

MEETING THE NEEDS OF CANADIANS AFFECTED BY MULTIPLE SCLEROSIS TODAY

BRIEF TO THE STANDING COMMITTEE ON FINANCE PRE-BUDGET CONSULTATION SUBMITTED AUGUST 13, 2010

EXECUTIVE SUMMARY AND RECOMMENDATIONS

The Multiple Sclerosis Society of Canada is pleased to provide input to the Standing Committee on Finance for its pre-budget consultation. Our perspective is that of people affected by MS, including the estimated 55,000 to 75,000 people who have the disease; their families and caregivers; health care professionals; researchers and MS Society of Canada supporters. Our overall focus is twofold: first, the need for immediate action on a pressing health research and, second, the need for the development of programs and policies to improve income security programs for people affected by MS and other episodic and chronic diseases and disabilities.

Multiple sclerosis – or MS – is an often progressive and disabling disease of the brain and spinal cord. Canada has one of the highest rates of MS in the world. MS is a costly disease. In addition to the indirect costs associated with the loss of productivity and the day-to-day activities of life, MS has an economic impact on the health care system because of increased visits to a doctor, longer stays in hospital and the need for often costly medications.

Specifically, the MS Society is asking the federal government to invest in programs that will more directly meet the needs of people affected by MS by advancing health research and by improving income security programs. Details about how these recommendations can be achieved are found in the text of this brief.

1. **Recommendation:** That the Government of Canada commits \$10 million to the budget of the Canadian Institutes of Health Research and earmarks it for research into chronic cerebro-spinal venous insufficiency (CCSVI) and its relation to MS.
2. **Recommendation:** That the Government of Canada commits to leading the development of a pan-Canadian income security program for people affected by MS and other episodic and chronic diseases and disabilities. The development should address how to replace the current hodgepodge of disability pensions, social assistance programs and tax credits, some of which cannibalize each other resulting in less money for people who are disabled because of MS and other conditions. In the meantime, some small but important steps should be taken today to help build better futures for these Canadians through changes to tax credits, Employment Insurance eligibility and bankruptcy act treatment of creditors.

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an often progressive and disabling disease of the brain and spinal cord. The disease attacks the protective myelin covering of the central nervous system, causing inflammation and often destroying the myelin in patches. In its most common form, MS has well defined attacks followed by complete or partial recovery — sometimes described as an “episodic disability”.

MS symptoms are unpredictable and vary greatly from person to person. Symptoms may include: vision disturbances such as double or blurred vision; extreme fatigue; loss of balance; problems with coordination; stiffness of muscles; speech problems; bladder and bowel problems; short-term memory problems, and even partial or complete paralysis. Very recently, a new and intriguing theory about MS has emerged. It suggests that MS may be related to a possible narrowing of veins in the neck, and chest area. This has been called chronic cerebro-spinal venous insufficiency (CCSVI).

Canada has one of the highest rates of MS in the world with an estimated 55,000 to 75,000 people affected by the disease across the country. MS is the most common neurological disease affecting young adults. It is most often diagnosed between the ages of 15 and 40, during the prime career and family building years.

THE IMPACT OF MULTIPLE SCLEROSIS

Multiple sclerosis is a costly disease. MS has a significant economic impact on the health care system because of increased visits to a doctor, longer stays in hospital and the need for often costly medications. One study, done in the late 1990s, estimated the lifetime cost of the disease is \$1.6 million per each person with MS.¹ In other research, the Public Health Agency of Canada estimated the total costs associated with MS in 2000-2001 were almost \$1 billion: \$139.2 million in direct costs (hospital care, physician care, drugs) and \$811.3 million in indirect costs (dollar value of production costs due to long-term disability or premature death).² The MS Society believes the actual total costs of MS are much higher since many other indirect costs such as the need to leave the work force prematurely were not captured.

MS has a profound impact on the ability to earn a living. Many people are diagnosed between the ages of 15 and 40, just when they are finishing school, starting careers and beginning families. As the disease progresses, it takes a toll on a person’s ability to stay in the work force. Over time, up to 80% of people with MS can no longer work. Sometimes, this is because the disability caused by MS becomes more severe, but at other times, it’s because of a lack of understanding and accommodation by employers and insufficient government supports.

