



**Submission to the
Standing Committee on Human Resources, Skills and Social
Development and the Status of Persons with Disabilities (HUMA)**

**Briefing from the Multiple Sclerosis (MS) Society of Canada
on the Government's Response to the COVID-19 Pandemic**

May 20, 2020

Introduction

Today's trying times resemble what it's like to live with multiple sclerosis (MS) – every single day. Every day, people with MS wake up to adversity and do everything in their power to persevere...

- The woman with progressive MS who struggles to button her shirt in the morning yet is determined to stand up and dance at her granddaughter's wedding.
- The high school athlete who ignores the tingling and numbness in his legs so that he can rally his team to victory.
- The lawyer with blurred vision and foggy thoughts. The father struggling to say his child's name. The avid cyclist feeling her balance go.

As our country has one of the highest rates of MS in the world, Canadians know that MS can be harsh. Unfair. Overwhelming. A disease that always takes away, never gives back, and always threatens to take again. The COVID-19 pandemic is exacerbating the challenges for this vulnerable population who is at greater risk due to isolation, but our community continues to do what we do best – remaining strong, resilient and solution-focused. We are adapting to these challenges in real time and innovating solutions to deliver upon our mission.

Today we face at least a 25 million drop in our income for 2020 and anticipate continued revenue uncertainty in 2021 as the economic impact of COVID-19 takes hold. The MS Society is unique in the health charitable sector in that we are almost 100% dependent on the generosity of donors. We are confronting this challenge with the resiliency of the MS community, but need the unprecedented support of our federal government to weather this uncertain time and help make sure people with MS get what they need during the crisis and their entire journey with MS.

Recommendation

Our goal is simple: Support People. Support Science.

***We ask the federal government to establish the
Imagine Canada's Sector Resilience Grant Program at \$7.2 billion.***

This funding will provide immediate stabilization for the MS Society to continue the critical support for people – thousands of Canadians affected by MS and support for science through our world class ground-breaking MS research program.

Our MS community is coming together to meet this challenge and find solutions as we pivot to find ways to meet our mission in innovative and virtual ways. #WeChallengeMS, a virtual fundraising platform, has been launched to galvanize our MS community into action. A unique example of this has been Gamers vs MS, a virtual live streaming video gaming fundraiser. Our researchers came together in a research townhall and committed to challenging themselves to fundraise. Our community members are coming forward to provide virtual wellness programs for free even though they themselves are unemployed. While we have this supportive community, we know we can't meet this challenge on our own and are reaching out to our government partners for stabilization support while we face this unprecedented time.

Federal Funding Does Not Go Far Enough

The biggest barrier to supporting people and science during this time of crisis is funding. Despite our best efforts as noted above, we are not able to sustain the level of revenue we need to continue our life-changing work.

The primary concern for the MS Society is for people living with MS and their families, a population facing considerable risk with COVID-19 due to the immune suppressant drugs typically used to manage their MS, progressive disability, and co-morbidities. The increased social isolation from public health restrictions puts them at greater risk for mental health issues, which is already much higher for people living with MS than the general population as well as longer term health impacts. And there's a gender dimension with MS, as women are three times more likely to be diagnosed than men. We are seeing the impact of COVID-19 on the daily lives of Canadians affected by MS including for example, access to virtual healthcare and supports due to lack of the technology (and affordability of) and basic internet access. Additionally, COVID-19 amplifies the challenges they already face, including financial difficulties and barriers in accessing appropriate care.

A lack of funding at this critical time could be detrimental to the progress we've worked decades to achieve. Many research institutions and centres rely heavily on funding from the charitable sector and anticipate devastating consequences on Canadian research, as a whole, if funding from charities is significantly reduced. Without health charities funding, researchers and research projects will lose key personnel and capacity, experience an erosion of expertise, lose progress on experiments and setbacks that will have a lasting impact on health outcomes for Canadians.

We are appreciative of the funding government has provided through a number of programs to support businesses and not-for-profits. Unfortunately, these programs have limited impact on our organization's bottom line, and we find ourselves slipping through the cracks on the currently announced government supports.

