

# MS Canada

**2022 IMPACT REPORT**

## **Stronger Together – We are MS Canada**





## Who We Are

### OUR VISION

A world free of multiple sclerosis.

### OUR MISSION

To connect and empower the MS community to create positive change.

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## Message from the CEO and Chair

Thanks to the collective action of the MS community, our resilience through an evolving environment has led to renewed vigour and purpose to move us towards a world free of MS. With adaptation and agility in mind, we explored ways to deliver programs to people in their homes, helping to provide services and stave off isolation. We continued to deliver virtual services and looked for opportunities for engagement and support in ways that offered people flexibility in how they access programs.

**2022 was a year marked by major breakthroughs in the field of MS research, offering hope that preventative and reparative treatments are on the horizon. The landmark identification of the Epstein-Barr virus as a leading risk factor in the development of MS has led to a potential pathway to prevention. The MS research field has made large strides in advancing our understanding of the underlying mechanisms of MS, leading to new pathways to developing treatments, halting disease progression, and even repairing existing damage.**

Our sustained and strategic research investments and partnerships on the national and global scale have created opportunities to quickly develop, share, and translate research knowledge into practice where it can truly impact the MS community.

Thanks to our MS community, we surpassed our 2022 fundraising goals. The dedication of our volunteers, donors, partners, persons affected by MS, and MS scientists, has enabled us to accelerate discovery, deliver supportive programs, and advocate with and on behalf of people living with MS for better federal and provincial benefits and accessibility.

MS Canada is focused on working with our community towards our impact goals to create system-wide change. Change that will positively impact individuals living with MS. It is important that we continue pushing for progress, as together we have arrived on the cusp of groundbreaking discoveries in MS that we are hopeful will one day lead to a cure. Working together, we can conquer MS.

Thank you for your support, and for being part of our community. You help us inspire and deliver hope for the future.

**Dr. Pamela Valentine**  
CEO, MS Canada

**Susan Senecal**  
Board Chair, MS Canada



# 2022

## At a Glance

**\$44,107,000**  
raised

**\$5,902,795**  
invested in research

**\$35,000,000+**  
active research portfolio

**\$1.8M**  
in leveraged funds

**158,739**  
meaningful connections

Supporting 315 researchers to  
focus on understanding, treating,  
and preventing MS

**\$1.2 million**  
invested in  
**15 research grants**  
to advance treatment  
and care

**\$255,145**  
invested in  
**2 research grants**  
to enhance  
well-being

**\$3.7 million**  
invested in  
**36 research grants**  
to understand  
and halt disease  
progression

**\$472,000**  
invested in  
**4 research grants**  
to prevent MS

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Our connection with MS Canada in the early years involved getting information and help. This helped us a lot, but afterward, there was more give and take. We really like to give back what MS Canada gave us when we first faced the diagnosis, and it's rewarding to be able to help newly diagnosed people. These people can believe us and connect with us, because we're able to understand them as the disease develops.

**Sylvie, lives with MS  
(and Mario)**

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# Stronger Together – We Are MS Canada

MS Canada aspires to be a hub for all individuals affected by MS across the country, which is why we take pride in placing the MS community at the core of our mission. We aspire to reflect and serve all members of the MS community in our work, our goals, our programs, and our services. After two years of limited availability, we were thrilled to begin re-engaging and reconnecting with members of our community. In 2022 alone, we have more than doubled our connections with MS community members through programs, events, and research – facilitating more than 150,000 meaningful connections among and with our MS community, continuing our journey of progress together.

We learn a lot through these connections, and we use those learnings to mindfully tailor our support, information, and resources to meet the needs of our MS community. Whether it's peer support, wellness programs, evidence-based information, advocacy, or help applying for income or disability benefits, we're here to support all Canadians affected by MS in navigating their unique MS journey.

And over time, we have leveraged research to improve that journey. Last year new avenues of treatment taught us more about the risk factors of MS. We are learning more about what triggers it and finding evidence-based ways for people to manage their symptoms. We are also learning much more about what prevention could look like.

By working together as volunteers, partners, or sponsors, to support people affected by MS, we have raised millions of dollars. We've accelerated research discoveries, and we have raised our voices to advocate for the MS community. Our combined dedication as a community will lead us to achieving our impact goals and arriving to a world free of MS.

