BRIEF FROM ALS SOCIETY OF CANADA

Executive Summary

The ALS Society of Canada (ALS Canada) is pleased to participate in the pre-budget consultation process, and appreciates the opportunity to share with the members of the House of Commons Standing Committee on Finance, our thoughts on the future of the Canadian economy.

This submission addresses one of the key themes the committee is focusing on: supporting families and helping vulnerable Canadians by focusing on health. ALS Canada recognizes that in addressing these questions our recommendations will have tax and budget implications. At the same time, we believe our recommendations support families and help vulnerable Canadians.

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease and the most common motor neuron disease in adults.[i] ALS cannot be "caught" – it is not contagious nor is it attributed to lifestyle choices. In 90% of cases, ALS strikes people with no family history of the disease. Only 10% of cases are classified as familial or inherited. It may occur at any age and many people are struck down in the prime of life.

ALS has no known cure or effective treatment yet. For every person diagnosed with ALS, a person living with ALS dies. Approximately 2,500 - 3,000 Canadians currently live with this fatal disease. Eighty per cent of people with ALS die within two to five years of diagnosis.

People living with the disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord. ALS usually becomes apparent either in the legs, arms, throat or upper chest area. Some people begin to trip and fall, some lose the use of their hands and arms, some find it hard to swallow and some slur their speech, but it will spread throughout the body regardless of the initial symptoms. Most often, death is a result of the eventual paralysis of the muscles in the throat and diaphragm as the patient loses the ability to swallow, cough and breathe.

ALS wreaks a devastating effect on patients as well as their families. Due to often rapidly advancing paralysis, ALS patients become solely dependent on their caregiver, and as a result, the quality of life of both patients and their families is dramatically affected. A result of ALS is often an immediate loss of household income due to rapid degeneration, as well as limited employment opportunities and income loss for family caregivers as significant demands to provide care and support increase.

As they struggle to cope with the prospect of advancing disability and death, ALS patients and their families may find their financial, physical and emotional resources exhausted. It is a costly disease – demanding expensive medical care, home modifications and equipment.

There is no cure for ALS. Although research has resulted in significant breakthroughs, more is needed to find a cure. Thanks to recent discoveries, there is hope for people diagnosed with ALS.

Together with ALS Canada, the federal government has built a network of hundreds of researchers focused on finding treatments of a cure for ALS; however, investment in targeted ALS research by the federal government has declined over the past several years. This declining research investment threatens the research capacity in Canada, but also the significant progress in ALS research for care and cure that Canada

has spent over a decade cultivating and which has the potential to change the lives of ALS patients, their families and the ALS world outside of Canada's borders.

ALS Canada, founded in 1977, is the only national voluntary health organization dedicated solely to the fight against ALS and support for those with the disease. ALS Canada is the leading not-for-profit organization working nationwide to fund ALS research and, with the Provincial ALS Societies, we all work to improve the quality of life for Canadians affected by ALS.

Our recommendations are:

1. That the government extend the Compassionate Care Benefits from its current 6 weeks to 35 weeks for caregivers of individuals living with ALS, with Benefit eligibility upon diagnosis.

2. That the government matches ALS Canada's fundraising efforts, with an investment of up to $1.5 million per year to continue research to find a cure for ALS.

Considerations

1. Compassionate Care Benefit

Eighty per cent of Canadians diagnosed with ALS will die within 2 to 3 years after onset. On average, when someone is diagnosed with ALS, a working age Canadian family can expect to incur costs averaging $150,000 - $250,000 during the short window of the diagnosed patient's life[ii]. To put this into context, patients with ALS have substantially higher mean annual costs than patients living with HIV/AIDS, stroke survivors during the first year after stroke, and Alzheimer's disease[i,ii].

Not all people with ALS experience the same symptoms or the same sequences or patterns of progression. However, due to universal progressive muscle weakness and paralysis, patients are often forced out of work shortly after diagnosis.

Although Canada has a universal, government-funded, public health care system and patients can receive limited home care support through provincially funded community care programs, these programs are inconsistently available across the country and significant personal expenses are still incurred.

In addition to progressive functional disability, the economic burden of ALS to patients and families is significant. Expenses associated with symptom management and care can be divided into direct (equipment, home renovations, palliative medication, mobility/communication aids, medical services) and indirect costs (income due to job loss, forced early retirement and extended unpaid absence of caregivers).