- **Canada Emergency Wage Subsidy (CEWS):** the MS Society is accessing this program but because it only supports part of an individual's salaries at a time when our revenues are down at least \$25 million which is not substantial enough and we require the support of the federal government through the **Sector Resilience Grant Program**.
- **Emergency Community Support Fund (ECSF):** At this time, we are not aware of the eligibility criteria nor the details of how this fund would impact our organization financially. We have concerns that the overall size of the fund is limited in comparison to the size of the sector. There is a need for larger sector support in the Sector Resilience Grant.
- **Canada Emergency Commercial Rent Assistance (CECRA):** The MS Society does not qualify for this program as the eligibility requires less than \$20 million in revenue consolidated across our offices in multiple locations across the country.
- **Canada Emergency Response Benefit (CERB):** The MS Society is facing the most unprecedented crisis we've ever faced in our lifetime, and had to make the difficult decision to reduce our staff



levels by a third in order safeguard our viability and sustainability in delivering on our mission for people affected by MS. These impacted staff members are accessing this program.

- **Canada Emergency Student Benefit (CESB):** The graduate students and postdoctoral fellows that the MS Society research program supports fall outside of this benefit. (Further details in annex below)

The Path Forward

The COVID-19 pandemic has compounded the challenges of life with MS. Now, more than ever, people affected by MS need support and connection to navigate their unrelenting challenges in an uncertain world. People need sustained access to the medications and care necessary to live well. People need to know they will be supported as they deal with the long-term health and economic impacts of social and physical isolation. People need to know that MS research progress and momentum towards an MS cure will continue with force.

While our entire MS community is rising to the meet the unique challenges with COVID-19 we cannot do it alone. **We urgently request the federal government support and partner to sustain our organization and continue to meet the needs of Canadians affected by MS now and into the future. We respectfully ask that the federal government establish the *Sector Resilience Grant Program* immediately.** Now, more than ever, people affected by MS are counting on their government to support the charitable sector.

About multiple sclerosis and the MS Society of Canada

Canada has one of the highest rates of multiple sclerosis in the world. On average, 11 Canadians are diagnosed every day. MS is a chronic autoimmune disease of the central nervous system (brain, spinal cord). It is considered an episodic disease meaning that the severity and duration of illness and disability can vary and are often followed by periods of wellness. Most people are diagnosed with MS between the ages of 20 and 49 and the unpredictable effects of the disease will last for the rest of their lives. The MS Society provides information, support and advocacy to people affected by MS, and funds research to find the cause and cure for the disease, bringing us closer to a world free of MS. More information is available at www.mssociety.ca.

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ANNEX – ADDITIONAL CASE FOR SUPPORT

The information below outlines the additional case for support for our ask of the federal government to establish the ***Sector Resilience Grant Program*** in three areas: Financial Impact, Support for People and Support for Science.

Financial Impact

The MS Society is committed to supporting Canadians affected by MS during this difficult period. However, given the likelihood of this health crisis lasting months and having significant impacts on our fundraising given we are almost 100% dependent on the generosity of donors, the MS Society is potentially facing a negative impact of at least \$25 million which is 50 percent of our annual budget.

We raise \$1 at a time, and the majority of those funds are raised through in-person events including MS Walk, MS Bike, and WAMS (Women Against MS) Galas that are directly impacted by this decline in both donations and sponsorships because of the COVID-19 Public Health restrictions. Our additional sources of funding including private and community foundations, individual donors through our direct mail as well as our major gift donors are already being impacted by market uncertainties, decrease in investment portfolios, and job losses leaving this revenue stream with a high degree of uncertainty.

By nature, charities are asked to run lean by the Canada Revenue Agency (e.g. cost of fundraising guidelines) and by donors, to put our funds to our mission work including investing in important Canadian led ground-breaking research, delivering community-based programming providing a support system and advocating for Canadians affected by MS and not to build large reserves. Therefore, due to the timing of COVID-19 all of our revenue generation for the year is impacted and without adequate reserves to be sustainable.

Facing a financial crisis also means facing a crisis in the delivery of our mission – both in the short term and in the long term.

Support for People Programs and Advocacy

Canadians affected by MS are the heart and soul of our organization. Canada has one of the highest rates of MS in the world — a population facing considerable risk with COVID-19 due to the immune suppressant drugs typically used to manage their MS, progressive disability, and co-morbidities. The increased social isolation they are currently facing puts them at greater risk for mental health issues, which is already much higher for people living with MS than the general population.