**Together we are stronger.  
Together we are MS Canada.**

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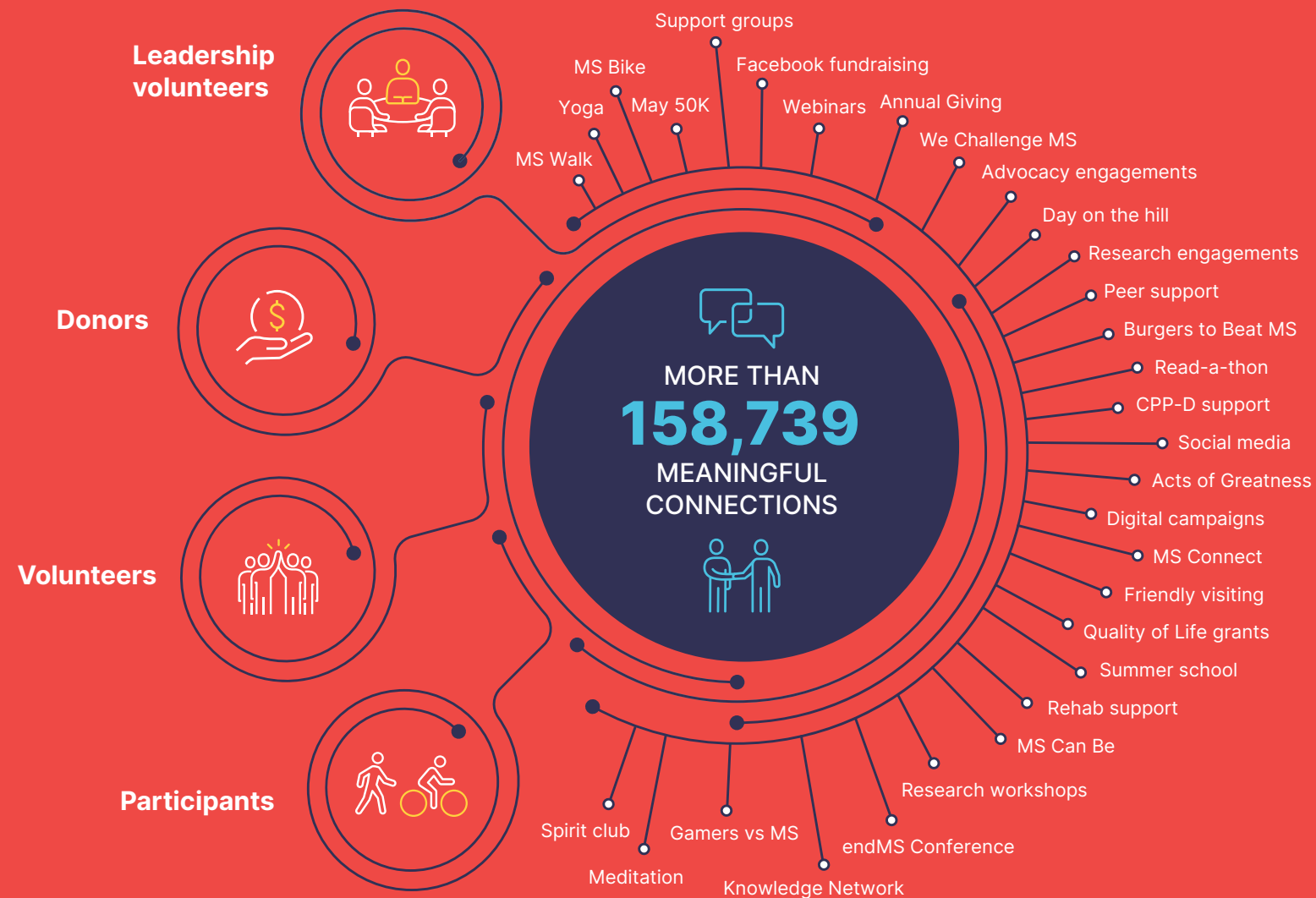
Volunteering has had a huge impact on my life. It reminds me that my contributions, however big or small, do make a difference. I can't control my disease, but I can control the effort I make to fundraise, educate, and contribute. I really just want to do as much as I can, in the ways that I can, for as long as I can.

**Karen, diagnosed in 2020**

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# Engaging the MS Community



Over 53,000 Canadians accessed support from our programs and services.

More than 40,000 people supported MS Canada through donations or events.

Almost 40,000 actions were taken to influence government policies to help people living with MS.

Almost 16,000 people participated in MS Canada events.

