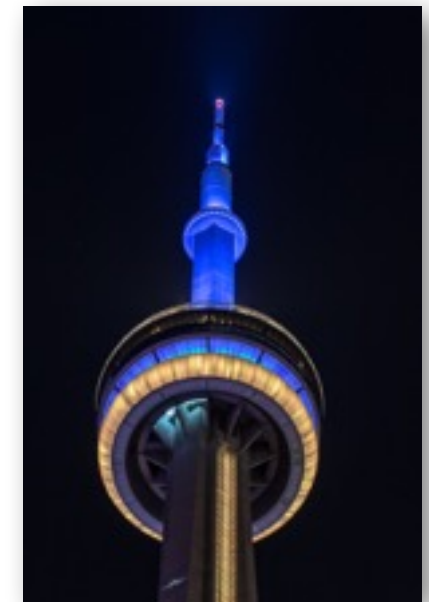


### Alberta:

Calgary Tower, City Hall of Lethbridge, City Hall of Red Deer, Edmonton Bridge & McMahon Stadium

### Saskatchewan:

SaskTel Centre



### Ontario:

Brant Street Pier, Canada Life (London & Toronto), City of Cambridge, City Hall in Kingston, City Hall of London, City Hall Clock Tower Brampton, CN Tower, Craigs Crossing, Fred A. Kundy Bridge, Hamilton Signature Sign, JA Taylor Building, Mississauga Civic Center, Niagara Falls, Riverwalk Commons, RBC Place (London), Toronto 3D sign, Town Hall, Oakville, Welland Canal Bridge.





# International MPS Awareness Day

## Member Highlight

The Canadian MPS Society launched a digital campaign to celebrate International MPS Awareness Day on May 15th, 2021 featuring photos of our kids and families





# International MPS Awareness Day



On International MPS Awareness Day, our partners at Atlas communications launched an animated video on MPS I-H.

[Click Here to watch the video.](#)



## Your Donations At Work

**The Canadian MPS Society receives no government funding and relies on private 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 \$95,000 +

- ♥ Community Foundations Canada
- ♥ Takeda Pharmaceuticals

### Donations of \$25,000 +

- ♥ Receiver General for Canada-rebate

### Donations of \$5500 - \$10,000

- ♥ Paypal
- ♥ BioMarin Pharmaceutical Canada Inc

### Donations of \$500 - \$1000

- ♥ Wyatt, A
- ♥ Byrne, T
- ♥ Langerak, D & B
- ♥ Linton, E & R
- ♥ Phillips, E
- ♥ Silveri, E
- ♥ Canada Helps
- ♥ United Way - Lower Mainland
- ♥ Amin, N
- ♥ Roth, Grace
- ♥ Trott, N

### Donations of \$1500 - \$3000

- ♥ Young, Dr. Robert
- ♥ Race Roster
- ♥ Canada Running Series Inc.
- ♥ Parker, Lloyd & Joanne
- ♥ Benevity Community Impact Fund
- ♥ The Calgary Foundations

### Donations of \$3000 - \$5000

- ♥ Regenexbio Inc
- ♥ Rose, H
- ♥ Abeona Therapeutics
- ♥ BioTalent Canada





## Your Donations At Work

**We are delighted to share with you the tremendous impact donors have made in the lives of our affected member families across the country.**

### Donations of \$0-\$499

- ♥ Lariviere, J
- ♥ MPS Europe
- ♥ Byrne, J & T
- ♥ Clarke, Lorne
- ♥ Fraser, Bruce
- ♥ Haggerty, Braden
- ♥ Lanese, S & N
- ♥ Nelis, Mary
- ♥ Dewarle, Patrick
- ♥ McFarland Industrial
- ♥ Cairns, A & A
- ♥ Chartier, B & C
- ♥ Cousineau - Spina, Joanne
- ♥ Di Illo, Kaitlyn
- ♥ Harkins, K
- ♥ Husberg, P
- ♥ Acheson, Janet
- ♥ Perry, R & E
- ♥ Walters, S
- ♥ Wharton, J & K
- ♥ Desjardins Financial Security
- ♥ Scardamaglia, Devan
- ♥ Di Illio, R & L
- ♥ Kaweski, V & F
- ♥ Boland, S
- ♥ Angel, Kim
- ♥ Anandan, Manoj
- ♥ Boone, Terri Lynn
- ♥ Chng, Beth
- ♥ Knox, Elizabeth & Derek
- ♥ Tiede, Cheryl
- ♥ Clare, W & J
- ♥ Johnson, Melody
- ♥ Krause, Lois
- ♥ Parent, C
- ♥ Sachs, S & Canada, J
- ♥ Brager, L & Ray, I
- ♥ Pahlavan, Nasrin
- ♥ Sampson, Lena
- ♥ United Way - Greater Toronto
- ♥ Pickering, L
- ♥ Lesley, Ian & Rae
- ♥ Lariviere, Julie
- ♥ Provincial Employees Community Service Fund
- ♥ Boucher, Annie
- ♥ United Way - Calgary
- ♥ Farnand, Deborah Elizabeth
- ♥ Thermolec Ltd.
- ♥ Melocco, Bianca
- ♥ Roth, Dan & Lori
- ♥ Stoll, J
- ♥ Swift, John

