



Transforming Parkinson's research in Canada:

Parkinson's is a complex disease that impacts every area of a person's life. A plan to better coordinate world-class Parkinson's research happening across Canada would create transformational change for people with Parkinson's and their caregivers to live well in their communities through effective use of health, social and economic resources.

What is Parkinson's?

In 1817, Dr. James Parkinson established what we know today as Parkinson's disease in his work, *An Essay on the Shaking Palsy*. In the short essay he describes symptoms like tremor, weakness, and stooped posture.

Research up to now has shown us that Parkinson's also includes a number of other motor and non-motor symptoms like rigidity, impaired balance, fatigue, soft speech, sleep disturbances and cognitive changes.

This year, Parkinson Canada is teaming up with global partners to #UniteforParkinsons.

It has been 200 years since Parkinson's was identified — and 200 years without a cure is too long.

Parkinson's by the Numbers



100,000

Canadians today have Parkinson's



30

the percentage of Canadians with Parkinson's that have dementia



50+

the percentage of Canadians with Parkinson's and depression



25 Canadians are diagnosed with the disease each day*

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



40 is the number of times greater direct health care costs are for people with Parkinson's than for other Canadians

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 years.

Canada is home to several world-renowned research centres focusing on Parkinson's disease. However, 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: Canadian Parkinson Network

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

The Network will include:

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

This initiative will build on and benefit from the existing and highly successful model of the Quebec Parkinson Network (QPN). The QPN is currently helping to run over 20 studies in 15 different research centres and university departments in Quebec. There are currently 900 patients registered, anatomical and functional measurements, fMRI, and it is actively sharing data with partners in other provinces.

The goals of the CPN are to:

- promote and facilitate multi-centric and multi-disciplinary research in Parkinson's;
- pool datasets to better understand pathophysiology;
- increase opportunity and participation in clinical trials;
- contribute to the development of new treatments;
- optimize translational research to clinicians and caregivers more rapidly;
- improve prevention and treatment strategies and accelerate the discovery of a cure.

Parkinson Canada is asking the Canadian Government to partner with us and our partners across the country by investing \$15 million into the CPN. Parkinson Canada has committed to invest \$1 million over the next five years towards this initiative.

Partners

Quebec Parkinson Network:

Dr. Anne-Louise Lafontaine
Dr. Guy Rouleau
Dr. Ron Postuma
Dr. Nicolas Dupré

Research Leads:

Dr. Oury Monchi,
University of Calgary
Dr. Edward A. Fon,
McGill University
A. Jon Stoessl,
University of British Columbia

Additional Research Partners:

BRITISH COLUMBIA:

Dr. Martin McKeown
Dr. Silke Cresswell
Dr. Vesna Sossi
Dr. Matthew Farrer

ALBERTA:

Dr. Richard Camicioli
Dr. Janis Miyasaki
Dr. Davide Martino

ONTARIO:

Dr. Antonio Strafella
Dr. Susan Fox
Dr. Robert Chen
Dr. David Park

ATLANTIC CANADA:

Dr. Harold Robertson

About Parkinson Canada

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 coast to individuals and the health care professionals that treat them, since 1965. The **Parkinson Canada Research Program** funds innovative research to search for better treatments and a cure. Parkinson Canada is an Imagine Canada accredited organization.

Research holds the key to unlock the mysteries of Parkinson's disease. Scientific excellence and the courage to test new ideas are vital in the global search for better treatments and a cure for the disease.

Since 1981, the Parkinson Canada Research Program has invested more than \$26 million in funding for:

- High-quality, innovative Canadian research by established and promising investigators;
- Discovery stage research where investigators test new theories and pursue promising new leads;
- Researchers at the beginning of their careers in order to foster the next generation of Parkinson's scientists;
- Novel research to build greater capacity, promote creativity and engage more researchers;
- More than 503 awards, fellowships, and grants that teach us more about diagnosing and treating Parkinson's disease.

Parkinson Canada is a leading member of Neurological Health Charities Canada (NHCC) and supports the NHCC's call for a Canadian Action Plan for the Brain. The Action Plan includes a focus on:

- Equitable and affordable access to drug treatments;
- Caregivers who are supported in their role through job protection and income enhancements;
- Improved palliative and end-of-life care services;
- Workplace supports and income security;
- Stigma and barriers to inclusivity ensuring these are addressed through public awareness; and
- Increased funding in neuroscience research to better understand cause, prevention, management and cures.



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