

Policy Priorities

MS Canada



#TakeActionForMS

A new name. same vision: a world free of MS.

At the start of 2023, the Multiple Sclerosis (MS) Society of Canada began operating under a new name – **MS Canada**. Resulting from the amalgamation of the MS Society and the MS Scientific Foundation, MS Canada will continue building on our 75 years of experience, trust, and connections.

MS Canada provides support to people affected by or living with MS. We do so in the form of advocacy, information, and fundraising – to

bring clarity in the face of ambiguity, connection in moments of isolation, advancements through collective action, and hope by funding life altering research.

We remain committed to increasing our understanding of disease progression, advancing treatments and care, enhancing the well-being of those affected by MS, preventing MS, and, most importantly, our vision: a world free of MS.

Our Vision:
A world free
of MS.

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

What is MS?

Multiple sclerosis (MS) is classified as an autoimmune disease of the central nervous system (CNS). The immune system attacks myelin (protective covering of the nerves) in the brain, spinal cord, and optic nerve, which disrupts communication between the CNS and the rest of the body. The disease course of MS is unpredictable, often occurring in a pattern of relapses and remissions also known as an episodic disability. In some people, the disease is progressive and will steadily worsen from the onset.



What are the symptoms?

Weakness or imbalance
Abnormal sensation (tingling
or numbness)
Mood and cognitive changes

Mobility issues
Vision problems
Pain
Fatigue



Unmet Needs: Assessing the Impact of COVID-19

Canadians across the country are concerned about our health care system. To better understand the effects of the pandemic on the well-being of our community, and inform potential solutions, MS Canada commissioned a report on the impact and economic cost of COVID-19 on MS in Canada.

The findings raise significant concerns. The reduction in health service access, coupled with the social and physical isolation from lockdowns, resulted in the accumulation of unmet health needs including:

- Delayed MS diagnosis: Delays in receiving an MS diagnosis delays life-altering disease-modifying therapies (DMTs) which reduce relapses and delay disability progression.
- Delayed, altered, or halted treatments: Fear and anxiety of a COVID-19 infection while on immunosuppressing treatments, therapies changed based on accessibility, limited non-urgent care, and a myriad of other

factors led to healthcare decisions that were suboptimal.

- Suspended or altered rehabilitation: Individuals living with MS were unable to access programs needed to maintain or regain their health and function.

The ongoing effects of unmet health needs, combined with the overall strain on the health system in Canada, continues to compound the challenges faced by the MS community. Challenges like the financial difficulties as families try to make ends meet, the struggles faced in the workplace, the frustrating barriers to accessing treatments, and MS care and housing.

Taking action to address the following key priorities are critical to addressing the unmet health needs, the rising economic burden of MS in Canada, and bringing us closer to a world free of MS.

Sylvie, diagnosed in 2003, and her husband Mario, Quebec



Who is affected by MS?

Canada has one of the highest rates of MS in the world. On average, 12 Canadians are diagnosed with MS every day. Over 90,000 Canadians live with MS.

The onset of MS is typically between ages of 20-49. Women are 3x more likely to be diagnosed with MS than men.

Key Actions:

MS Research

Make MS Research a Priority

Commit \$15 million to fund MS research in partnership with MS Canada, leveraging our connections and expertise to focus and further our understanding of MS, pursue leading edge research on repair and regeneration, and explore prevention strategies targeting the Epstein-Barr Virus (EBV).



Income Security

Make Ends Meet

Support the Canada Disability Benefit at every opportunity and provide adequate funding in the next federal budget to guarantee it meets its goal of lifting individuals with disability out of poverty.



Employment Security

Make Work... Work

Continue modernizing the EI Sickness benefit by reducing the hours needed for eligibility from 600 to 400.



MS Treatments

Make Access a Reality

Improve the current regulatory and price negotiation processes to enhance timely access to all Health Canada approved MS disease-modifying treatments.



MS Care and Housing

Invest in the Right Supports

Ensure federal funding investments improve home care supports by focusing on options, diversity, and choice, as well as safe long-term care that is age-appropriate and offers meaningful comprehensive supports.





