

## Brain Canada-Parkinson Canada Platform Grant Canadian Parkinson Network and Registry (CaPNeR) Request for Applications (RFA)

### About Parkinson Canada

Parkinson Canada provides support services and education to people living with Parkinson's disease, their families, and the health care professionals who treat them. Operating since 1965, the organization advocates on issues that concern the Parkinson's community in Canada. The Parkinson Canada Research Program funds innovative research for better treatments and a cure.

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 Canada participates in numerous coalitions and partnerships to effectively fulfil its mission.

- Parkinson Canada is a founding member of Neurological Health Charities Canada (NHCC), whose primary aim is to seek a national brain strategy. In partnership with the Public Health Agency of Canada, a national epidemiological study of neurological disease, [Mapping Connections](#), was published in 2014.
- Parkinson Canada cooperates with a vast range of international, provincial or locally based organizations, whenever it advances the cause of the Parkinson's community.
- Parkinson Canada is a member of the Best Medicines Coalition, Carers Canada, Canadian Coalition for Genetic Fairness, Health Charities Coalition of Canada, Research Canada and the World Parkinson Coalition.

### About Brain Canada

Brain Canada is a national non-profit organization that enables and supports transformative, original and outstanding brain research in Canada. For more than a decade, Brain Canada has made the case for the brain as a single, complex system with commonalities across the range of neurological disorders, mental illnesses and addictions, brain and spinal cord injuries. Looking at the brain as one system has underscored the need for increased collaboration across disciplines and institutions, and a smarter way to invest in brain research that is focused on outcomes that will benefit patients and families.

The Canada Brain Research Fund is an innovative collaboration between the Government of Canada (through Health Canada) and Brain Canada to encourage Canadians to increase their support of brain research, and maximize the impact and efficiency of those investments. Brain Canada is raising up to \$120 million from private and non-federal sources, which is being matched by the Government of Canada on a 1:1 basis. The Fund supports "the very best Canadian neuroscience, fostering collaborative research and accelerating the pace of discovery, in order to improve the health and quality of life of Canadians who suffer from brain disorders."

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## Rationale

Parkinson's disease (PD) is the second most common neurodegenerative disorder and affects more than 100,000 individuals in Canada. It is traditionally characterized by the loss of dopaminergic neurons in the substantia nigra leading to tremor, rigidity, slowness of movement and difficulty with walking and postural stability. However, the clinical manifestations and evolution of symptoms amongst patients are much more heterogeneous than initially thought, likely being the consequence of multiple pathologies. Indeed, it is now well recognised that the pathophysiology is complex and that non-motor symptoms such as cognitive and neuropsychiatric dysfunction play an essential role in the patient's quality of life. While dopaminergic treatments and deep brain stimulation have improved the quality and longevity of life of PD patients, there is still no cure for the disease, which becomes extremely debilitating in the late stages. Furthermore, these treatments only address the motor symptoms and do not have any effect on the frequently more disabling non-motor symptoms.

New research breakthroughs are needed to significantly improve Parkinson's disease care. Given the complexity and heterogeneity of PD, this goal can only be achieved by combining resources across multiple centres, which would result in more cost and time effective research. Some examples of why this is the case include: (i) While familial cases of PD are fairly rare they can be very informative in providing insights into the evolution of early and even preclinical disease, thereby guiding therapies even for more common types of PD; (ii) Some investigative tools such as positron emission tomography (PET) are extremely costly and require different centres to combine their data. (iii) Given the heterogeneity of patients and the importance of characterizing differences in the pathophysiology, it would be almost impossible to find a given subpopulation for a large-scale clinical trial (pharmaceutical or public research) at a single site.

While many centres in Canada are recognised worldwide for their research in PD and related disorders, no platform currently exists to link data from these different sites to make them accessible to a wider number of researchers. Yet such network initiatives exist in the U.S. and in Europe. To put Canada on the map for Parkinson's research worldwide and to benefit from the advantages of combining resources across Canada, it is essential to create a network with a common platform similar to the models that already exist in Canada for other neurological and psychiatric conditions such as Stroke, Mood Disorders, and Alzheimer's dementia. Establishment of a Canadian Parkinson Network and Registry (CaPNeR) is a key initiative of Parkinson Canada.