More than 3,000 people volunteered for MS Canada.

Almost 6,000 people follow MS Canada social media channels.



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When I was first diagnosed, I made three phone calls: one to my family, one to my partner, and one to MS Canada.

**Karen, lives with RRMS**

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## Our Impact Goals

Our strategic framework, **Discover. Innovate. Act.** lays out our impact goals which are a roadmap for our journey to accomplish our vision: a world free of MS. We know that accomplishing these impact goals will require many hearts and hands – a group of change agents with a passion and commitment to drive collective action within our MS community, and to make progress on these goals we’ve set out to achieve:

- Advance treatment and care,
- Enhance well-being,
- Understand and halt disease progression,
- Prevent MS.



# Advance Treatment and Care

**We are relentless in our work towards a future where each individual in the MS community has access to effective and timely treatment and care options for symptom management, wellness, and self-care, throughout their unique MS journey.**

## Focusing on the importance of self-care and rehabilitation

We found a way to fill in the gaps during a time when healthcare resources were scarce and in-person activities remained a concern to many. We leveraged partnerships with health practitioners and researchers to run care programs aimed to improving physical and mental wellbeing. We also supported research to achieve improvement in the longer term.

Through partnerships, we continue offering virtual rehabilitation programs, providing access to exercise – an essential component of self-care for people living with MS. **NEUROSASK** is a physiotherapist-led, adapted movement and exercise-at-home program that incorporates opportunities for connection and education. **TIME™ at Home**, is a program brought to us by an active community member, Patti Burns. It is a community-based balance and mobility program offered by the Toronto Rehabilitation Institute.

We initiated these partner programs to fill an unmet need in the community – the need for virtual opportunities for exercise and connection. We continue offering them as an accessible, nationwide option for people living with MS to build and recover strength and mobility. These evidence-based programs provide opportunities for self-care through exercise, which is proven to reduce levels of fatigue while improving mood, balance, strength, and overall quality of life.

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The TIME at Home program has benefitted me greatly and I thank the MS Society for making it available. I’m certain I’ve said this before, but as a rural resident where a suitable exercise program isn’t offered, this has helped me to manage my fatigue levels because I am able to exercise and not have to spend “spoons” on getting to and from an urban location.

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Thank you for offering the TIME exercise program for persons with MS! Exercise is important for everyone, but when walking just a few steps is difficult, following these simple but effective exercises help with balance and mobility.

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Research on symptom management and physical activity in MS has grown tremendously in the past decade. Now we are beginning to see research specifically about the type of exercises, length of engagement, and number of sessions a week that will bring optimal results for people living with MS. This evidence-based guidance will give the community tangible options and will empower people living with MS with knowledge and tools to help manage their symptoms. One such **study led by Dr. Englund**, demonstrated that participation in a high intensity resistance training program led to a reduction in fatigue, one of the most common symptoms reported by people living with MS.

At the same time, we are strengthening the field of rehabilitation research and care. Leading Canadian MS experts are gathering to establish a clinical trials platform, MSCanRehab!, that will accelerate the testing of new rehabilitation therapies and technologies that can help restore function and improve quality of life.

Yet self-care is not limited to exercise and rehabilitation. The last several years have sharpened focus on mental health challenges faced by people affected by MS. Our MS Knowledge Network, which provides information, navigation and connection to programs for people affected by MS, received over 9,000 calls this year, many of which were related to mental health and connection. This prompted us to launch WeTalkMS – a digital platform that enables people to connect with peers across the country and find support quickly and easily, without waiting for a “match”.

There is still much we don’t understand in the field of mental health and MS, and we continue funding research that will have an impact on our community’s wellbeing - including research to support a cognitive behavioural therapy program to help manage symptoms of depression and anxiety.

## Research Highlights

**Dr. Mike Holmes** assessed the use of a state-of-the-art robotic device to improve upper limb mobility and strength, and ultimately increase independence for people with immobilized or MS-affected limbs.

**Dr. Anthony Feinstein’s** research found that people with progressive MS showed a delayed onset of depression, emotional distress and decline in physical health not observed early in the pandemic. This emphasizes the importance of enhancing the monitoring and treatment of mental health symptoms in addition to physical symptoms and the need for increased mental health and self-care supports.

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**It’s very important for me to put myself first. Self-care is also a form of self-love in the MS community.**

**Christina, lives with RRMS**

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## Expanding treatment options...

