



CHANGING LIVES, ONE DONATION AT A TIME



 *Living our best lives*

www.mpsociety.ca



giving the gift of hope 

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



#ignitehope

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WHAT IS MUCOPOLYSACCHARIDOSIS (MPS)?

Mucopolysaccharidosis (MPS) and related lysosomal storage disorders (LSDs) are rare inherited metabolic disorders that affect the body's ability to break down certain sugars and other substances. These disorders can cause a range of physical and neurological symptoms, including developmental delays, vision and hearing loss, joint stiffness, and cognitive impairment.

Affected by MPS, the child's health can deteriorate every day and just in the first few years of their life, many undergo multiple surgeries, having progressively less movement due to problems with joints & spine. There is often the eventual need for a wheelchair, breathing, & other equipment, with the possible loss of neurological & cognitive abilities. Treatment consists of hours every week hooked up to an in IV for enzyme replacement therapy. All the while knowing that time is limited & that as of yet there is no cure.

LOTS OF AWFUL SURGERIES

So far, I have had 24 surgeries, including:

- Having metal put into both my knees and ankles;
- Having hip reconstruction and metal put into both my hips;
- Having my adenoids taken out twice;
- Surgery to lengthen my Achilles tendons;
- 8 surgeries to put in ear tubes;
- Cornea transplants in both my eyes, which required 5 surgeries;
- Carpal tunnel surgery and finger surgery on both hands; and
- A bone marrow transplant.

Jessica Gentle (MPS I-H) - at age 12.

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LIVING WITH MPS

LOTS OF MEDICAL APPOINTMENTS

I see 17 doctors and medical professionals on a regular basis:

- Family Doctor
- Orthopedics (Neck & Spine)
- Plastic Surgery (Hands)
- Orthopedics (Feet, Knees & Hips)
- Orthodontist
- Ears, Nose & Throat
- Registered Massage Therapy
- Endocrinology
- Heart
- Pediatrician
- Respiratory
- Oncology
- Genetics
- Dentist
- Audiology
- Psychology
- Ophthalmology

Images by
Jessica Gentle
(MPS I-H)



After knee and ankle surg



After cornea transplant – the bright spots are the light reflecting off the stitches.



After Hip Surgery

Parents face many challenges as they navigate the care and treatment of their child's condition. The Canadian MPS Society exists to alleviate those challenges and help MPS affected families and children live their best lives.

We cannot do what we do without the generosity of our donors.

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YOUR DONATIONS ENABLE VITAL SERVICES

MPS is a rare disorder, and it can take a long time to get a proper diagnosis as many medical professionals are unfamiliar with this disease. This can be frustrating and stressful for parents who are trying to find answers for their child's health problems. Parents feel isolated and alone in their quest to receive help. Receiving a diagnosis of MPS can be overwhelming and emotional for parents, as it is a rare, debilitating and life shortening condition. There is no cure.

FAMILY SUPPORT

Your donations enable The Canadian MPS Society to provide several essential support services.



NEW DIAGNOSIS SUPPORT



BEREAVEMENT SUPPORT



CRISIS SUPPORT



CONNECTION

The Canadian MPS Society hosts online support groups for parents and caregivers of MPS, offering a safe space for families to share their experiences and get support from others who understand what they are going through. A National Family Conference is hosted bi-annually enabling families to come together for both education and peer support.



YOUR DONATIONS FOSTER CONNECTIONS & COMMUNITY

“

These family conferences are so important to my family, we share experiences, my kid gets to see other kids like him and not get judged. We laugh, we cry, but most importantly we just get each other. The Rae Family

”



“

The Canadian MPS Society conferences are quite simply the greatest thing the society does for its members. They've been the times we've been able to feel most 'normal' as a family and just enjoy the now ~ The Byrnes

”

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YOUR DONATIONS ENABLE UNDERSTANDING

It can be difficult for parents to navigate the complex medical information and terminology associated with MPS. The Canadian MPS Society provides access to information and resources about MPS to help affected families in understanding the condition and the resources available to them.

Your donations enable The Canadian MPS Society to provide several awareness services.

EDUCATION AND AWARENESS



EDUCATIONAL PUBLICATIONS IN ENGLISH AND FRENCH



RESOURCES AND CLINICAL TRIAL UPDATES VIA E-NEWSLETTER



TIMELY NEWS VIA SOCIAL MEDIA



ADVOCACY

The Canadian MPS Society advocates for MPS I-H to be included in newborn screening across Canada. It is imperative to ensure those diagnosed have the best prognosis, health outcomes and quality of life in their future. Advocating for better access to medical care and resources is also important in ensuring families receive the support they need.



MPS AWARENESS CAMPAIGNS

The Canadian MPS Society runs several awareness campaigns aimed at healthcare providers and the general public. If MPS is recognised and diagnosed early, it can be treated early and irreparable damage to the child's body and brain can be minimised.