Priority: MS Research

For Canadians affected by MS, advancements in health research hold the hope for a better quality of life, for new treatments to manage symptoms, and, ultimately, a cure for MS.

Canada is home to world-renowned scientific experts and well-established collaborations among the MS research community such as the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo). Designed to better understand disease progression in MS, it integrates scientific expertise from many different fields and MS Canada is proud to be part of this innovative, multi-sector partnership that brings together academia, industry, government, and not-for-profit sectors under one umbrella.

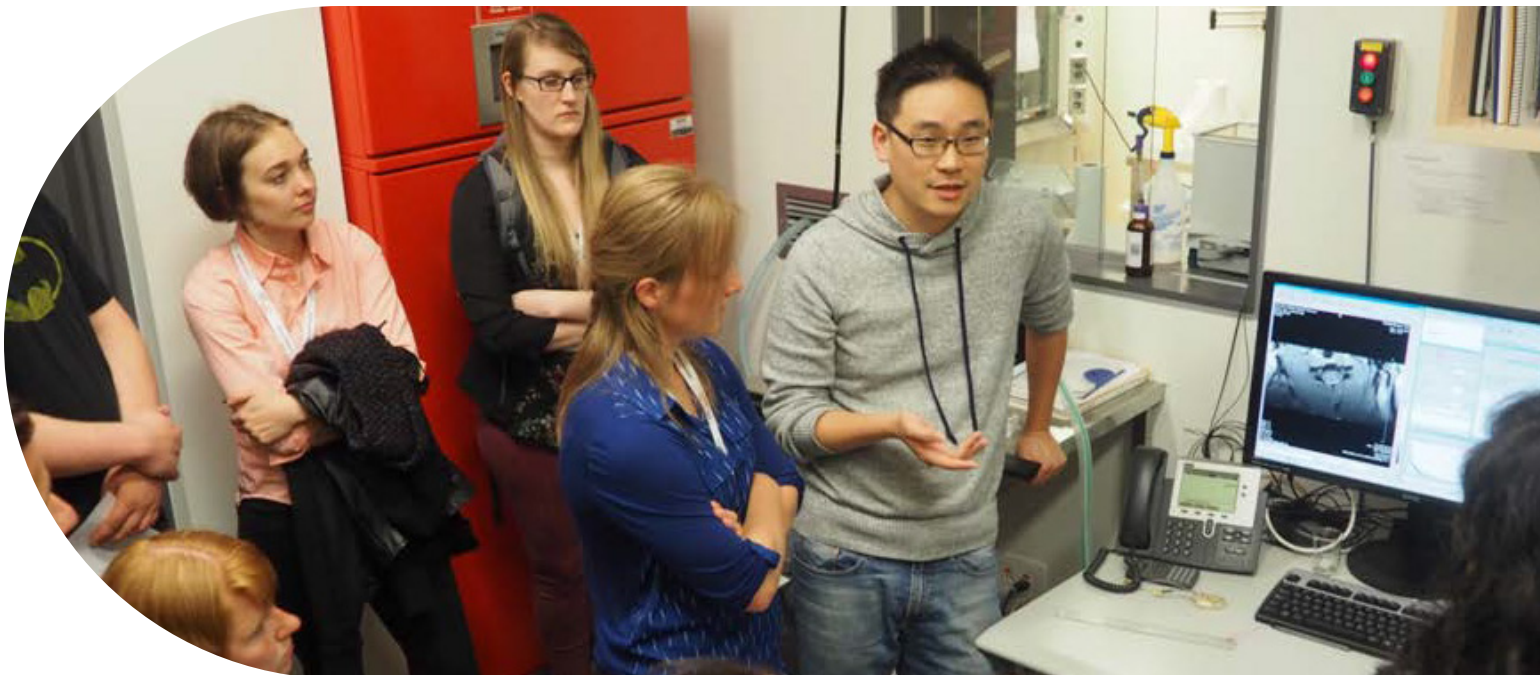
As a managing member of the International Progressive MS Alliance (The Alliance), MS Canada works with national organizations, trusts, foundations, donors, pharmaceutical companies, leading scientists, and healthcare professionals from across the world. The Alliance ensures a coordinated approach



to the most promising new research and breakthroughs by delivering global leadership to leverage research already underway.