## Grant details

The Platform Grant is intended to support the development and maintenance of a large-scale Canadian Parkinson Network and Registry that is built on the foundation of the established and successful FRQS [Quebec Parkinson Network](#), involving multiple provinces, in the field of Parkinson's disease and related disorders, as well as its operating costs, for a period of three years. The total amount available to support the platform grant is CDN \$2,000,000.

The platform will have to provide added value to the Canadian Parkinson research. Brain Canada and Parkinson Canada will not prescribe any approaches, but wish for the applicants to answer three questions:

- How can Canada become a leader in Parkinson's research?
- What can be learned and implemented from models in other countries?
- How can nationwide collaborations in the field of Parkinson's disease research be made more efficient?

More specifically, the application should address the following points:

- Establish a patient registry and a comprehensive database and biobank for the storage and rapid dissemination of clinical, biological, imaging and genetic information across the scientific community in order to accelerate PD research.
- Establish the right set of standards in order for the registry and database to be compatible with other international platforms;
- Establish a data sharing plan across the major Movement Disorders centers in Canada;
- Establish a plan to collect data allowing study of the impact of biological biomarkers as well as environmental exposure;
- Promote and facilitate multi-disciplinary and multi-centric research in PD and related disorders across Canada.

By doing so, the platform will result in the following outcomes:

- Performance of studies that can address the heterogeneity of PD and identify subgroups of patients;
- Identified biomarkers that can predict the evolution of both motor and non-motor symptoms;
- Facilitate implementation and coordination of clinical trials across multiple sites;
- Give access to a large database and bio-samples to Canadian researchers in the field;
- Increased international collaborations

### Use of funds

The funds must contribute towards the direct costs of the research for which the funds were awarded, and the benefits should be directly attributable to the grant. The institution pays for the indirect or overhead costs associated with managing the research funded by Brain Canada and Parkinson Canada.

Platform grants are non-renewable.

This grant is not intended merely to replace current sources of funding or sustain current levels of existing platform service and capability.

### Eligible and ineligible costs

Eligible	Ineligible
<p>Purchase of service contracts, equipment repairs and other improvements to prolong the life of the platform and ensure it remains “state of the art”; and to increase its performance, capacity and the number of users supported. <i>Purchase of equipment and hardware may not exceed one quarter of the total value of the grant.</i></p>	<p>Renovation or construction of space, purchase of standard office and laboratory furniture (cabinets, stools, computer desks, etc.)</p>
<p>Specialized supplies and services necessary for operation, to increase the platform’s performance and number of users supported.</p>	<p>Basic laboratory services (heat, light, HVAC, municipal water supply, natural gas, security, cleaning, etc.) and research support services normally provided by an academic institution (e.g. libraries and other repositories of published works, basic animal care, technology transfer functions)</p>
<p>Salaries and benefits for technical and professional personnel responsible for developing, operating, and maintaining the platform.</p>	<p>Salaries and consulting fees of the Lead and Members of the group applying for the Platform grant, and salaries of Associate Members of the group, or students at any stage of training, or postdoctoral fellows.</p>
<p>Development and dissemination of, and access to: databases; data repositories; and patient registries. Development of informatics platforms and portals to access and deposit data; development of technical protocols; data standards; and standard operating procedures.</p>	<p>Costs involved in meeting regulatory or ethical requirements, occupational health and safety requirements, audits or requirements for licensing, etc. Insurance. Costs associated with protection of intellectual property.</p>
<p>Training programs for new users and technical staff; advertising the availability and capability of the platform to users; communications between users intended to improve utilization and operation of the platform; meetings of management committees for purposes of improving operations of the platform.</p>	<p>Costs for the operation of platforms that are for other than neuroscience research, and incurred by users who are ineligible to receive funding from the federal granting agencies (CIHR, NSERC and SSHRC).</p>
<p>Operating costs of a demonstration research project intended to demonstrate the utility and value of a newly-formed platform and secure sustaining funding from other sources, <i>not to exceed one-half of the total value of the grant.</i></p>	<p>If the platform integrates research with other activities, such as service delivery or education and advocacy, costs that are not directly attributable to research and associated knowledge translation activities.</p>

Note that this list is not exhaustive, and Brain Canada and Parkinson Canada may rule any other expenditure eligible or ineligible. Please contact Brain Canada about the eligibility of expenditures not listed above.

