Open letter to party leaders on M.E.

OUR READERS WRITE

With a federal election called, we are writing to you about the public health crisis affecting 600,000 Canadians who are living with Myalgic Encephalomyelitis (ME) without adequate health care.

Together with loved ones, who often act as caregivers, this represents millions of voters. We are asking for your party's plan to address this neglected disease as well as your commitment to improving health care and research for Canadians living with this severely disabling, life-altering illness.

Over 75% of people with ME acquired the illness following an infection, mostly viral in nature, from which they never recovered. As the COVID-19 pandemic ravages our world, we are now seeing a public health catastrophe unfolding with 30% of survivors developing Long COVID.

According to the New England Journal of Medicine, this ?disaster-in-the-making? is not at all surprising as post-infectious illnesses like ME foreshadowed the looming Long COVID catastrophe. Many with Long COVID are now meeting the criteria for and being diagnosed with Myalgic Encephalomyelitis as the links further below reveal.

This in turn will result in hundreds of thousands of additional Canadians whose health has been severely compromised, raising disability rates, affecting workforces, increasing demands on our already fragile health care system and driving economic costs substantially higher.

A recent submission to the National Academy of Medicine places the annual economic cost of ME pre-pandemic in the billions of dollars.

Following are a few facts about ME:

75% are unable to work costing billions in lost productivity;

25% are housebound or bedridden;

there is no cure or approved treatment;

patients have a lower quality of life than many chronic diseases including cancer, heart disease, stroke and multiple sclerosis;

appropriate medical care is scarce with less than a dozen doctors across Canada knowledgeable in understanding the disease; contraindicated therapies are routinely prescribed; there is an urgent need for physicians trained in diagnosing and treating ME;

patients often travel to the US at great personal and financial cost for symptom management and the limited therapeutic options that exist;

medical gaslighting, discrimination, marginalization, stigmatization and trauma are experienced on a regular basis ? all factors contributing to the higher suicide rate;

research funding by the Canadian government is almost non-existent at 49¢ per patient, whereas multiple sclerosis, a chronic illness with similar disease burden affecting significantly less people (108,600) has a research investment of $97.08 per patient.

Exactly where you and your party stand on issues that affect our health is of the utmost concern to us as patients, advocates and voters. We are asking for your prompt reply to the questions that follow so that we can share them with voters in the Canadian ME community:

ME is a serious, chronic, complex, systemic disease that can profoundly impact and incapacitate patients yet has little research funding. What actions will you take to significantly increase research funding into this debilitating illness?

What specific commitment will you make to Canadians living with Myalgic Encephalomyelitis so that, if elected, you can effectively represent their concerns in the House of Commons and on Committees as their elected representatives?

Whether or not your party is successful at winning the election, it is incumbent upon you as leaders in our country to learn about ME and prioritize taking action to bring equitable research funding and increased public awareness to the hundreds of thousands of Canadians impacted by this disease.

Barbara Fifield Millions Missing Canada