



Standing Committee on Finance

Speaking Notes for

Benjamin Davis, Senior Vice-President, Mission, MS Society of Canada

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Good afternoon. My name is Benjamin Davis and I'm the Senior Vice President, Mission, for the Multiple Sclerosis Society of Canada. I'm pleased to present to your committee on key priorities for Canadians affected by MS.

A bit of context about MS in Canada. Canada has one of the highest rates of MS in the world. An estimated 1 in every 385 Canadians live with the disease. It's a chronic, episodic, progressive, and 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. Women are three times more likely to be diagnosed with MS than men. On average, 11 Canadians are diagnosed with MS every day.

The MS Society has heard the personal and profound stories of life with MS from Canadians. The struggles in the workplace. The financial difficulties families are facing to make ends meet. The frustrating barriers in accessing Health Canada approved therapies, appropriate care, housing, and social supports. And of course, the hope that research gives to the tens of thousands of Canadians living with this disease.

To address these realities, I'll present our recommendations in employment and income security, access, and accelerating research.



First, employment security. People with MS want to work but struggle to continue to work. We need to update the definition of disability to include episodic (periods of wellness followed by periods of disability). A staggering 60% are unemployed and that needs to change.

Often the problem is one of flexibility and accommodation and an understanding of episodic disability. Last year, the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) studied Motion M-192 episodic disabilities. Their report *“Taking Action: Improving the Lives of Canadians with Episodic Disabilities”* made 11 important recommendations that now need to be implemented including extending the duration of the the EI Sickness benefit from 15 to 26 weeks.

The second area of priority is income security. The cost of paying for medication, services, equipment, and treatment is a significant burden for people with MS and their families. Intertwined with this burden are complicated application processes, requirements for numerous verified medical forms, and strict eligibility criteria for programs. When MS stops someone from working, they should be able to access adequate income and disability support.

This situation is amplified for women. In Canada, MS affects women three times as often as men. They also have, on average, lower incomes and earnings thus making them more susceptible to poverty.

We recommend the following:

- First, making the disability tax credit refundable
- Second, as already highlighted implementing the 11 recommendations in the HUMA Committee’s Motion M-192 report
- Third, changing eligibility criteria for the Canada Pension Plan – Disability and Disability Tax Credit to include those with episodic disabilities using the new Accessible Canada Act’s definition of disability



The third area of priority is access. Access throughout our communities and access to comprehensive treatment, care and appropriate housing is a must.

We recommend the following to make access a reality for Canadians:

First, implement the Accessible Canada Act to ensure a barrier-free Canada with a specific focus on programs and service delivery; employment; built environment; and transportation.

Second, we recommend, through intergovernmental health agreements investing in comprehensive homecare and for those unable to remain at home, fund the development of appropriate housing through the national housing strategy.

Third, we recommend increasing access to Health Canada approved treatments as early intervention is vital to avoid many of the long-term economic and personal costs that result from unnecessary irreversible disability. The needs of people with MS and their families should be at the centre of health and drug policy decisions.

The fourth and final priority area is accelerating research.

Research is key to new treatments, better quality of life, and ultimately a cure.

Canada remains at the forefront of MS research around the world. Through generous contributions from donors, corporate sponsors, and fervent fundraisers, the MS Society of Canada has invested over \$175 million dollars in research since its inception in 1948.



The MS Society continues to fund fundamental research as we still don't know what causes MS, or how we could prevent it in the future. We recommend the federal government continue to invest in basic scientific research.

Secondly, we recommend that the federal government connect with health charities to ensure the patient voice is part of setting research priorities. We believe that federal research funding programs should be informed by the perspectives of patients, their caregivers and healthcare providers.

Our third recommendation is to partner with health charities to turn innovative research into real-life treatments. There are a number of partnership opportunities within the MS Society's new strategic plan's impact goals - Advance Treatment and Care, Enhance Well-being, Understand and Halt Disease Progression and Prevent MS. For example, the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo) is an innovative public, private, and philanthropic partnership that will allow researchers and clinicians to observe a large group of people living with MS from across Canada over a period of time and collect data from them. Analyzing this data will identify characteristics and markers of MS progression, answering fundamental questions as to why and how progression occurs which is key to improve diagnosis, treatment, optimize health services, and improve health outcomes.

Thank you for this opportunity to speak and share with you the priorities Canadians affected by MS want you to take action on – Employment, Income, Access and Research.