## Eligibility

- This opportunity is open to groups of two or more investigators who are eligible to apply for research grants from the Canadian federal granting agencies (CIHR, NSERC, and SSHRC).
- The group must comprise a Leader and at least one Member, and may include one or several Associate Members:
  - The **Leader**, nominated by the group, will be the individual responsible for submitting the application on its behalf, and for all communication with Brain Canada. The Leader will normally be the individual responsible for overall management of the grant. He/she is also accountable for the group's research activities and use of funds that will be reported on an annual basis with a progress and financial report;
  - A **Member** is an individual who contributes directly to the platform-related activities;
  - An **Associate Member** may include foreign investigators, or investigators from industry or government sectors who can contribute their own funding to the activities of the grant, but they cannot receive funding from the Brain Canada/Parkinson Canada grant except as contractors who undertake specific fee-for-payment activities associated with the establishment or operations of the grant.

## Criteria for Assessment

**Excellence and impact of the research** that is to be conducted using the platform. The platform enables excellent researchers to generate novel results that contribute to the advancement of theory and concept, or lead to the development of new approaches for prevention, diagnosis and treatment of PD and related disorders. The research conducted includes sex and gender considerations. The research enabled by the platform grant could not be conducted in its absence, except at much greater cost and more slowly, and support for the platform will enhance Canada's capability in neuroscience research. The ultimate impact of this research will be to reduce the burden of disease, improve quality of life, and/or stimulate economic development in Canada. The platform enhancements will stimulate intersectoral (e.g. university/industry, university/health care service) or international collaboration.

**Distinctiveness of the platform.** The platform is unique in its capabilities within the nation, region, or locality.

**Exemplary management.** The group managing the platform is well-qualified, experienced and pan-Canadian in scope. The governance and organizational structure created with the platform grant is strong, effective, and widely understood by users. There is an equitable and user-friendly process for access, and users receive training and assistance, allowing them to use the existing platforms and its services in the most efficient and economical fashion. There is regular budget planning for operations and maintenance, and for technical modifications to keep pace with scientific progress. The operation of the group is reviewed or audited regularly against defined performance benchmarks and identified deficiencies are corrected.

**Data sharing, ethics and privacy.** Standards and protocols for data collection and sharing permit the maximum interoperability with other databases or repositories, and also ensure the security of the data and protect the confidentiality of personal information. Linkages to other databases, repositories, biobanks, and registries are described. The applicants must explain how their platform that includes repositories, databases and registries containing information about

patients or human subjects conforms to the relevant sections of the “Neurological Registry Best Practice Guidelines” published in Canadian Journal of Neurological Sciences, Vol. 40 No. 4 Supplement 2, July 2013 and also available at <http://canadianregistrynetwork.org/>. A strategic plan is put in place to develop exemplary standards in governance, ethics and privacy.

**Sustainable commitment to platform support.** The application is clear on the extent to which the existing platform, or the components that will be coordinated or integrated using the platform grant, is/are supported from other sources. These sources provide assurances that the platform will not displace their financial commitment. There is a credible plan for sustaining the platform after the three years of Brain Canada/Parkinson Canada funding.

## Review process

### Letter of Intent

The LOI Peer Review Panel recommends the applicants that should be invited to submit their LOI proposals as Full Applications. All LOI applicants receive anonymized reviewers’ comments, and notes of the Panel discussion for those applications that were discussed at the Panel meeting. Brain Canada and Parkinson Canada will not entertain appeals against the assessment of the LOI Peer Review Panel.

### Full Application

Only those invited by Brain Canada and Parkinson Canada following the LOI review will be able to submit full applications.