## The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

### Statement of Financial Position as at March 31, 2021

#### ASSETS

##### Current

Cash

Accounts receivable

Government remittances receivable

Prepaid expenses and deposits

**2021**

\$240,245

\$84,578

\$9,970

\$15,251

**2020**

\$161,410

\$28,662

\$10,664

\$14,523

**\$350,044**

**\$215,259**

#### LIABILITIES

##### Current

Accounts payable and accrued liabilities

Government remittances payable

Deferred revenue (*Note 3*)

CANADA EMERGENCY BUSINESS ACCOUNT LOAN (*Note 4*)

\$23,294

\$8,534

\$155,462

\$227,290

\$122,754

**\$350,044**

\$20,305

\$5,239

\$45,000

\$70,544

\$144,715

**\$215,259**



## The Canadian Society for Mucopolysaccharide & Related Diseases Inc. Statement of Financial Position as at March 31, 2021

Net assets, beginning of year  
Excess (deficiency) of revenue over  
Expenses for the year

**Net assets, end of year**

	2021	2020
Net assets, beginning of year	\$144,715	\$173,198
Excess (deficiency) of revenue over Expenses for the year	(\$21,961)	(\$28,483)
<b>Net assets, end of year</b>	<b>\$122,754</b>	<b>\$144,715</b>



# The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

## Statement of Operations for the year ended March 31, 2021

### REVENUE

	2021	2020
Donations and grants	\$135,506	\$79,602
Fundraising	\$13,523	\$78,519
Membership fees	\$100	\$244
MPS II Research Fund	\$89	\$3,057
Conference	-	\$106,153
Dividend Income	-	\$1,191
	<b>\$147,218</b>	<b>\$268,766</b>

### EXPENSES

Salaries and contract fees	\$81,282	\$80,845
Office and miscellaneous	\$41,486	\$11,325
Professional fees	\$40,100	\$57,666
Computer	\$12,672	\$7,223
Research grants	\$10,000	\$12,000
Family Assistance Program	\$8,732	\$8,837
Meetings	\$6,920	\$70,352
Conference	\$2,819	\$342
Telephone and internet	\$2,615	\$3,008
Advertising, communication and promotion	\$2,394	\$572
Fundraising	\$2,072	\$33,106
Office lease	\$1,560	\$1,560
Insurance	\$1,479	\$1,479
Travel	\$1,018	\$8,695
Printing and postage	\$601	\$239
Membership dues	\$50	-
	<b>\$215,800</b>	<b>\$297,249</b>



# The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

## Statement of Operations for the year ended March 31, 2021

	2021	2020
<b>DEFICIENCY OF REVENUE OVER EXPENSES FROM OPERATIONS</b>	<b>\$68,582</b>	<b>\$28,483</b>
<b>OTHER INCOME</b>		
Canada Emergency Business Account	\$20,000	-
forgivable portion ( <i>Note 4</i> )	\$26,621	-
Canada Emergency Wage Subsidy		
	<b>\$46,621</b>	-
	<b>\$(21,961)</b>	<b>\$(28,483)</b>

# The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

## Statement of Cash Flows for the year ended March 31, 2021

	2021	2020
<b>OPERATING ACTIVITIES</b>		
Deficiency of revenue over expenses for the year	(\$21,961)	(\$28,483)
Item not affecting cash:		
Canada Emergency Business Account forgivable portion	(\$20,000)	-
	<b>(\$41,961)</b>	<b>(\$28,482)</b>
<b>Changes in non-cash working capital:</b>		
Accounts receivable	(\$55,916)	(\$17,158)
Government remittances receivable	\$694	(\$6,846)
Prepaid expenses and deposits	(\$728)	(\$12,137)
Accounts payable and accrued liabilities	\$2,989	\$7,167
Deferred revenue	\$110,462	-
Government remittances payable	\$3,295	\$3,734
	<b>\$60,796</b>	<b>(\$25,240)</b>
<b>INVESTING ACTIVITY</b>		
Sales of investments, net	<b>\$18,835</b>	<b>(\$53,723)</b>
<b>FINANCING ACTIVITY</b>		
Canada Emergency Business Account loan	<b>\$60,000</b>	<b>\$140,902</b>
<b>INCREASE IN CASH FLOW</b>	<b>\$78,835</b>	<b>\$87,179</b>
<b>CASH, BEGINNING OF YEAR</b>	<b>\$161,410</b>	<b>\$74,231</b>
<b>CASH, END OF YEAR</b>	<b>\$240,245</b>	<b>\$161,410</b>





*Thank You!*