The deep integration of MS Canada in both national and international efforts has been essential in ensuring we fund the most promising developments. Over our 75-year history, we have raised more than \$212 million to fund research efforts and used that funding to leverage millions more.

Today, we believe we are on the precipice of new discoveries that will help us understand the cause of MS, prevent the disease before it starts, find new treatments to halt the disease progression, and repair and regenerate the damage to the central nervous system caused by MS.





A recent landmark study by a research team at Harvard University found that in almost every case of MS, onset occurred after an infection by the Epstein-Barr Virus (EBV), an association that was not found with any other common virus. As EBV is now established as the leading risk factor, the finding by the Harvard research team cannot be understated: it provides researchers a distinct target to focus their efforts and pursue MS prevention and therapeutic strategies by targeting EBV.

Important breakthroughs are within our grasp. Now is the opportune time to partner with MS Canada and fund research that will improve the lives of people living with MS and bring us closer than ever to a world free of MS.

✓ Key Action:

Commit \$15 million to fund MS research in partnership with MS Canada, leveraging our connections and expertise to focus and further our understanding of MS, pursue leading edge research on repair and regeneration, and explore prevention strategies targeting the Epstein-Barr Virus (EBV).

Make MS Research a Priority

"As a parent living with MS, the possibility of my kids developing MS weighs heavily in the back of my mind. It was a question that my husband, Matt, and I had for my doctors when we decided to try and start a family.

Could our children develop MS? Is it hereditary? The truth is they can't say with 100% certainty if our kids would develop MS. It was a risk we had to take.

That doesn't have to be the answer forever. We are so fortunate to have outstanding MS researchers working right here in Canada. The outcomes of their work are often life-changing for those of us living with MS."

– Julia, diagnosed in 2003, Alberta





1948–1989

- 1949** MS Society of Canada (MSSC) awards first grant of \$10K to Dr. Roy Swank for diet research.
- 1973** The Multiple Sclerosis Scientific Research Foundation (MSSRF)* is established to support innovative and transformative research in MS.
- 1981** First magnetic resonance imaging (MRI) pictures of an MS-affected brain revolutionizes diagnosis.



2000–2004

- 2000** MSSRF funds a \$4M Canadian Bone Marrow Transplantation (BMT) clinical trial that aims to determine whether wiping out the immune system and transplanting autologous hematopoietic stem cells (AH SCT) can effectively treat MS.
- 2001** McDonald Criteria for diagnosing MS is established — the first diagnostic criteria to incorporate both clinical and imaging measures.
- 2003** CCPGSMS becomes the largest population-based MS DNA bank with genetic information on people living with MS and their biological relatives.
- 2004** MSSRF funds a \$4.3M multi-centre Canadian Pediatric Demyelinating Disease Network (CPDDN) to study children and adolescents who experience an initial demyelinating event. The CPDDN is one of the largest and most comprehensive pediatric MS cohorts in the world.



2010–2014

- 2012** Launch of the International Progressive MS Alliance (IPMSA), a group of global MS organizations committed to accelerating the development of treatments and resources for progressive MS. MSSC is a founding member of IPMSA.



2016

Launch of the MS Society Innovation Opportunity research fund for wellness, health and affected by

Results from Canadian Brain Bank that the treatment participants inflammatory the treatment activity. As a treatment at select sites

1990–1999

- 1993** MSSRF funds its first collaborative team research grant for \$2.2M for the Canadian Collaborative Project on Genetic Susceptibility to MS (CCPGSMS).
- 1995** First disease-modifying therapy (DMT) for relapsing-remitting MS (RRMS) is approved in Canada (Betaseron®; interferon beta-1b).
- 1996** First evidence published that shows exercise improves quality of life in people with MS.



