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Finance Committee pre-Budget Recommendations 2014.

Summary

The following recommendations will improve the lives of over 800,00 Canadians and their families affected by chronic Neuro-Immune Diseases - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia. Current systems do not accommodate the needs for research and a review is required to address the rights of Canadians disabled by these illnesses.

These two initiatives are needed for patients and their families. These initiatives will also benefit all Canadians who value an efficient, effective health care system and a fair and inclusive society.

Background

"If you are sick, you want to have an illness that is well understood and respected. You don't want to have ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) or Fibromyalgia."

Lydia Neilson MSM, CEO of the National ME/FM Action Network since 1993.

According to Statistics Canada's Canadian Community Health Survey 2010

- There were 756,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both. This is equivalent to the population of New Brunswick.
- ME/FM patients were predominantly female and predominantly of working age.

People with ME/FM reported high levels of

- unmet health care needs and unmet home care needs. They are poorly served.
- needing help with tasks, difficulty in social situations and permanently unable to work. They are disabled even if they are rarely thought of as disabled.
- low income, isolation and even food insecurity. They are socially disadvantaged.

The ME/FM community is a vulnerable community in crisis. Canada can do much better. The Federal government has an important role to play. The two recommendations are major steps toward addressing the needs of this vulnerable community.

Recommendation 1:

ME/CFS and FM are complex multi-system illnesses with abnormalities in the neurological, immune, endocrine and metabolic systems. Research is needed to support prevention, diagnosis and treatment of these illnesses. Canada has almost no ME/FM research activity. There has been almost zero funding from CIHR over the past decade.

The mandate of CIHR includes developing research capacity in emerging areas. Current strategies haven't worked for this emerging area. CIHR needs a new strategy.

Our recommendation asks for the **creation of a new institute at CIHR** with long term designated funding to attract research to this neglected area of study and to provide the health system with a solid foundation for diagnosing, treating and preventing ME/CFS and FM.

Expected cost :

\$20 million per year over 5 years after a two-year phase in period

Funds can be reallocation within CIHR. CIHR has \$1Billion per year for research. Almost none has been allocated to ME/FM research. Designating some of the CIHR funding for ME/FM research would allow a ME/FM research community to develop to the point that it can eventually compete for funding on an equitable basis with established research areas.

Who will Benefit:

- people with ME/CFS and/or FM, their families and caregivers
- health professionals who are grappling inefficiently and ineffectively with these illnesses
- taxpayers who are paying for the inefficient and ineffective health system
- the economy which is losing valuable human resources to these illnesses
- Canada's international reputation in health and research

General impacts:

With better understanding of these illnesses, some cases could be prevented or minimized while the quality of life of other people could be substantially improved.

Recommendation 2:

ME/CFS and FM have been plagued by lack of information and misinformation. The seriousness of the illnesses and resulting disability have been grossly underestimated. It is hard enough dealing with the illnesses without having to deal with misinformation and stigma as well. We are asking for an interdepartmental team to fix the problems right away so that people with ME/FM do not have to deal with this additional burden.

Create an interdepartmental task force to address the discrimination and stigma facing Canadians with ME/FM. The task force would:

- review government publications and websites to ensure that information is complete and correct
- review government programs and services to ensure that they are inclusive and that deserving applicants are approved without undue effort or delay
- implement a public awareness campaign to ensure that Canadians are informed about these illnesses and resulting disabilities
- identify additional initiatives needed to ensure justice and equality for Canadians with ME/FM.

Expected cost :

\$10 million over 2 years, with much of this going to public advertising

Health Canada funds the Mental Health Commission to undertake an anti-stigma anti-discrimination strategy in the area of mental health, a parallel exercise. Other funding could come from participating departments and agencies.

Who will Benefit:

- people with ME/FM, their families and caregivers
- officials who want to provide optimal, inclusive programs and services
- members of the public who encounter people with ME/FM such as employers, co-workers, teachers, fellow students, neighbours and friends
- taxpayers who are paying for an inefficient, ineffective and unfair social system
- the economy which is losing valuable human resources to these illnesses
- Canada's international reputation for justice and equity

General impacts:

This recommendation will go a long way toward addressing the social disadvantage experienced by the vulnerable ME/FM community. With better public understanding of the illnesses, there will be less sense of isolation. With better programs and services, there will be less economic and social distress.