All applications will be reviewed by two members of a Full Application Peer Review Panel composed of Canadian and International members with broad experience and expertise in PD and related diseases, who are not applicants, to ensure that all funded proposals are assessed against similar standards of excellence. In addition, the application will be reviewed by one or two external reviewers to judge on a specific aspect of the application.

Applicants can provide suggestions for the membership of the Peer Review Panel, and for the selection of the external reviewers who will provide the Panel with expert advice on specific applications.

The Peer Review Panel will provide a merit score for each full application, and recommend to Brain Canada and Parkinson Canada those applications that have received a sufficiently high merit score to deserve funding.

Applicants will receive anonymized written comments from the Peer Review Panel and external reviewers, but if considered uncompetitive by all reviewers, certain applications will not be discussed in detail at the Peer Review Panel meeting and will not receive notes of the Panel discussion. Brain Canada and Parkinson Canada will not entertain appeals against the assessment of the Peer Review Panel.

## How to apply

Leaders should contact Brain Canada ([programs@braincanada.ca](mailto:programs@braincanada.ca)) if they have enquiries about the application process. All LOIs and applications must be submitted using Brain Canada’s electronic grant management system (<https://braincanada.smartsimple.ca/s/Login.jsp>) that will be available on the first week of October 2017. The Leader must complete all required application

fields in the Brain Canada’s electronic grant application system before 16:00 ET on the deadline dates listed below.

## Timeline

Launch of Request for Applications	September 15, 2017
Deadline for receipt of Letters of Intent	November 13, 2017 at 16.00 ET
Invitation to submit Full Applications	January 2018
Deadline for receipt of Full Applications	March 30, 2018 at 16.00 ET
Notification of Award	June 2018
Funding begins (earliest date)	August 2018

## LOI Components

### Platform Summary

- Title of proposal and name and affiliation of the Leader;
- Project start and end dates (note: choose dates within a 36-month window);
- Keywords (including freeform): up to 10 words describing the platform;
- Provide a summary description of the platform and how it will be used to advance research in PD and related disorders, including an explanation of the special services, capabilities or expertise that the platform will offer to researchers in the locality, region, nationally, or internationally. Explain how the data or materials acquired, curated or analysed by the platform will be made available to other qualified researchers, with appropriate safeguards in the case of human data. (Maximum 500 words).

### Impact

- A description of the anticipated impacts of the platform including potential for intersectoral and international collaboration, and on Canada’s capabilities in PD research. Emphasize the added value of the platform grant in improving the platform’s accessibility, performance, and reach into the neuroscience research community (maximum 500 words).

### The Group

- If not registered already, please have the Members register with the Brain Canada grant management system ([https://braincanada.smartsimple.ca/s\\_Login.jsp](https://braincanada.smartsimple.ca/s_Login.jsp)). Registered applicants will receive a Brain Canada PIN found under their “Personal Profile” and have access to co-write the application with the Leader.
- List the names and affiliations of up to ten Members and Associate Members of the group. It is recommended to include for each name a URL for their institutional or personal webpage or CV, so that reviewers can find out more about the member’s research interests and achievements;
- If there are more than ten Members and Associate Members, select those most essential to the platform.
- Group Member publications: For each of the ten most important group Members, cite up to five of their publications, of which at least three must have been published in 2012 or later. “Publications” means any type of document or medium, print or electronic, which best illustrates the Member’s relevant research experience, expertise and achievements and

demonstrates the Member's ability to contribute to the development and operation of the platform grant. Each item should be annotated with a brief reason for its selection. Include the DOI, URL or PMID of publications where applicable so that reviewers can access them;

- Explain the role that each applicant will play, and conclude with an overview of how the entire team will work together. For those ineligible to receive Brain Canada funding, explain how their contribution to the project will be funded (maximum 300 words).
- Please note that CVs are not required.

### **Budget**

- Provide an outline budget for the full period of funding, listing the major line items as described under "Eligible Costs", above, supplemented by a brief statement explaining how this line item will support the intended development and operation of the platform (maximum 600 words);
- Each amount for a category as well as the sum of all categories must be rounded to a multiple of \$1,000;

### **Attachments**

- Figures and references (maximum 1 page);

### **Optional information**

- Provide names and contact information for up to **five individuals outside Canada** and not in conflict who would be competent to review the LOI and the subsequent full application, if invited.
- If applicable, list individuals to whom the application should not be sent for review;

Reviewers will be selected by Brain Canada and Parkinson Canada, taking these and other suggestions into account.