Their needs at this time of crisis remain paramount, so we're not taking our foot off the gas pedal and we continue to offer programs and supports to meet their current and emerging needs which include:

1. [The MS Society's FAQs](#) and [webpage on COVID-19 and MS](#) including *Hear from Experts – MS & COVID-19 webinar series, wellness resources and programs*
2. [Disease-Modifying Treatment guidelines](#) for COVID-19
3. [The MS Society's Knowledge Network](#): connects people with MS Navigators who can provide information on all aspects of life with MS and are available to assist anyone in Canada from 8am to 8pm ET, Monday to Friday. MS Navigators can be contacted through:
 - [Live Web Chat](#) on the MS Society website
 - Email at msnavigators@mssociety.ca,
 - Phone at 1-844-859-6789.
4. [The MS Society's 1:1 Peer Support Program](#): This program is a telephone and internet-based program for individuals living with MS, and for caregivers and loved ones of people with MS. It connects people to someone who has had similar experiences so that individuals are better able to navigate the challenges and questions that arise as a result of MS.

What's Needed

We are seeing the impact of COVID-19 on the daily lives of Canadians affected by MS. Coupled with this impact are the challenges they already face, including financial difficulties and barriers in accessing appropriate care. Canadians affected by MS are in need of our programs and advocacy now more than ever.

Increased financial capacity through the **Sector Resilience Grant Program** will ensure we can proactively deliver information, programs and support that educate our community and address their needs, while also responding to those contacting us in crisis.

- **People Have a Dedicated Partner to Navigate Their Challenges:** Whether it's an inability to visit their healthcare provider, struggles with depression and anxiety caused by isolation, or navigating a recent layoff and loss of insurance coverage. The funding from the **Sector Resilience Grant Program** will ensure every person contacting the Society can connect with our MS Knowledge Network and a



MS Navigator for as much time as they need, to uncover solutions to address their immediate challenges and to ultimately arrive at long-term sustainable solutions.

- **People Feel Less Isolated and Discover New Ways to Maintain Their Wellness:** MS is already isolating especially for those with more progressive disease, and this isolation is amplified due to the disruptive effects of COVID-19. We also know that remaining active and mentally engaged is critical for people with MS, but that is very challenging in the current circumstances. The MS Society supported through the ***Sector Resilience Grant Program*** will offer people with MS the crucial programs and connections they need to live well, such as our Peer Support 1:1 when they need them, from the comfort of their own homes, while also innovating new approaches to long-term program delivery.
- **People Are Empowered with Accurate and Rapid Deployment of Information and Education:** Providing educational opportunities is a critical MS Society program and through the ***Sector Resilience Grant Program*** funding we can connect individuals to relevant evidence-based information such as the important need for info on COVID-19 and MS and offer empowering educational opportunities through virtual options (webinars and virtual conferences).

Support for Science World Class Ground-Breaking MS Research

Canada is known for having not only one of the highest rates of MS in the world but is also renowned for being a leader in MS research. This leadership has led to significant results for Canadians affected by MS.

Each year the MS Society funds approximately \$10 million in research to support studies that investigate all aspects of MS both biological and clinical. The MS Society also supports research and training programs which cultivates a network of bright young minds and engages them in activities that fine tune their skills and knowledge in MS research.

More specifically, the contributions by donors, fervent fundraisers, and corporate sponsors to MS Society funded studies have fueled discoveries in areas such as imaging, diagnosis, genetics, tissue repair, rehabilitation, and disease-modifying therapies. With each passing year research continues to reveal new knowledge around the cause of MS, as well as the mechanism by which MS impacts the central nervous system. This momentum, these discoveries, this pipeline, this workforce, this ecosystem is all at risk due to COVID-19.

Our annual research competition has over 80 active projects (see table below), which includes multi-year research programs and targeted research competitions.

MS Society Research Program 2020 - 2021 Annual Research Competition – Funding https://mssociety.ca/information-for-researchers/funding-announcements	
Operating and Pilot Research Grants	13 Operating Grants and 2 Pilot Grants
endMS Postdoctoral Fellowships	14 Postdoctoral Fellowships
endMS Research Studentships	24 Doctoral Studentships and 7 Master's Studentship

****We have over 50 on-going multi-year research projects****

Targeted Research Competitions https://mssociety.ca/information-for-researchers/funding-opportunities/targeted-competitions
<ul style="list-style-type: none"> • AI & MS Discovery Research Grant • Canadian Prospective Cohort (CanProCo) for People Living with MS • Team Grant: Cannabis & MS Research • International Progressive MS Alliance (Alliance)

However, due to COVID-19, and the suspension of research (outside of COVID-19 specific research) to protect the health and safety of researchers, their staff and people affected by MS participating in the

research, there is a need to ensure the sustained funding of the projects from our 2019-2020 competition (see table below) that will require supplemental funding to get re-started or replace lost data.

