



COMMUNITY FUNDRAISING
IN SUPPORT OF PARKINSON SOCIETY
CENTRAL & NORTHERN ONTARIO

**PARKINSON SOCIETY
CENTRAL & NORTHERN
ONTARIO**

COMMUNITY EVENT IMPACT GUIDE



Parkinson Society Central & Northern Ontario
Société Parkinson du Centre et du Nord de l'Ontario
In Partnership with Parkinson Society Canada

Community Fundraising in Support of Parkinson Society Central & Northern Ontario

Thank you for considering Parkinson Society Central & Northern Ontario (PSCNO) as the recipient of your fundraising revenues. By committing to host a fundraiser in support of Parkinson's, you acknowledge that the need is great and the concerns are many. At PSCNO we feel that the opportunities for our fundraisers to demonstrate their impact are just as great, and we look forward to working toward our shared vision of a better life and a brighter future for Canadians living with Parkinson's today, a world without Parkinson's tomorrow.

Parkinson's is a neurodegenerative disease that affects approximately 100,000 Canadians and their 400,000 care partners. Movement in our bodies is normally controlled by dopamine, a chemical that carries signals between nerves in the brain. When cells that produce dopamine die, the symptoms of Parkinson's appear, which include tremors; difficulty with fine movement; slowness and muscle stiffness; difficulty with balance and walking; loss of volume and clarity of speech; tendency to shuffle when walking; and handwriting difficulty.

Although Parkinson's is known as a movement disorder, in reality it affects all aspects of life, including one's ability to eat, sleep, walk, talk, think, and reason. But perhaps more devastating than the change in motor skills, are the non-motor symptoms – changes in mental health, such as depression, dementia, sleep disorders, and impulsive behavior. Parkinson's changes everything from finances to relationships. It changes lives.

According to a recently published study conducted by Neurological Health Charities Canada, of which both Parkinson Society Canada and PSCNO are active members, the incidence of Parkinson's is set to rise dramatically. The findings indicate that:

- The number of Canadians over 40, living with Parkinson's disease, will *increase* by 65%, from 99,000 in 2016 to 163,700 by 2031.
- The numbers of Canadians over 65, living with Parkinson's disease, will more than double to 148,800 by 2031.
- Parkinson's has the third highest level of direct health care costs.
- People living with Parkinson's disease have the highest use of prescription medication. The average annual, out-of-pocket expenses for each person with Parkinson's is \$1,100.00

With that in mind, PSCNO knows the need for research funding is becoming more pressing. Moreover, the need for an organization focused on support services, education and advocacy has never been more relevant. While researchers who we support work hard to find a cure, PSCNO positions itself as an organization that is there for people living with Parkinson's in our region and across the country. Your support allows us to fund vital research, while continuing to work on behalf of those affected by Parkinson's.

Your Event, Your Impact

Investing in research is one of the cornerstones of what we do at Parkinson Society Canada (PSC). The search to uncover more effective treatments, and ultimately a cure, is the biggest priority for the over 100,000 Canadians living with Parkinson's disease.

PSC funds investigator driven discovery research. By not targeting specific areas of research, this funding methodology allows researchers to be creative and try novel ideas, an approach that promotes discovery and breakthroughs.

75% of our research budget is committed to this discovery research, which represents early stage research that is essential in the research process. Basic Science research is what leads to or is "translated" into breakthrough/therapy. A further focus on clinical fellowships and new investigator awards, in addition to psychosocial research streams, gives physicians the opportunity to receive additional training and/or acquire specialized expertise in clinical aspects of PD and other movement disorders. By providing funding to new investigators and new ideas, PSC's Research Program creates a generation of committed Parkinson researchers and allows for opportunity to investigate new ideas that other research programs may not support.

PSC funded research is Canadian, our supported research projects are Canadian based as part of an international collaborative environment. It supports novel ideas, with grants designed to help research that otherwise may not get started - pilot grants to help researchers collect data for a novel idea are scarce. We provide small pilot grants to address this gap so that researchers can then obtain larger grants from other funding agencies once they gather data and confirm their novel idea. It is focused on funding movement disorder specialist to ensure high quality of care for people living with Parkinson's and on growing the field of Canadian Parkinson's researchers. PSC funded research breeds hope.

PSC Funded Research: Building New Opportunities

By promoting research into novel ideas PSC supports new ideas that otherwise may not be investigated. Providing an opportunity to explore these new concepts and develop the data required to support their ideas PSC provides researchers an opportunity to get the process started for new and exciting research. From there, they are able to leverage PSC's funding into additional support for their research projects.