We continue to be relentless in our pursuit of hope, answers, and treatments that can improve the lives of the MS community. We are supporting cutting edge research initiatives that use new platforms and techniques to accelerate results and enable their translation into new treatments and therapies.

And the global MS community is not slowing down either. MS Canada, along with six founders of the International Progressive MS Alliance, are collectively investing three million Euros to drive research on treatments that will support people living with progressive MS in the very near future. Our Canadian MS community continues to see growth in their treatment options; this year, **generic teriflunomide** was approved by Health Canada, and **ublituximab (TG Therapeutics)** was approved by the FDA with hopes that we will soon see this treatment approved in Canada.

## ...and building hope for the future.

We are keenly focused on ensuring that research is funded to facilitate the steady flow of progress through the drug development pipeline. There are currently **many new treatments under development** that aim to target MS more effectively, based on our increasing understanding of the underlying biology of MS. We fund research projects that are approaching treatment from different angles, including neurological repair, protection by decreasing inflammation, and even using medications already approved by Health Canada, which could speed up their approval for use in MS.

## Research Highlights – Drugs on the horizon

Early evidence shows that metformin, a drug widely used to treat type II diabetes, enhances brain repair (white matter). MS Canada funded **Dr. Ann Yeh** to conduct a pilot trial to investigate whether metformin enhances neurological repair in children and young adults.

**Dr. Soheila Karimi and team** received funding to increase our understanding of the role of neuregulin (a growth factor normally present in the body) in regeneration, repair, and neurological recovery. Neuregulin is a safe and effective drug already approved by the US FDA, which could be repurposed if proven effective for MS.

**Dr. Marcus Koch** showed promising results in the treatment of primary progressive MS using a repurposed antimalarial drug, hydroxychloroquine.

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Now, I'm really optimistic. I sometimes feel a little bit like an imposter, since I'm doing so well with my MS. But obviously that's because I'm reaping the benefits of tons of research and tons of fundraising and everything that's gone into this.

**Mel, lives with MS**

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The interdisciplinary projects encourage trainees to explore MS-related topics outside of their own field with an interdisciplinary group of colleagues. This interaction fosters the development of a variety of skills that are crucial to conducting meaningful research, and that can often not be obtained in individual academic programs.

(SPRINT participant)

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Research talent is needed to maintain and grow this pipeline of discovery and treatments for MS. We invested \$1.1 million dollars in the renewal of the **endMS National Training Program**, as well as supporting the **endMS Summer School** and **endMS Scholar Program for Researchers in Training (SPRINT)**, to attract young talent to MS research. These programs bring together trainees with leading researchers in Canada to learn about and tackle some of the most challenging research questions facing us today.

## By The Numbers

40,960

people attended/were supported by our programs

7,455

touchpoints through **81 active Peer Support Groups** at the local and national level

9,146

inquiries to our Knowledge Network

## Enhance Well-Being

We help remove physical and social barriers within communities to ensure equitable access to opportunities and support for people affected by MS.

### Helping change policy, together

We continued to strengthen the collective action of tens of thousands of Canadians by increasing opportunities for Canadians affected by MS to engage and make an impact. We've been relentless in our advocacy efforts to the government to address the complex challenges faced by people affected by MS.

This year we've seen the Canada Disability Benefit Act (Bill C-22) go from a hope to being passed into law, helped by more than 18,000 individuals who took part in our spring 2022 petition campaign. Importantly, Bill C-22 includes people with MS by using the episodic definition of disability from the Accessible Canada Act. MS Canada was at the table through the legislative process and will continue advocating with and on behalf of the MS community as we push for strong regulations to implement Bill-C22.

### Helping make ends meet

This year the MS community made sure that income security for those living with disabilities was a top priority for the federal government. We were thrilled to see the federal government amend the Canadian Disability Benefit to increase income support. We, along with the MS community, also played a pivotal role in the long fight to improve Employment Insurance sickness benefits, which were extended from 15 to 26 weeks. Former Minister Qualtrough recognized MS Canada as a strong partner at the national level, a testament to the power of our MS community.

It takes a community

46,388

actions to help change policy, focused on **5 priority issues:** income security, employment security, MS treatments, MS care and housing, and MS research

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The anxiety of not knowing when or how long my MS symptoms may last is more than enough; but, on top of worrying about my health, I have always worried about my employment. For far too long we've been stuck with the idea that disability is an on/off switch – of being able to work or unable. These changes to the EI sickness benefits will give someone like me the protection and additional time I need to fully recover from a relapse, easing some of the stress associated with an unpredictable disease like MS.

