



**Written Submission for the Pre-Budget Consultations in  
Advance of the 2020 Budget**

**Provided by: Parkinson Canada**

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## **Recommendation**

- **Recommendation 1:** That the government provide funding in the amount of \$30M over the next five years to expand the Canadian Open Parkinson Network (C-OPN).

A group of renowned researchers recently determined that Parkinson's is becoming a **pandemic** due to the growing prevalence of the disease in all regions around the world<sup>1</sup>. By 2040, the global prevalence of Parkinson's is expected to **double** from 6M to 12M<sup>2</sup>.

Prevalence of Parkinson's disease in Canada has increased nearly 50 percent over the past 10 years<sup>3</sup>. There are currently **100,000** people living with Parkinson's disease and related disorders (parkinsonisms) in Canada<sup>4</sup>. The number of Canadians diagnosed with Parkinson's will continue to rise dramatically, particularly with the growing seniors' population. The common age of onset for Parkinson's disease is 60; however, younger people can also be diagnosed with the disease. Neurologists in Canada diagnose more than 25 Canadians with Parkinson's disease each day and by 2031 that number is expected to rise to more than **50 people a day**<sup>5</sup>. The economic burden of Parkinson's in Canada is more than **\$1.215B** in direct and indirect costs associated with the disease<sup>6</sup>.

Parkinson's disease is the **fastest-growing** neurological disease in the world and a leading cause of disability<sup>7</sup>. Parkinson's disease is also the **most prevalent** neurodegenerative movement disorder<sup>8</sup>.

Among the myriad of symptoms experienced, people with Parkinson's overwhelmingly agree that the non-motor symptoms have the most negative impacts on quality of life<sup>9</sup>. These symptoms include changes in cognition and memory, fatigue, sleep disturbances, anxiety and depression.

### **Opportunity for Canadian Leadership**

There is an opportunity now for Canada to lead in Parkinson's disease research that will produce a better understanding of Parkinson's (e.g. causation and potential risk reduction), optimized care, and overall improvements in quality of life, and a reduction in disease burden.

Canada is home to several world-renowned research centres focusing on Parkinson's disease. Unfortunately, these centres do not share a common platform which limits their ability to pool databases, effectively share information, and optimize and build on new discoveries.

Parkinson Canada is partnered with the leading Parkinson's disease researchers in the country to create the **Canadian Open Parkinson Network (C-OPN)**. C-OPN is designed to address the challenges limiting Parkinson's researchers' ability to accelerate discoveries and increase research involvement from patients. C-OPN is a shared platform with an open data concept with the goal to accelerate breakthroughs, improve patient outcomes, increase clinical trial involvement, and ultimately find a cure for this life-limiting disease.

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<sup>1</sup> Dorsey E.R., Sherer T., Okun M.S., Bloem B.R. (2018). The Emerging Evidence of the Parkinson Pandemic. Journal of Parkinson's Disease, 8(Suppl 1): S3–S8.

<sup>2</sup> Ibid.

<sup>3</sup> Public Health Agency of Canada, using Canadian Chronic Disease Surveillance System data files contributed by provinces and territories (2017). Retrieved from: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/parkinsonism.html>

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

<sup>6</sup> Canadian Institute for Health Information (2007). The Burden of Neurological Diseases, Disorders and Injuries in Canada (p. 84): Ottawa, Canada. *Additional calculations done based on this information to account for the growth in the number of people with Parkinson's and inflation rates in Canada.*

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> Ipsos Reid (2017). Parkinson's Community Stakeholder Survey. Retrieved from: <https://www.ipsos.com/en-ca/news-polls/parkinson-canada-stakeholder-survey-2018>

The goal of C-OPN 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), Positron-Emission Tomography (PET), as well as a bio-bank to collect genetic data and patient-derived cells. This infrastructure will help execute 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.

Some examples of how research will be efficiently and effectively accelerated in the C-OPN include:

- Sharing data on familial cases of Parkinson's, while fairly rare, can be very informative in guiding therapies;
- Sharing some investigative tools such as Positron Emission Tomography (PET) which is extremely costly and require different centres to combine their data;
- 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,
- 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. National models for common platforms already exist in Canada for other neurological and psychiatric conditions such as Stroke, Mood Disorders, ALS, Cerebral Palsy and Alzheimer's disease.

C-OPN is 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. QPN is a confirmed partner of C-OPN and has their data included in the Network.

Since its establishment in 2013 QPN has exceeded its goals and expectations. The key accomplishments of QPN include:

- 1250+ Parkinson's patients included in the patient registry and the list grows daily. 400 of the registered patients self-enrolled. 670 registered patients have participated in research projects and 785 have provided samples to the biobank;
- Enabled 59 research projects that have leveraged \$9.6M toward Parkinson's research in the form of grants;
- The biobank has accelerated research progression by providing study materials, merging datasets to increase statistical power, and reducing duplication efforts. The biobank along with the cutting-edge technology through the platform has leveraged over \$6.5M from major public and private partners;
- QPN has been instrumental in accelerating research projects that has led to publication in 25 peer-reviewed papers, which have been cited in over 188 publications; and,
- Four QPN projects involve clinical trials, as well as one project assessing wearable technology to help neurologists monitor patients outside of clinic appointments.

Currently eight centres in four different provinces (QC, ON, AB, BC) that include more than 50 researchers known for their excellence in movement disorders research have joined C-OPN, and are contributing to building the platform. In the future the Network will be open to any researcher or clinician in Canada and will be expanded to include international partners. In particular, anonymized data will be made accessible to other researchers and clinicians 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 the mechanisms and markers of Parkinson's progression, novel treatments and treatment strategies, as well as clinical trials.

Parkinson Canada has already committed \$1M over the next five years towards this initiative and is acting as a facilitator, catalyst, and fundraiser for the development of this initiative. Parkinson Canada's funding was matched by Brain Canada in 2018 to implement the first phase of C-OPN over the next two years.

The initial investment in C-OPN from Parkinson Canada and Brain Canada has led to the establishment of the first C-OPN centre called the Calgary Parkinson Research Initiative (CaPRI) based at the University of Calgary. To-date, CaPRI has already recruited over 300 people with Parkinson's for the patient registry. CaPRI is the coordinating centre for C-OPN.

C-OPN 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 leading to better treatments and ultimately a cure.

### **Funding Request**

Establish of the Network across the country requires a large number of personnel to coordinate the acquisition, normalize and curate data from different acquisition modalities and sites, and national management of the platform. These necessary roles include a project manager, various clinical research coordinators, research associates, research nurses, psychometrics, and information technology specialists.

Parkinson Canada is requesting funding in the amount of \$30M over the next five years into the establishment of C-OPN in centres across Canada. The \$30M in funding will be managed and administered through the University of Calgary as the coordinating body for the C-OPN research centres.

## **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.