2005–2009

- 2008** Dr. Paolo Zamboni identifies a possible association between chronic cerebrospinal venous insufficiency (CCSVI) and MS. MSSRF in partnership with Canadian Institutes of Health Research, provinces of British Columbia, Manitoba, and Quebec later launch a funding opportunity to investigate CCSVI as a treatment option for people living with MS.

MSSC and MSSRF launch a \$20M endMS Research and Training Network, a comprehensive multi-platform initiative designed to attract, train, and retain the next generation of MS researchers.

MSSC hosts its first endMS Conference — the largest MS scientific conference in Canada aimed at fostering knowledge exchange.



2015

CPDDN receives \$3.2M from the MSSRF to further understand quality of life, health care service utilization, brain development, cognitive performance, and the immune system in pediatric MS.

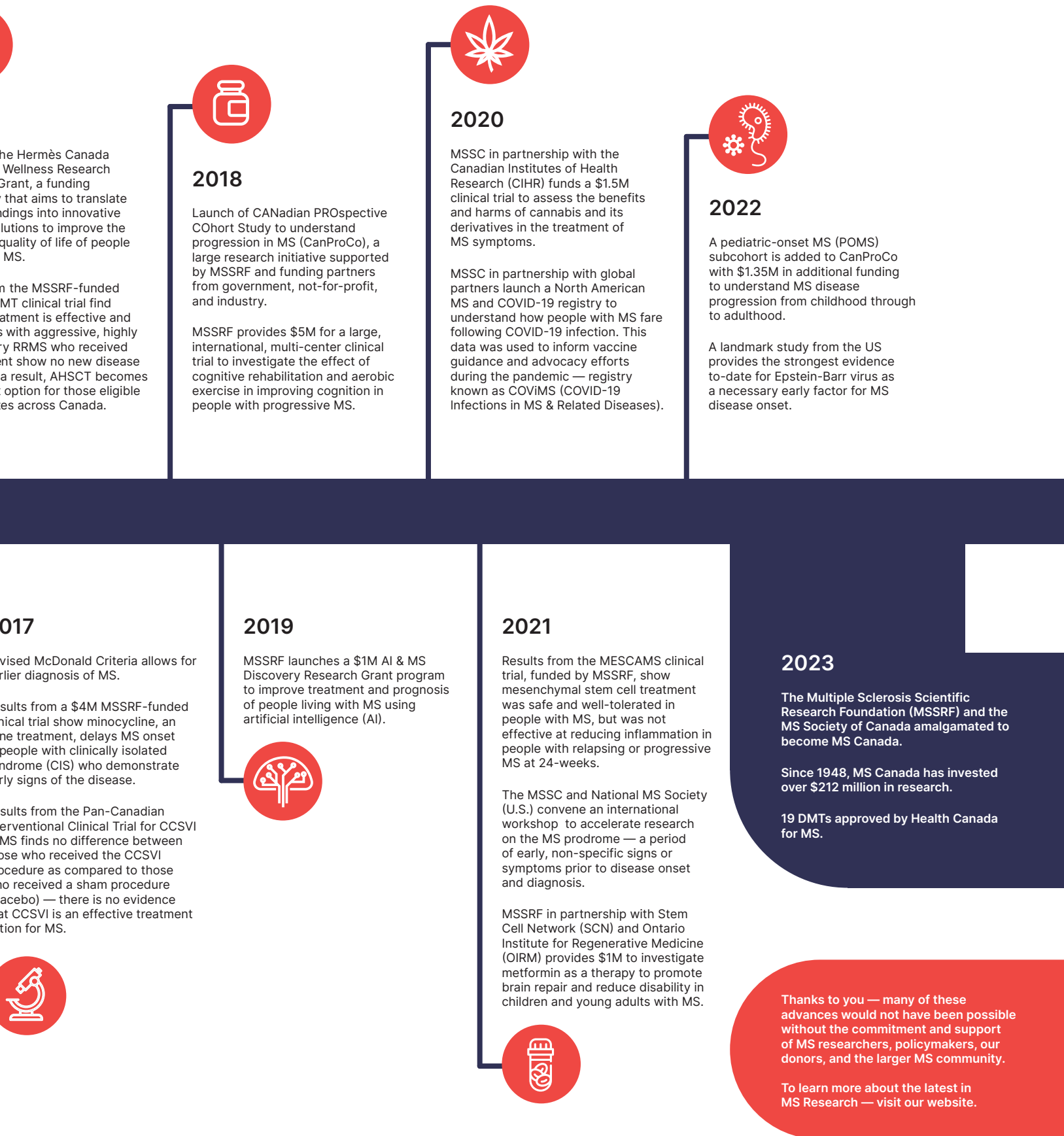
MSSRF funds \$4.2M for a Mesenchymal Stem cell therapy for Canadian MS patients (MESCAMS) clinical trial at two sites in Canada — aims to use mesenchymal stem cells as a treatment option for MS.