- Direct costs: average annual cost per patient = $32,337 (61% - $19,574 are out-of-pocket expenses)
- Indirect costs: average annual cost per patient = $56,821[ii]

At almost double the value of the direct costs, indirect costs represent a huge burden to ALS patients and families. The degeneration of muscles and motor skills in ALS patients results in a loss of independence making it necessary to have daily, and in many cases, around-the-clock care. Additionally, the specialized, multi-disciplinary requirements for people with ALS, who must overcome unique physical and communication disabilities, are not readily achievable in many Canadian healthcare institutions (hospitals, long-term care facilities, etc.). Therefore, unlike other neurodegenerative diseases, the daily caregiving

activities required by patients are normally performed by their own family members, not out of preference, but out of necessity. This often requires loved ones to take an extended unpaid leave of absence from their jobs, which exacerbates the negative effects of the direct costs incurred by the family. For many caregivers, in addition to a loss of income when they can least afford it, their career path is often significantly impacted and will have future negative employment and income impacts. In the event that the caregiver is the spouse of the ALS patient, which is often the case, the ALS diagnosis can mean immediate and significant financial strain as both incomes are lost due to the demands related to caring for an ALS patient.

Currently, ALS patient caregivers are only eligible for 6 weeks of benefits under the Compassionate Care Benefit program. Given the significant financial strain that ALS causes for both patients and families, extending this benefit is a necessary and appropriate step that recognizes the financial realities and hardships associated with an ALS diagnosis and the needed home care.

Recommendation

That the government extends the Compassionate Care Benefit from its current 6 weeks to 35 weeks for caregivers of individuals living with ALS, with Benefit eligibility upon diagnosis.

2. ALS Research

The vision of ALS Canada is to make ALS a treatable disease by 2024. That vision can only be realized through a commitment to research. In 2013, ALS volunteers raised $1.5 million for ALS research, but we cannot achieve our goal without ongoing, dedicated government funding for ALS research.

The past 15 years have seen an enormous growth in the number of research projects (both basic and clinical) devoted to ALS, many of which have been supported by the Government of Canada through the Canadian Institutes for Health Research (CIHR). In fact, CIHR's investment in ALS research, alone and through the Neuromuscular Research Partnership with ALS Canada, has helped to support hundreds of researchers and more than 25 laboratories in Canada working towards understanding ALS, and more importantly, developing therapies to slow down progression of the disease.

Unfortunately, the CIHR funding model has changed and, as a result, targeted ALS research funding has seen a significant decline since 2012. Without dedicated ALS research funding, the ALS research community will not be able to sustain the momentum achieved from years of federal funding, and Canada is at risk of not fully leveraging the research investment that the federal government has made over the past decade.

Building on the research of the past 15 years, the ALS research community has reason to believe that it is close to identifying the first effective therapy for ALS; the first in the world. To support this breakthrough research, ALS Canada has just launched its biggest initiative to date, the Arthur J. Hudson Translational Team Grant, which will provide $1 million to a team of Canadian researchers (from multiple institutions) to develop new therapeutic options and move them to clinical trial.

This work will indeed be ground-breaking and world leading, but it is also an example of the type of research opportunity that the ALS community and federal government should jointly support. After years of investment in the necessary basic research, Canada is now close to bringing this research to the patient and making a measurable impact in the lives of Canadian patients and their families. We can't afford to stop now.

The Arthur J. Hudson Translational Team Grant is but one example of ALS research projects that could be jointly funded to advance ALS research and achieve truly world-leading advancements in the care and cure for ALS. By matching the grassroots fundraising of the Canadian public, the government could help to fund either multiple translational grants or increase the impact by making each one more lucrative.

Recommendation

That the government matches ALS Canada's fundraising efforts, with a dedicated investment of up to $1.5 million per year to continue research to find a cure for ALS.

[i] Julio Lopez-Bastida, Lilisbeth Perestelo-Perez, Fernando Monton-Alvarez, Pedro Serrano-Aguilar & Jose Luis Alfonso-Sanchez (2009). Social economic costs and health-related quality of life in patients with amyotrophic lateral sclerosis in Spain. Amyotrophic Lateral Sclerosis; 10:237-243

[ii] Matthew Gladman, Celinda Dharamshi & Lorne Zinman (2014). Economic burden of amyotrophic lateral sclerosis: A Canadian study of out-of-pocket expenses. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2014; July 15 : 1–7 [Epub ahead of print]

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