MS Society Research Program 2019-2020 Annual Research Competition – Funding	
Operating and Pilot Research Grants	13 Operating Grants and 2 Pilot Grants
endMS Postdoctoral Fellowships	14 Postdoctoral Fellowships
endMS Research Studentships	24 Doctoral Studentships and 7 Master's Studentship

We were pleased to see the recent announcement of the Canada Emergency Student Benefit. We, too agree in the critical importance that as stated by the Prime Minister *“the future of our economy and our country relies on the opportunities and support we provide to Canadian students today.”* However, the graduate students and postdoctoral fellows that the MS Society research program supports fall outside of this benefit as described below:

- This student emergency benefit supports those students that have been awarded grants through the Tri-councils. Our MS Society grants do not fund trainees who hold Tri-council awards; therefore, this does not apply to MS Society trainees.
- To compound the situation for these research trainees who do not qualify under the student benefit they also fall outside of the category for the Canada Emergency Response Benefit as master and doctorate students are not employees rather students in a department at a university. Furthermore, Postdoctoral fellows are in a strange employment category as they aren't students, and yet they don't have full rights of employees and thus fall outside of any emergency support.
- We understand there may be additional costs due to the suspension of research activities on some Discovery Research grants funded by the Society that falls outside the current supports.
- Additionally, the MS Society's discovery and pilot grants support technical and professional staff not covered in this student benefit.

What's Needed

The COVID-19 outbreak has the power to significantly jeopardize the MS research progress and momentum that the Society has worked decades to create – if we let it.

The **Sector Resilience Grant Program** funds will provide the resources necessary to fortify our current annual research program, the multi-year research grant funding commitments, an 80-project portfolio, as disrupted activities resume. It will also ensure continuity of the Society's ongoing strategic activities like the International Progressive MS Alliance and other targeted research programs and help prepare for new future research investments from the multiple requests we receive annually that are crucial to the long-term health of the MS breakthrough pipeline.

- **Ensuring the Sustainability of Our Funded Research Projects and Grants** - MS researchers need to know that the critical funding they've worked so hard to secure from the Society will not go away. Through the **Sector Resilience Grant Program** funds, researchers will be confident that their careers and their breakthrough ideas will continue to fuel the treatments and solutions that people

affected by MS, especially those living with progressive MS, are relying on. This fund will also give the Society the vital capacity to make new commitments to future projects and initiatives as we enter new granting cycles. The MS Society have a longstanding track record of bringing the right priorities, partners, processes and funding together to deliver breakthroughs. The ***Sector Resilience Grant Program*** funds will prevent the disruption of this powerful mechanism.

- The MS Society's research commitments have produced incredible breakthroughs and learnings over several decades. From our annual grant competition to large scale collaborative efforts like the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo), sustaining these commitments is critical to sustain forward momentum in MS research and include:
 - Unlocking the Mysteries of MS Progression through a Shared Data Platform (CanProCo and the Canadian Pediatric Demyelinating Disease Network)
 - Sustaining Existing MS Research Commitments (2019-2020 Annual Research Competition, Multi-Year Research Projects, and Targeted Research Competitions)
 - Sustaining New MS Research (2020 - 2021 Annual Research Competition)
- **Sustaining the Training of the Next Generation of MS Researchers** – Sustained funding will ensure these talented young minds we support through our research program continue to receive the support, opportunities and vital funding they need to launch their MS research careers and cement their commitment to MS.
 - SPRINT/EndMS Summer School - The MS Society provides a variety of education and networking programs to enhance knowledge and skill in MS research, foster knowledge exchange, and establish valuable connections and collaborations amongst peers in the field. These programs include endMS Summer School, and the endMS Scholar Program for Researchers IN Training (SPRINT).
 - Fellowships and Studentships - The annual studentship and fellowship award competition is a key plank of the MS Society's research training program that allows us to build a robust network of bright minds in the field and is aimed at graduate students and postdoctoral fellows intent on furthering their knowledge and training in MS.