



Parkinson Canada Priorities for the 2018 Federal Budget

Submitted to the House of Commons Standing Committee on Finance

August 4, 2017

For more information please contact:
Jacquie Micallef
Sr. Manager, Public Affairs and Partnerships
Parkinson Canada
Jacquie.Micallef@Parkinson.ca
1-800-565-3000 ext. 3501

Executive Summary

Parkinson Canada has partnered with leading researchers from across Canada to create the Canadian Parkinson Network and Registry (CPNR). CPNR will bring together Canada's best in Parkinson's research and will give them a platform to share information and make new connections.

The CPNR will include: a patient registry with comprehensive clinical information; database with information from diagnostic (MRI, PET scans), anatomical (neuroimaging, sleep, behavioural and neuropsychological information) and functional measurements; biobank (i.e. patient biomaterials such as blood samples and DNA for genetic studies).

The connection of Parkinson's research centres is a model that exists in the USA and in Europe. In Canada, current models for common platforms already exist for other neurological and psychiatric conditions such as Stroke, Mood Disorders, ALS, Cerebral Palsy and Alzheimer's disease. This initiative will also build on the existing and highly successful model of the Quebec Parkinson Network (QPN).

The Canadian Parkinson Network and Registry (CPNR) will enable Canada to increase its research leadership in the pathophysiology and treatment of Parkinson's and related disorders by providing access to large datasets required to understand the pathophysiology of the disorder, to develop new treatments and improve the quality of life of patients, their families and caregivers. Through strategic partnerships with local, national and international organizations the CPNR will help to translate research into clinical practice and transfer the knowledge to clinicians and caregivers. This will provide prevention and treatment strategies, while reducing financial costs to Canada's health care system.

Parkinson Canada is asking the Canadian Government to partner with us and our collaborators in Parkinson's research from across the country by investing \$15 million into the CPNR. To date, Parkinson Canada has invested \$1 million over the next five years towards this initiative.

Parkinson disease Research in Canada

The Challenge

As the population continues to age, the number of Canadians diagnosed with Parkinson's will dramatically increase. In several regions in the country, there has already been a more than 40 per cent increase in the prevalence of Parkinson's over the past 10 years¹. Canada is home to several world-renowned research centres focusing on Parkinson's disease. Unfortunately, research centres in Canada are limited in their ability to share data and resources because they are all working on different platforms that prevent them from pooling databases, effectively sharing information, and optimizing and building on new discoveries.

The Solution

Parkinson Canada and our research partners across Canada (named below) are working towards the creation of a **Canadian Parkinson Network and Registry (CPNR), which is a joint initiative between Parkinson Canada and Parkinson Disease Centres across the country.**

The goal of the proposed network is to promote and facilitate multi-disciplinary and multi-centric research in Parkinson's disease and related disorders across Canada. The proposed platform will incorporate a patient registry with comprehensive clinical information, a de-identified database including anatomical and functional Magnetic Resonance Imaging (MRI), PET, as well as a bio-bank to collect genetic data and patient-derived cells. This infrastructure will help the execution of large-scale projects that cannot be addressed without a nationwide database. It will also encourage patients' participation into studies and clinical trials while informing them about the latest research and therapies available.

To-date eight centres known for their excellence in movement disorders research in four different provinces (QC, ON, AB, BC) have expressed an interest in building the platform. In the future the network will be open to any researcher or clinician in Canada. In particular, anonymized data will be made accessible to other researchers and clinicians throughout Canada who wish to join the Network as users or contributors. The infrastructure will be able to support many types of projects from bench to bedside that will inform us on mechanisms and markers of Parkinson's progression, novel treatments and treatment strategies, as well as clinical trials.

The implementation of such a network requires a large number of personnel to coordinate the acquisition, normalize and curate data from different acquisition modalities from the different sites as well as to manage the platform nationally. These include a project manager, various clinical research coordinators, research associates, research nurses, psychometrics, and information technology specialists.

While many centres in Canada are recognized worldwide for their research in Parkinson's and related disorders, no platform currently exists to link data from these different sites to make this data available to a wider number of researchers. New research breakthroughs are needed to significantly improve our understanding of Parkinson's disease on many levels. Given the complexity of Parkinson's disease, this goal can only be achieved by combining resources across multiple Parkinson centres in Canada, which would result in more cost and time effective research.

¹ Institute for Clinical and Evaluative Services (2016). *Response to an Ontario Ministry of Health and Long-Term Care Applied Health Research Question*. Report available upon request to Parkinson Canada.