WHAT IS NEEDED

The MS Society is asking the federal government to invest in both health research and income security programs that will directly improve the lives of people affected by MS today.

1. Research into CCSVI

In November 2009, Italian researcher Dr. Paolo Zamboni made headlines worldwide with his report of CCSVI or chronic cerebro-spinal venous insufficiency. He suggested that opening narrowed veins that drain the central nervous system can improve MS symptoms and quality of life. As with any new

hypothesis, many questions remain and early results need to be replicated and validated in well-designed, controlled studies. The MS Society shares the hope and optimism of all Canadians touched by MS and moved quickly to initiate the additional research needed to examine this hypothesis and to determine if further study is warranted with respect to the potential for treatment.

On June 11, 2010, the MS Society of Canada and the National MS Society (USA) announced funding of more than \$2.4 million to support seven new research projects focusing on the relationship between CCSVI and MS. The total amount of funding committed by the MS Society of Canada is \$700,000 for four projects. By funding research into MS and CCSVI, the MS Society joins other MS societies around the world to ensure that answers about CCSVI are found as quickly as possible. If evidence is found that treatment of CCSVI is a valid therapeutic treatment option for MS, then the MS Society will advocate vigorously to make testing and treatment widely accessible for people with MS across the country.

The MS Society has also asked the federal government to contribute. In May, **the MS Society asked the Minister of Health to commit \$10 million to the budget of the Canadian Institutes of Health Research (CIHR) and to earmark the funds for CCSVI and MS research.** The MS Society is pleased Minister of Health Leona Aglukkaq requested CIHR to immediately provide her with advice on how to advance this crucial research. An important initial response was the August 26 CIHR-hosted workshop to identify clinical research priorities for Canada to accelerate research and innovation on MS, with a focus on potential links between neurovascular issues and MS. The MS Society of Canada urges the federal government ensure that funding for CCSVI research is available when it is needed.

The MS Society is committed to ending MS through an annual research program which supports the very best research projects and researchers from coast-to-coast and fellowships and scholarships for young scientists to attract them to the challenging world of MS research.

All of these efforts build on the solid foundation provided by the Canadian Institutes of Health Research (CIHR), Genome Canada, the Canadian Foundation for Innovation and the Stem Cell Network. The MS Society's research program, and those of other health charities, both partner with and rely on federally-funded agencies to support the basic discovery research³ that scientists from all disciplines build on to sustain our health system, improve care and enhance the prevention of disease. The MS Society applauds CIHR's commitment to patient-oriented care and treatment and urges the government to **provide additional funding for the implementation of CIHR's Strategy for Patient-Oriented Research (SPOR) to ensure discoveries can quickly move from laboratories to Canadians as soon as possible.** Research into CCSVI and MS is a compelling example of patient-oriented research.

It is important to note our request for additional CCSVI and MS research funding was for the funds to flow through CIHR, and not through the MS Society. In the view of the MS Society, it is vital that CIHR, the federal government's premier research funding agency, has the financial resources required to be able to increase Canada's leadership role in health research. In our view, this is best achieved by **ensuring that the Government of Canada continue to commit taxpayer-paid dollars for health research through CIHR** and not to disperse those dollars to external organizations.

2. Strategy for income security

Income security for people affected by MS is of utmost importance, since significant costs of the disease are borne by individuals and their families. **Our overall recommendation is for the Government of Canada to commit to leading the development of a pan-Canadian income security program for people affected by MS and other episodic disabilities, chronic diseases and disabilities.** Development of the strategy should involve provincial governments since the current hodgepodge of disability pensions, social assistance programs and tax credits, often cannibalize each other, resulting in less money for people with disabilities. Persons with disabilities and organizations representing persons with disabilities as well as researchers must be part of the strategy development.

It is important the strategy build on the excellent work that has been accomplished or is underway. We applaud the development of the Registered Disability Savings Plan (RDSP) – although improvement is needed for the inclusion of Canadians who are in their 50s before they become disabled – as well as the Working Income Tax Benefit (WITB). We also commend the Office of Disability Issues (ODI), within HRSDC, for recognizing the policy gap between the existing federal policy and program framework in relationship to people with episodic disabilities who have at times a compromised ability to participate in the workforce.⁴ ODI has commissioned research with results expected later this year that should assist policy and program development going forward.