### **Certification and Signatures**

The Leader must click the "I Agree" box to certify the following agreement: "I certify that all members of the group have agreed to their inclusion in this LOI, and allow me to represent them throughout the application process. I also certify that all team members permit Brain Canada to circulate this LOI and subsequent full application to third parties, under a confidentiality agreement, for the purpose of securing additional funding." Please note that institutional and group signatures are not required for the LOI application.

It is the sole responsibility of the applicants to ensure their LOI submission is acceptable and received before the deadline. Those received in any other format, exceeding the page limits, incomplete, or late, will be rejected.

## **Full Application Component**

Details of the application process will be provided along with the invitation to submit a full application.

## Confidentiality and Ownership

Brain Canada and Parkinson Canada will keep all materials submitted to it for this funding opportunity confidential, and will take reasonable steps to keep these materials confidential, and divulge them only to reviewers, Peer Review Panel members and observers, who have signed confidentiality agreements. Funded applications will be retained for comparison of intended and actual outcomes, as part of the final evaluation of the Canada Brain Research Fund.

Brain Canada and Parkinson Canada does not claim ownership of intellectual property (I.P.) arising from research it funds, and expects that its funds will be used to create I.P. that is developed and commercialized according to the policies of the research institutions in which the research is performed. The Leader and Members of the group must resolve I.P. ownership issues with funding sponsors before submitting an application. Where the Sponsor is a for-profit entity, Brain Canada and Parkinson Canada must be consulted to determine if the I.P. arrangements are acceptable, and this will be a component of the Partnership agreement.

## Due diligence

In order to reduce the burden on applicants, Brain Canada may require documentation (e.g. quotations for services, or repair/upgrade estimates, ethics approval where relevant) only from the Leader after the platform grant proposal has been conditionally approved. Where the platform grant involves the management of personal information or material derived from or to be used in human studies, the Leader will be required to provide copies of appropriate institutional ethical, confidentiality and other approvals as necessary before funds are released. The required documents must be received and other conditions resolved within a reasonable period specified by Brain Canada and Parkinson Canada, before funds can be released to the institution of the group Leader. For this multi-institutional platform, the Leader is responsible for distributing funds to the other cost centers, through their institutions.

## Reporting, Communications, and Evaluation

Brain Canada and Parkinson Canada will support truly innovative and therefore risky research and needs to know that these risks are acceptable. As a condition of continued annual funding of Platform Grants, Brain Canada requires a brief yearly narrative and financial progress report from the Leader, outlining use of funds, project achievements and impacts realized, as well as difficulties encountered and steps taken to overcome them. Continued funding will be based upon a satisfactory review of the progress report by Brain Canada and Parkinson Canada. If Brain Canada and Parkinson Canada consider that a progress report is questionable, after discussion with the group, the funding partners may agree to extend the period over which the funds are available, or cancel further funding. Details of the reporting process will be provided to funded researchers.

In order to demonstrate to Canadians, the ongoing value of the Canada Brain Research Fund, platform grant members must contact Brain Canada and Parkinson Canada in advance of the publication, release or public presentation of research results obtained with the platform grant, so that a press release or other publicity can be prepared. Embargoes will be strictly respected.

Acknowledgment of Brain Canada, Parkinson Canada and Health Canada must accompany all publication, release or presentation of such research results.

At the end of the current Canada Brain Research Fund, Brain Canada wants to show that exceptional value was received for the investments of the federal government and funding partners. It needs to know the impact of every grant and award. Ten percent of the final year's funding will be withheld and released on receipt of a satisfactory final progress report that describes the current and estimated future outputs and impacts of the platform.

### For Further Information

For any other information or questions:

- About the Platform grant competition and application process, please contact [programs@braincanada.ca](mailto:programs@braincanada.ca)
- About Brain Canada and the Canada Brain Research Fund: go to <http://braincanada.ca/>