Some examples of why this is the case and how research could be accelerated include:

- (i) Sharing data on familial cases of Parkinson's, while fairly rare, can be very informative in guiding therapies;
- (ii) Sharing some investigative tools such as positron emission tomography (PET) which is extremely costly and require different centres to combine their data;
- (iii) Finding a given sub-population for a large-scale clinical trial at a single research site in Canada is almost impossible given the diversity of patients and the importance of characterizing differences in their disease progression; and,
- (iv) Developing a more effective and efficient sharing of information by pooling databases optimizing and building on new discoveries.

Connecting Parkinson's research centres is a model that exists in the USA and in Europe. In Canada, current models for common platforms already exist for other neurological and psychiatric conditions such as Stroke, Mood Disorders, ALS, Cerebral Palsy and Alzheimer's disease. The

The proposed initiative will be built upon and will benefit from the existing and highly successful model of the Quebec Parkinson Network (QPN), which already has a patient registry as well as a clinical/imaging database and a bio-bank. The QPN is currently helping to run over 30 studies in 15 different research centres and University departments in Quebec that includes 900 patients (with a target of 1,000). Nearly 80 clinicians and researchers are members of the QPN and over 25 neurologists participate in the registry by implicating their patients. There are also many associate members and students who participate in the QPN as well (e.g. research assistants, research nurses, graduate/post-graduate students and interns). It is also already sharing data with partners in other provinces such as Alberta (the Calgary Parkinson Initiative, CaPRI). The guiding principles and philosophy for data sharing will be similar to that of the QPN.

Funding Request

Parkinson Canada is requesting the support of the Canadian Government to partner with us and our research partners across the country by investing \$15 million over the next five years into the development and implementation of this Canadian Parkinson Network and Registry.

Parkinson Canada has already committed a minimum of \$1 million over the next five years towards this initiative and is acting in a facilitator, catalyst, and fund raiser for the development of this initiative. This investment will allow for significant nationwide improvement in Parkinson's research by reducing the overall research cost through combining and sharing costly data and information and optimizing data collections and avoiding redundancy.

The creation of the proposed Canadian Parkinson Network and Registry will be the key driver to propel Canada to a leadership position in Parkinson's research and treatment by providing access to the large datasets required to understand the disease, to develop new treatments and to improve the quality of life and keep Canadians participating in all areas of life, including in the workforce, for as long as possible.

Canadian Parkinson Network and Registry Partners

Dr. Oury Monchi, University of Calgary

Dr. Edward A. Fon, McGill University and A. Jon Stoessl, University of British Columbia

British Columbia:	Dr. Martin McKeown Dr. Silke Cresswell Dr. Vesna Sossi Dr. Matthew Farrer
Alberta:	Dr. Richard Camicioli (proposed UoAlberta site leader) Dr. Janis Miyasaki Dr. Davide Martino Dr. Justyna Sarna
Ontario:	Dr. Antonio Strafella Dr. Susan Fox Dr. Robert Chen Dr. David Park
Quebec:	Dr. Anne-Louise Lafontaine Dr. Guy Rouleau Dr. Ron Postuma Dr. Nicolas Dupré

About Parkinson Canada

Parkinson Canada, operating since 1965, is the recognized voice and central resource for people living with Parkinson's, their caregivers and health care professionals. Parkinson Canada's mission is to transform the lives of people living with Parkinson's through research, education, advocacy and support services.

Parkinson Canada's Research Program funds innovative research for better treatments and a cure.

As a national registered charity, Parkinson Canada fulfils its mission through the generosity of donors and is an accredited organization under the Imagine Canada Standards Program.

Parkinson's disease in Canada

Canada is experiencing a steep rise in age-related neurological conditions. Current projections estimate this unprecedented growth rate to continue over the next 15 years. Today there are approximately 100,000 Canadians diagnosed with Parkinson's. By 2031, the number is expected to rise dramatically to over 163,000².

Parkinson's touches every aspect of daily living, including: movement (slowness and stiffness, rigidity of muscles, impaired balance), mood, speech, eating and drinking, sleep and cognitive changes. Parkinson's leads to dementia in approximately 30 per cent of Canadians diagnosed and more than 50 per cent have depression.

² Public Health Agency of Canada (2014). *Mapping Connections: An understanding of neurological conditions in Canada*: <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>

Parkinson's is progressive, which means it worsens over time resulting in a loss of independence and ultimately premature death.

While medication treatments and deep brain stimulation have improved the quality and longevity of life of individuals with Parkinson's, there is still no known cause or cure for the disease.

2017 marks 200 years since Parkinson's disease was first identified. 200 years without a cure is too long.