MS is Canada’s Disease

Canada has the highest rate of multiple sclerosis in the world, and consequently, it is often referred to as “Canada’s Disease.”

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance, and mobility. It is one of the most common neurological diseases affecting young adults in Canada.

Most people with MS are diagnosed between the ages of 15 and 40. MS is three times as likely to occur in women as in men. The unpredictable effects of MS are physical, emotional, and financial and can last forever. MS impacts all Canadians - not only the individuals living with the disease, but also their friends, families, workplaces and healthcare teams - who all come together to manage the realities of MS.

The Multiple Sclerosis (MS) Society of Canada provides services to people with MS and their families, and funds research to find the cause and cure for this disease. We have a membership of 17,000 and are the only national voluntary organization in Canada that supports both MS research and services. Since our founding in 1948, the core support of the MS Society has been from tens of thousands of dedicated individuals, companies and foundations in communities across Canada.

Our mission: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.
The MS Society believes that **Accelerating Research** will lead to new treatments, better quality of life and a cure.

The MS Society funds approximately $11-13M of MS research each year, largely conducted in Canada.

Overall, since 1948, the MS Society has provided over $160M of funding for MS research and researchers in Canada.

Thanks in part to this support, Canada has developed a pipeline of exceptional MS researchers and has become a leading contributor to discovery in the field of MS.

**SYMPTOM MANAGEMENT & QUALITY OF LIFE [14%]**
- Healthcare utilization
- Cognition
- Exercise & rehabilitation
- Population patterns
- Co-existing conditions
- Pain and fatigue

**PROGRESSION & THERAPIES [38%]**
- Stem cells
- Clinical trials
- Imaging
- Drug repurposing
- Neuroprotection
- Treatment assessment and development

**CAUSE & RISK FACTORS [21%]**
- Genetics
- Immune triggers
- Modifiable risk factors
- Viral infection

**NERVE DAMAGE & REPAIR [27%]**
- Remyelination
- Neuropathology
- Imaging
- Immunology
- Cell signaling

This graph shows a breakdown of research topics that are covered by studies funded by the MS Society and its affiliated MS Scientific Research Foundation.
MS is Canada’s disease and as we gather to celebrate our country’s 150th birthday this year, we hope our government will step up and take action to improve life with MS.
RECOMMENDATIONS

The MS Society is focused on ensuring Canadians living with MS and their families have the opportunity to participate fully in all aspects of life.

We are advocating for policy changes that:

**Improve Income and Employment Security**

- **Make Work...Work** by including more flexible employment to allow people with MS and other episodic disabilities to remain in the work force.

- **Make Ends Meet** by improving income and disability supports for people with MS who are unable to work or can only work on an intermittent basis.

**Enhance Access**

- Implement accessibility legislation
- Increase access to treatments
- Invest in comprehensive home care
The MS Society of Canada recommends the Government of Canada:

Improve the coordination of basic definitions and program parameters across the income, disability, employment and support system to include those living with episodic disabilities.

- This includes all 7 programs offered by different providers (federal, provincial, and private). Canada Pension Plan – Disability (CPP-D); Employment Insurance (EI) Sickness Benefit; Employment-based long-term disability (LTD) plans; Worker’s Compensation benefit; Veterans’ benefits; Tax measures; Provincial/Territorial social assistance programs.

Enhance the EI Sickness Benefit program by:

- Extending the duration of EI Sickness benefits from 15 weeks to 26 weeks to match compassionate care benefits
- Reducing/eliminating the clawback
- Creating a flexible work-sharing program so that a person can reduce work hours while receiving EI income.

Create a system for the expert dissemination of information and hands-on support to employers on roles, best practices and resources when an employee or family member is diagnosed with a chronic or episodic disability, and requires time away from work.