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FINANCIAL ASSISTANCE PROGRAM

The cost of medical care for MPS can be significant, and many families face financial strain as they try to cover the costs of treatments, medications, and medical equipment. Insurance may not cover all necessary treatments and therapies, and some families may need to rely on fundraising or other forms of financial assistance.

The Canadian MPS Society provides financial support to help families manage the extraneous costs associated with MPS and related diseases. 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 DIRECTLY FUND FAMILIES

Grants are regularly given for assistance in the following categories:



UNINSURED MEDICAL EXPENSES



MOBILITY APPLIANCES



HOME RENOVATION FOR ACCESSIBILITY



PHYSICAL THERAPY



RESPIRE



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YOUR DONATIONS HELP FAMILIES ACCESS VITAL MEDICAL SERVICES

“Teuvo, was 9 months old when he was diagnosed with MPS I. Teuvo was admitted to SickKids in Toronto for his cord blood stem cell transplant. We're still currently in Toronto, as he is recovering and needs to stay by the hospital. I am self-employed and do not qualify for unemployment. As parents, having to move our family for a few months we panicked about our bills at home along with ones in Toronto. We received funding from the Financial Assistance Program, which have helped with our travel costs for transplant and we are ever so grateful.”

GIVING THE GIFT OF MOBILITY AND INDEPENDENCE

“After having lived for 9 years at the Montreal Children's Hospital, Loic had to move at the age of 18 to 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. Loic'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! ~ Anik Pilon”





YOUR DONATIONS CAN HELP ALLEVIATE THE EMOTIONAL BURDEN

NEW COMPASS PROGRAM*

*This program is still in development and in need of funding to be able to continue.

The diagnosis of MPS can be emotionally challenging for parents, who may feel overwhelmed, scared, and uncertain about their child's future. Parents of children with MPS can feel isolated or unsupported, as the condition is rare and not well-understood by the general public.

Since the Covid-19 pandemic, requests for assistance to the Society has dramatically increased. 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 which 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 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 Lysosomal Storage Diseases.

YOUR GENEROSITY CAN CHANGE LIVES

LET'S MAKE A DIFFERENCE TOGETHER



Donate
Today

“ My daughter Danika was diagnosed with Sanfilippo Syndrome just over 4 years ago. Sanfilippo is a type of MPS that causes all kinds of nasty symptoms like cognitive and physical decline, hyperactivity, sleeplessness and sadly has an average life expectancy in mid teens. There is also no treatment or cure.

In this difficult time and the years since, my daughters and I have relied on the guidance, support, education, financial assistance and most importantly community provided by the Canadian MPS Society. When it felt there was nowhere to turn, they have become family and we're incredibly grateful to have them in our corner. ~ Rebecca Cousineau ”

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[MPSSOCIETY.CA/DONATE](https://mpssociety.ca/donate)

IT'S YOUR CHOICE!



WAYS TO DONATE

With your ongoing support, we can continue to provide direct support to families and help fund a cure for the thousands of children, adults and families affected by MPS and related lysosomal storage diseases.



DONATE TO THE GENERAL FUND

This fund enables the Canadian MPS Society to provide family support, raise awareness, advocate, and advance research for treatments and ultimately for a cure.



DONATE TO THE ANNUAL FUND

Proceeds from the Annual Fund strengthens the leadership and overall effectiveness of the Canadian MPS Society, expands the Society's leadership role in public policy formation, and supports the structure for the Financial Assistance Program.



MAKE A TRIBUTE GIFT

Celebrate the life of a friend or loved one by making a donation in their honor or memory. Make a gift in honor of a milestone such as a transplant anniversary or to celebrate a special occasion like a birthday.



MAKE AN ONGOING IMPACT

You can make an ongoing impact in the lives of others. If you prefer to make automatic monthly donations, contact us at info@mpssociety.ca and we can set this up.

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GIVING MADE EASY



DONATE ONLINE

The easiest way to give is online at:
mpssociety.ca/donate



DONATE BY MAIL

Make your cheque payable to the Canadian MPS Society and mail to: Canadian MPS Society #218 - 2055 Commercial Drive Vancouver, BC V5N 0C7

OTHER WAYS TO GIVE

Matching Gift Programs

Does your company have a matching gift program? They might be willing to double your support of the Society.

United Way

You can support the Society when donating to the United Way. Just designate your contribution to the Canadian MPS Society through the section "Others." Our Society number for reference is ##12903 0409 RR0001

Give Stocks to the Canadian MPS Society and Reduce Your Taxes

By donating stocks to the Canadian MPS Society instead of cash, you can support our cause while reducing your capital gains taxes.

Planned /Legacy Giving

With Legacy Giving you can designate a major gift to to the Canadian MPS Society in life or as part of an Estate Plan. The gift could include cash, real estate, life insurance, equity, or personal property.

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THANK YOU FOR GIVING YOUR TIME TO LEARN ABOUT US!



Image by Jessica Gentle (MPS I-H)

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