In addition, several provincial governments have developed programs to benefit people with disabilities and their caregivers. The province of Manitoba has introduced a refundable caregiver tax credit that spouses and others can claim. Nova Scotia has initiated a caregiver allowance program for which spouses are eligible.

It is time to capitalize on these efforts and determine what could be done in a practical and immediate way to maximize income security for people affected by MS and other episodic disabilities, chronic diseases and disabilities. **In the meantime, some small but important steps should be taken today to help build better futures for these Canadians:**

- Allow spouses to claim the Caregiver Amount (Tax Credit) – right now this isn't allowed.
- Make Employment Insurance sickness benefits more flexible to allow people with MS and other episodic diseases to work part-time and receive partial benefits.
- Make the Disability Amount (Tax Credit) a refundable benefit.
- Change the Bankruptcy and Insolvency Act so that employees on long-term disability are at the top of the list of creditors in the case of bankruptcy.

Additional Information

Allow Spouses to Claim the Tax Credit for Caregiving – Currently, a spouse, the person who provides most of the caregiving for a person with a disability or chronic disease, is not allowed to claim the Caregiver Amount (caregiver tax credit). Making spouses eligible for the Caregiver Amount would send a strong signal that the federal government recognizes the exceptional contribution that spouses make as caregivers. In our view, the cost of allowing spouses to claim the caregiver amount would not be significant. We were delighted at the introduction in the House of Commons in June 2010 of a private member's bill that would extend the Caregiver Amount to spouses.

Make EI Sickness Benefits More Flexible – Allowing people who have an unpredictable and episodic disease – diseases such as MS, lupus, some forms of mental illness, cancer, arthritis and Hepatitis C and HIV – to have the option to work part time while receiving partial Employment

Insurance sickness benefits, encourages them to stay in the work force. EI rules could be changed to allow individuals to work part time and receive partial sickness benefits for 150 half-days instead of the current 15 weeks or 75 full-days. While this change has the potential to increase the number of EI sickness benefit payouts, this cost will be substantially offset by the increased number of people who will be able to remain at work, earning salaries and paying taxes.

Make the Disability Amount Refundable – The MS Society recommends the Disability Amount (disability tax credit) should be made refundable for people who cannot use the credit because their income is too low or in the case where they cannot transfer the credit. This would provide some modest income for a group of people who unfortunately have some of the lowest incomes in Canada. We understand this has been costed internally.

Change Bankruptcy and Insolvency Act to Assist People with Disabilities – The bankruptcy of Nortel Networks has highlighted the problem faced by employees whose companies have self-insurance benefit plans and go bankrupt. Nortel former workers who are disabled will no longer receive disability benefits after 2010; after that date, they will be considered “creditors” and will have to compete with other creditors to divide the remains of the company’s assets. The MS Society recommends that changes be made to the federal Bankruptcy and Insolvency Act to ensure employees on long-term disability are at the top of the list of creditors to be paid if a company goes bankrupt.

The MS Society works with the Episodic Disabilities Network and Neurological Health Charities Canada to enhance employment and income security for people with episodic disabilities and for neurological conditions.

In closing, the Multiple Sclerosis Society appreciates being able to provide recommendations that will help meet the needs of people affected by MS today and speed the end of this devastating disease through health research.

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- 1 The Canadian Burden of Illness Study Group, “Burden of Illness of Multiple Sclerosis: Part I: Cost of Illness,” *The Canadian Journal of Neurological Sciences*, 1998, 25: 23-30.
 - 2 “Multiple Sclerosis,” Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007: 72-81.
 - 3 Discovery health research is the kind of research that leads to the creation of fundamental knowledge that makes possible commercialization and improvements to the health of Canadians.
 - 4 People with episodic disabilities like MS can often only participate in the workforce intermittently due to the unpredictable nature of the disease. Periods of relative overall good health are followed, unpredictably, by periods of poor health that render it challenging or impossible to work for a period of time.