“The issues in question are confronted by more than one million Canadians living with episodic or some form of chronic illness: you want to work, you can work, but the income and social support systems governing our labour market are designed with a binary switch — you’re either in the workforce and off assistance, or you’re out of the workforce completely and on assistance.”

iPOLITICS—September, 16, 2015
MAKE ENDS MEET!
Income & Employment Security
Recommendations for Change

The MS Society of Canada recommends the Government of Canada: (Short Term)

- Make disability tax credits fully refundable and increase it to put much needed income directly in the hands of low-income people with MS and other disabilities;
- Change eligibility criteria (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to ensure people with episodic disabilities have access to public insurance and tax credit systems for those unable to work or who can only work on an intermittent basis;
- Harmonize the EI sickness benefits duration of 15 weeks to match the 26 weeks duration of compassionate care benefits.
- Ensure the national poverty reduction strategy includes all Canadians including those with episodic and progressive disabilities to have adequate income;
- Increase existing federal benefits (e.g. EI sickness benefit amount) and credits (e.g. caregiver tax credit, family caregiver tax credit, disability tax credit) for people with disabilities.

The MS Society of Canada recommends the Government of Canada: (Long Term)

- We recommend as published in report by the Caledon Institute of Social Policy, that the federal government, in close cooperation with other governments, give serious consideration to a basic income program that would replace provincial/territorial social assistance for most working-age persons with severe disabilities. The Basic Income program would be a close model of the Old Age Security (OAS) and Guaranteed Income Supplement (GIS) programs for seniors.

“You can’t live off of the CPP-D amount. And you can’t really work because they take the little they are giving you away if they find out you are earning money somewhere else. So you get stuck in a bad cycle that you can’t get out of.”

Respondent, MS Society Listening Initiative, 2013
ACCESSIBILITY LEGISLATION

Access Recommendations for Change

THE MS SOCIETY OF CANADA RECOMMENDS THAT THE GOVERNMENT OF CANADA IMPLEMENT ACCESSIBILITY LEGISLATION THAT:

• Establishes clear, broad, inclusive definitions of “disability” and “barrier.” The legislation should include and protect all Canadians with disabilities whether they are visible or invisible, and whether they are permanent or episodic (periods of wellness followed by periods of disability). This definition needs to include the notion of the changing dynamic of disability which is the case for individuals living with progressive neurological diseases like MS.

• Addresses all kinds of accessibility barriers, such as physical barriers in the built environment inside and outside buildings, communication barriers, technology barriers, information barriers, transportation barriers, attitude barriers, legal barriers, and policy or bureaucratic barriers in health, income, employment and disability programs.

• Is comprehensive and broad based and be inclusive of all people with disabilities including episodic which is key for people affected by MS.

• Contains measures for effective enforcement.
ACCESS TO TREATMENTS
Access Recommendations for Change

The MS Society of Canada recommends that the Government of Canada ensure people with MS have equitable and timely access to treatments based on the best possible health outcomes rather than the ability to pay. Canadians living with MS need access through public drug programs to all Health Canada approved treatments for MS.

The MS Society of Canada recommends that the Government of Canada implement the Health Charities Coalition of Canada’s (HCCC) Access to Medicines recommendations:

- HCCC asks the Government of Canada to address access to medicines issues through the creation of an Advisory Panel and development of comprehensive, evidence-based pan-Canadian pharmacare standards.

- HCCC recommends the Government of Canada take a leadership role and share the cost of implementing comprehensive, evidence-based, pan-Canadian pharmacare standards to ensure Canadians have equitable access to prescription therapies regardless of geography, settings, or disease state.

- HCCC recommends that health charities and the Canadians they represent be active participants in federal, provincial and territorial consultations to support the development of comprehensive, evidence-based, pan-Canadian pharmacare standards that meets the needs of Canadians.
ACCESS TO HOME CARE
Access Recommendations for Change
The MS Society of Canada recommends that the Government of Canada increase investments in comprehensive home care for people with long-term chronic health conditions such as MS.

- Comprehensive home care needs to focus on the family and include nursing and personal care, supplies (e.g. incontinence supplies) and equipment, meal preparation, home making, child care, rehabilitation, technology (home monitoring), and meaningful respite services.

- (Health Accord) Ensure provinces and territories are accountable to deliver measurable improvements for those who need home care because of a long-term chronic disease and not only to those whose access to homecare is for short period of time as is the case for those requiring post-acute or palliative care at home.

The MS Society of Canada recommends that the Government of Canada through the National Housing Strategy, create a range of age-appropriate housing and care options for Canadians with disabilities who cannot remain at home.

- The MS Society of Canada recommends that the Government of Canada in conjunction with the National Housing Strategy and the Health Accord, create a nation-wide funding program for accessible home modifications for people with disabilities to remain in their homes.

#LIFEWITHMS

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