Julia, lives with MS

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## Ensuring inclusion of disabilities in future government plans and policies

In 2022, the federal government launched its first-ever **Disability Inclusion Action Plan**, which will define priorities and principles to support people with disabilities in the coming years. The goal is to take a consistent approach to disability inclusion across the Government of Canada and make it easier for persons with disabilities to access federal programs and services of all kinds. MS Canada and members of our community will continue to advocate for an action plan that is inclusive of people living with MS and applied widely across the government.

Advocacy takes time, constant pressure, and collaboration with others. We are proud of our community's efforts to move these issues forward. The incredible commitment and enthusiasm of our MS community is leading us on this successful path to change.

## Helping Canadians access equipment to maintain their independence

648 individuals across Canada benefitted from Quality of Life grants, which make a tremendous difference to their mobility and independence by helping to purchase equipment that helps them in their home and daily life.



## Assisting Canadians with their disability benefits

Applying for the Canada Pension Plan Disability benefit (CPP-D) can be a complex and detailed process. Many people living with MS are denied benefits simply because they don't have the required information, skills, or physical wellness to allow them to complete the application.

In 2022, we launched the **CPP-D Application Support Program** to help people navigate disability benefits. We match a trained supporting volunteer with participants to help them understand the necessary information to complete the application.

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I wish people knew that MS is not always a visible disability. Sometimes I feel extremely tired, like my body has given out. People don't see that. They see that I'm ready to go and I'm happy all the time, but sometimes there's something deep inside that I need to explore, and I need to get out.

Richard, lives with MS

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# Understand and Halt Disease Progression

To stop MS in its tracks, we continue to support efforts to gain a deeper understanding of how and why MS progresses. Determining these basic biological mechanisms provides key answers towards finding a cure.

## Accelerating the discovery and development of progressive MS therapies

As a founding partner of the **International Progressive MS Alliance** (Alliance) we are helping fund and drive the global research agenda to find answers and develop solutions to end progressive MS. By working collectively across disciplines and countries, the Alliance facilitates research in ways that would otherwise be impossible to achieve by any one country alone.

We are already seeing the results of these investments. This year, **several projects** that built on past funding and collaborations have helped advance the pipeline of new therapeutics for progressive MS.

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Dr. Francisco Quintana (Harvard Medical School) is leading a study with prominent Canadian researchers including **Dr. Jack Antel** and **Dr. Alexandre Prat**. They have built a platform for rapid clinical trials for MS treatments and are now identifying promising compounds to create new therapeutic targets to halt the progression of MS.

With a seed grant from the 2022 Alliance Research Challenge Awards, **Dr. Jennifer Gommerman** is working to better understand disease progression at the cellular level using imaging mass cytometry.

A recent project, **published in Nature Communications** and co-authored by Dr. Doug Arnold, used an open-access machine learning model to predict who would be more likely to respond to immune-modifying therapies. This model will help speed up clinical trials and reduce the number of participants needed to test drug therapies that target progression.

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## Answering the big questions with big data - CanProCo

Understanding the value of investing in long-term projects that will yield big results, such as the Canadian Prospective Cohort Study to Understand Progression in Multiple Sclerosis (**CanProCo**), is foundational to the longer-term investments of MS Canada.

Established in 2019, this unprecedented data platform allows researchers from all over the world to answer critical questions about progression. Only a few short years into building the platform and collecting data, researchers are already generating important new knowledge.

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Evidence suggests that the economic burden of MS may be higher than anticipated due to absenteeism, unpaid work and **productivity loss** in Canadians with early MS who have a mild or not clinically detectable disability. Providing accommodations in the workplace aimed at helping with fatigue and enhancing patient care could potentially reduce these system costs and improve the lives of people living with MS.

Another CanProCo study shows that better disease management strategies can improve the quality of life and **offset future costs** (e.g., the cost of disease modifying therapies) and the economic burden on the healthcare system, society, and individuals.

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The power of CanProCo is expanding by adding data from people with pediatric-onset MS, enabling researchers to use this rich data set to better understand disease progression across a lifespan. A \$1.35 million partnership with Biogen Canada Inc., Hoffmann-La Roche Limited, and Brain Canada Foundation created this opportunity.



