



**Submitted to The House of Commons Standing Committee on Finance
August 5, 2016**

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Background

Parkinson's is a neurodegenerative disease of the brain that touches almost every aspect of daily living including: movement, mood, speech, ability to smell, eating and drinking, sleep, and cognitive impairment.

Parkinson's disease is commonly treated through drug therapies; however, evidence shows that access to a range of different therapies is vital. Exercise, dietary changes, physiotherapy, speech and occupational therapies, as well as counselling have been shown to improve the health and wellbeing of people with Parkinson's disease.

Parkinson's is an incredibly challenging disease to manage. People with Parkinson's have the highest rate of prescription drug use compared to other neurological conditions. Many people with the disease must take upwards of 50 pills a day, on a regimented basis, to be able to function. Over time, the benefits of medication become less effective at controlling symptoms associated with Parkinson's disease, and in some cases become the cause of undesired side effects, like involuntary movements (dyskinesia).

More recently surgical treatments such as Deep Brain Stimulation (DBS) – the implanting of electrodes in the brain – have surfaced as an invasive treatment option for the small number of people (5-10%) with Parkinson's disease who qualify. This therapy, like drug treatment, is not curative and targets symptom management – rather than addressing the underlying cause of the disease.

There is no known cure for Parkinson's disease.

In Canada today, Parkinson's disease is the second most common neurodegenerative disorder and affects more than 100,000 Canadians. Over the next 15 years, the number of Canadians diagnosed with Parkinson's is expected to increase by 65%.

Although Parkinson's is the second most common neurodegenerative disorder, next to Alzheimer's disease and dementia, it is growing at the same staggering rate as the top condition. This is due to the steep increase in the incidence of Parkinson's disease in individuals over the age of 65; which makes up 85% of the population with Parkinson's.

Recommendation: Establish a Canadian Parkinson Network, which includes a Parkinson's disease registry and a structured surveillance system, to more accurately and consistently track relevant data about Parkinson's disease.

Purpose and Rationale

While many centres in Canada are recognized worldwide for their research in Parkinson's disease and related disorders, no platform currently exists to link data from these different sites, to make them accessible to a wider number of researchers.

A Canadian Parkinson Network (CPN), which includes a Parkinson's registry and structured surveillance system, are needed to more accurately and consistently track relevant data about Parkinson's disease, including population-based trends. This direction would also address the current gap in epidemiological data. A lack of information on the prevalence and incidence of Parkinson's disease is concerning, particularly as the population ages and more people are diagnosed. This gap in knowledge will hamper health planning and impact the appropriate allocation of resources.

The CPN will unite the resources of eight Canadian centres, including the Quebec Parkinson Network, the Pacific Parkinson's Research Centre at the University of British Columbia, the Parkinson Research Consortium in Ottawa, the Movement Disorders Centre at the Toronto Western Hospital, the Movement Disorders Program of the University of Alberta, the Movement Disorders Program of the University of Calgary, the Neurology division of the Memorial University, and the Neurosurgery department of Dalhousie University. Each of these centres will provide clinical, imaging and/or genetics/biological data of idiopathic and familial Parkinson's patients to a central database that is ready to be coordinated at the Centre de Recherche Institut universitaire de gériatrie de Montréal.

The CPN will build on existing government investments, such as the national population health study of neurological conditions (know as Mapping Connections: An Understanding of Neurological Conditions in Canada). Neurological Health Charities Canada, of which Parkinson Canada is a leading member, co-managed this research project with the Public Health Agency of Canada (PHAC). This project resulted in PHAC building some surveillance into its annual surveillance plan, which could be specifically leveraged by the CPN. The project also funded the development of guidelines and a toolkit of resources to assist in the design and implementation of new neurological registries in Canada, which will be a valuable asset to leverage in the development of a Parkinson disease registry as a component of the CPN.

The CPN would also leverage the ground-breaking research and partnerships that are already happening across the country.

The CPN will enable Canada to increase its research leadership in the pathophysiology and treatment of Parkinson's disease, develop new treatments and improve the quality of life of patients, their families and caregivers. It will also provide a more comprehensive database that will help to inform health and social planning and policy.

Funding request for the establishment, coordination and management of the CPN is \$10 million over five years.

Parkinson Canada is the national voice of Canadians living with Parkinson's. We provide education, advocacy and support services in communities coast to coast to individuals and the health care professionals that treat them, since 1965. The National Research Program funds innovative research to search for better treatments and a cure. Parkinson Canada is an Imagine Canada accredited organization.