*The Multiple Sclerosis Scientific Research Foundation (MSSRF) is an affiliate of the MS Society of Canada that was established to support innovative MS research that extends beyond the scope of the MS Society's regular granting program. In 2023, MSSRF amalgamated with MS Society of Canada to become MS Canada.

Research milestones in multiple sclerosis

A look back at 75 years of progress





Priority: Income Security

Living with MS means living with uncertainty. Will today be a good day? Will switching to a new disease modifying treatment slow my MS? Will I be able to go back to work again?

Last year, MS Canada launched a series of petitions and open letters inviting our community to take action on the priorities that concerned them. Overwhelmingly, people spoke up about the need for stable and secure income supports they could rely on.

Income levels have a direct impact on the health and wellbeing of people living with MS. Research published in the scientific journal *Neurology* has shown that socioeconomically disadvantaged people living with MS tend to have greater disability. Further research findings presented in 2021 suggests that socioeconomic status also impacts the speed at which the nervous system is damaged.

Far too often, existing support programs exclude those with episodic disabilities. That's why it was so important for our community to see the Canada Disability Benefit amended to contain a definition of disability that included episodic disabilities. And when it passed through the House of Commons with unanimous support, our community celebrated.

People with disabilities are more likely to live in poverty compared to the general population. The cost of paying for medication, services, equipment, and treatment hasn't stopped with the introduction of Bill C-22.

The urgency remains, and, unfortunately, the community remains without additional support. The Canada Disability Benefit has yet to reach those most in need, while bills and expenses continue to pile up, causing significant economic strain for people with MS and their families.

Make Ends Meet

"I was 25 when I was diagnosed with MS. I'm 44 now, working full-time and looking into a murky future. My condition has progressed, and I'm starting to wonder about how much longer I can continue at the pace I push myself to. I do know when my "stop-work" day happens, I'll likely fall within the category of persons with a disability living below the poverty line, perhaps for the rest of my life. Until then I will work until I stop, because that's all I can do."

– Ray, diagnosed in 2005,
British Columbia



✓ Key Action:

Support the Canada Disability Benefit at every opportunity and provide adequate funding in the next federal budget to guarantee it meets its goal of lifting individuals with disability out of poverty.



Priority: Employment Security

For too long, we have treated the ability to work as a binary choice – an on/off switch of “you can work” versus “you can’t work” – and our support programs have reflected this. But for people living with an episodic disability like MS, it’s more akin to a journey marked with hills and valleys as cycles of relapses and remissions come and go.

The rigidity of the Employment Insurance system and employer attitudes makes life difficult for people living with MS who wish to remain in the workforce. People with MS have disproportionately high unemployment rates given their educational and vocational experience.

We can overcome these barriers with greater flexibility in employment supports, a workplace culture more accepting of accommodation, and increased understanding of episodic disability (periods of wellness followed by periods of disability) that characterize a disease like MS.

The government’s recent efforts to modernize the Employment Insurance system with the extension of the EI sickness benefits in December 2022 was welcomed by the MS community, whose advocacy efforts were instrumental in this change.

But with more than 60 per cent of people living with MS eventually reaching unemployment, it’s clear that more needs to be done to support those who live with episodic disabilities.

Many people with MS have precarious employment that fails to generate the minimum hours requirement to receive EI Sickness Benefits. By reducing the hours needed for eligibility, we can enhance the flexibility of our current system to support those living with MS.