# Prevent MS

Early identification and early treatment has a significant impact on the trajectory of MS. To prevent MS, we are funding and advocating for additional investments into research examining the risk factors that lead to MS and how to intervene prior to MS development or progression.

## Prevention by identifying risk factors for developing MS

MS is thought to be caused by a combination of genetics, lifestyle, and environmental factors. Identifying risk factors for developing MS is key to prevention, early detection, and treatment. With every year we grow closer to a complete picture of the factors that interact and ultimately lead to the development of MS.

Childhood is considered a key risk period in the development of MS since many of the known environmental and lifestyle factors can derive from it, including, obesity, low vitamin D, and second-hand smoking. New research by Dr. Eid of Norway highlights the importance of safeguarding emotional wellbeing in children. Dr. Eid found that adverse childhood experiences, such as emotional, sexual, or physical abuse in women were associated with an increased risk of developing MS.



Dr. Shannon Dunn is working to understand how a given risk factor, obesity, contributes to inflammation, autoimmunity, and MS development. The mechanistic understanding of factors leading to MS, such as the work of Dr. Dunn, is important to understand how these risk factors trigger MS and symptom onset.

## Epstein-Barr Virus (EBV) - a possible trigger for MS

Researchers have long suspected the Epstein-Barr Virus (EBV) — a virus that causes infectious mononucleosis — as a risk factor for MS. In 2022, one of the most notable breakthroughs in research was a **landmark study at Harvard** which identified EBV as an initial trigger in the development of MS.

Understanding triggers like EBV can lead to interventions, like an EBV vaccine, that might prevent MS before it starts. We are working with our global partners to accelerate our understanding of EBV and its relation to MS. For example, we have funded **Dr. Horwitz and his team**, who are examining how EBV infection increases the susceptibility and progression of MS.

## Making EBV research a funding priority

On the heels of the EBV breakthrough, we presented a parliamentary petition calling on the government to make MS research funding ‘a primary research priority for Canadians by committing to **funding MS research** in partnership with MS Canada to focus efforts to **pursue MS prevention and therapeutics strategies targeting Epstein-Barr Virus (EBV)** and to improve our understanding of EBV in the MS disease course.’

These exciting developments mean that exploring opportunities for prevention will be an increasing focus in the coming years.





## New avenues to stopping MS in its tracks

**Early intervention matters.** Delays in diagnosis or treatment of MS can have an irreversible negative impact on disease trajectory. But what if we could treat MS before it appears clinically? That is the question researchers posed and explored by treating a group of people who had MRI lesions consistent with MS, prior to clinical symptoms with disease-modifying therapies (DMTs). These people experienced an 82% reduction in their chance of being diagnosed with MS.

### Research highlights

**Dr. Helen Tremlett** found a survival advantage in taking a first or second-generation DMT, which is associated with up to 33% lower risk of mortality in persons living with MS.

Another important avenue that MS Canada continues to invest in is research focused on identifying **biomarkers** that can predict future relapses, the severity of the disease, and how people diagnosed with MS will respond to different therapies. Biomarkers could be used to identify MS before it is symptomatic to enable disease prevention, choose the most effective treatment plan, and help prevent or postpone relapses.

### A biomarker of neuroaxonal damage

**Dr. Simon Thebault** published work showing that a biomarker called neurofilament light chain (NFL) is predictive of impending MS relapse and can be used to identify individual people with MS who could benefit from early treatment.

### Genetic variations associated with MS severity

**Dr. Adil Harroud**, along with an international MS genetic consortium, have identified two gene variants associated with MS disability progression and disease severity. This study offers new targets for future development of therapeutics.





# Financial Highlights

Of the \$44,107,000 raised\* in 2022:

**\$22,158,000 (50%)**  
funded life-saving research,  
programs, and advocacy

**\$16,456,000 (37%)**  
invested in community  
fundraising activities

**\$4,127,000 (9%)**  
went towards  
administration

**\$1,366,000 (3%)**  
surplus to be invested  
in community\*\*

[VIEW THE FULL FINANCIAL REPORT AT MSCANADA.CA](https://mscanada.ca)

\* Combined Society & Foundation

\*\* Thanks to the generosity of donors and other circumstances which resulted in expenditure savings, we were fortunate to have an unexpected surplus which we look forward to reinvesting in research and programs for the community in 2023.





**MS Canada**

**[mscanada.ca](https://mscanada.ca)**