✓ Key Action:

Continue modernizing the EI sickness benefit by reducing the hours needed for eligibility from 600 to 400.

Make Work... Work

“I used to do photography, particularly wedding photography. When people booked me a year in advance, I was really concerned. I could never be certain when my MS might flare up. I kept wondering; can I really pull this off a year later?”

With an invisible disease like MS, people look at you and they think, oh, well, she should be able to do X, Y, Z, or why is she tired now, or whatever the case is. So I always had to consider, at what point do I share that with them? Or do I?”

– Kelly-Ann, diagnosed in 2019,
Ontario





Priority: MS Treatments

As work continues towards a cure for MS, timely access to early intervention and treatments is vital.

Just as MS doesn't affect everyone the same way, no two people respond the same way to the same medication. What works in one person with MS may not be as effective in another. That's why having every treatment option available is so important.

Access to all Health Canada approved disease modifying treatments (DMTs) is not equal across the country. Many Canadians living with MS can't get sufficient, equitable, or affordable access to all DMTs. Too many in our community face unnecessary regulatory, administrative, and financial barriers that vary from one part of the country to the next.

We must ensure that every Canadian can access all Health Canada approved treatments, regardless of where they live. We must ensure that new breakthroughs in MS treatments are brought to Canada as quickly as possible. We must ensure that people can afford the treatment best suited to them, so they can avoid the long-term economic and personal costs that result from unnecessary and irreversible disability.

✓ Key Action:

Improve the current regulatory and price negotiation processes to enhance timely access to all Health Canada approved MS disease-modifying treatments.

Make Access a Reality

"I was diagnosed with Primary Progressive MS in October of 2019. The only DMT available for my form of MS has an approximate cost of \$33,000 annually. My private insurance refused to cover it and the province's pharmacare program has a deductible of \$17,000 and co-payment of \$14,000. How on earth can I afford this? Without it, my MS can progress to the point where I can't work, or worse. On top of dealing with my MS I have to worry about how I'll be able to pay for my treatment."

– Jorge, diagnosed in 2019,
Nova Scotia





Priority: MS Care and Housing

Comprehensive care means more than a trip to the doctor's office. It means care that includes nursing and personal support at home, supplies (like those for incontinence), mobility equipment, meal preparation, childcare, rehabilitation, and technology (e.g. home monitoring). It means care and support that includes the whole family, like respite and mental health supports.

When we're able to live in our own home in our communities, we have healthier outcomes. Research, like the 2021 Deloitte study, has shown that providing home care supports, even for those with high needs, is considerably less expensive than the costs of long-term care (LTC) facilities.

But there are times when a LTC facility is the only option. The services, programs, and supports provided in these facilities is almost exclusively focused on seniors.

While younger adults with disabilities are the minority in Canada's LTC facilities, many individuals living with MS are residents for decades. Younger residents tend to be cognitively intact and be more physically disabled, with complex care needs relating to fatigue, pain, and depression. The physical and emotional characteristics of younger residents differ markedly from most residents, who tend to be an average age of 85 and have some form of dementia.

As Canada's population ages, more programming and services will be developed to support those who need assistance, whether living at home or in care. Let's not miss the opportunity to support all those who need it.

Invest in the Right Supports

"Everybody's support system looks differently. We're very lucky that we have a beautiful family that supports us and friends that are extremely understanding. But not everyone has that. Access to mental health supports, those groups, those online chats, are so useful. It can be a scary thing to just even open up and go to a support group, but it's so worth it.

There's a lot of potential for mental health supports to benefit so many people, not just for those living with MS but their families and support networks too. It can be done, we just have to get to work."

– Marc (below, left), spouse of Richard who was diagnosed with MS in 2015, Ontario

✓ Key Action:

Ensure federal funding investments improve home care supports by focusing on options, diversity, and choice, as well as safe long-term care that is age-appropriate and offers meaningful comprehensive supports.



#TakeActionForMS



Photo by Walter Tychnowicz/Wiresharp Photography

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