Recent Leverage Funding Successes

Leveraged funds from PSC Pilot Project Grants (from 2012 reports)			
Researcher	Cycle	Amount awarded	Amount leveraged
Drs. Tim Kennedy & Abbas Sadikot	2011-2013	\$45,000	\$632,935
Dr. Ron Postuma	2011-2013	\$45,000	\$587,750
Dr. Connie Marras	2011-2013	\$45,000	\$2,000,000
Dr. Joanne Nash	2013-2015	\$45,000	\$270,000
Dr. Edward Fon	2012-2014	\$45,000	\$75,000
Drs. Oury Monchi & Guy Rouleau	2012-2014	\$45,000	\$515,338
Dr. Jeremy Lee	2012-2014	\$44,100	\$250,000
TOTAL		\$314,100	\$4,331,023

Examples of the Impact of PSC funded projects

In 2013 Dr. Marc Ekker's lab was able to produce zebrafish in which they could selectively kill the dopaminergic neurons. They are now in the position to examine the possible regeneration of these neurons. Understanding how zebrafish regenerate dopaminergic neurons should be instrumental in the development of methods to stimulate the regeneration of such neurons in PD patients.

In 2010, Dr. Ron Postuma developed two tools to help people with Parkinson's and their physicians identify and manage non-motor symptoms, such as hallucinations, REM sleep behaviour disorder, constipation and several other symptoms that were not in the past generally associated with PD: *'A Guide to the Non-Motor Symptoms of Parkinson's Disease' (for people with Parkinson's)* and the *Physician Guide to Non-motor symptoms of Parkinson's Disease*. These Guides help patients record what they are experiencing and discuss the symptoms with their doctor.

In 2007, Drs. Frederic Calon and Francesca Cicchetti's pilot grant resulted in the first published study that showed the protective effect of a diet rich in omega-3 fatty acids against Parkinson's. With further research, this finding could prevent the disease and, potentially, slow down its progression.

In 2014, Dr. Oury Monchi has made it possible to identify first stage Parkinson's patients who will go on to develop dementia. People with PD disease have a six times greater risk of developing dementia compared to the rest of the population. This study opens the door to further research on medication or on non-pharmacological approaches that can be used before patients develop dementia.

Parkinson's (before age 40) occurs in 5-10% of people diagnosed. 20% are under the age of 50. Some challenges in Parkinson's are universal, regardless of age, but there are a number of issues specific to younger people, such as career, finances and living long-term with a potentially disabling condition. In 2014, Mr. Mike Ravenek, PhD candidate developed a resources to address these issues: *Young Onset Parkinson's Disease - Advice for Those Newly Diagnosed and Advice for Physicians from Individuals Living with Young Onset Parkinson's Disease*. The booklets are now available.

Support Services: A Link to Positive Health Outcomes

Studies of people living with neurological conditions have previously shown that one of the highest needs of both the patient and the caregiver is information, education, and referral, throughout their lives at different stages. Doctors are simply too busy to answer all of a patient's questions; reading information whether from a pamphlet or online can be overwhelming; and people are not only uncertain who to ask, but are often too embarrassed to discuss very personal issues.

Support provided by Parkinson Society Central & Northern Ontario – through its many channels including staff support of questions and concerns with people living with Parkinson's, our network of 50 community Chapters and Support Groups, and access to information via our certified Information and Referral Associate and on staff Registered Nurse – is therefore an essential part of the journey of people affected by Parkinson's.

Our support group network supported by Community Development Coordinators working in five districts throughout our region serves an important purpose – connecting people with support, information and resources in the communities in which they live. More than anything, these groups affirm for people that they are not alone with a condition that can otherwise be isolating.

Information & referral is known as the art and science of bringing people together with services. It is not simply enough to hand someone a package of information. The question that prompts the call to our offices may not be the actual problem that is imperative to address. Careful assessment of not only the client's situation, including emotional capability of processing information is one way we are successful in delivering effective client services. Correctly diagnosing the concern, answering their many questions, informing them of available financial, emotional and physical supports, and connecting people to resources in their communities are the key outcomes of our information and referral program.

Support Services: A Growing Need

The results from the recent National Population Health Study of Neurological Conditions have just been released. Parkinson Society played an active role in this process as part of their partnership with Neurological Health Charities Canada, and the results show a need for action.

The study involved 130 researchers and clinicians from 30 institutions across Canada, as well as 177,000 Canadians affected by neurological conditions who offered their insights and personal experiences. This study gives us our first evidence-based overview of Parkinson's disease and its impacts in Canada, as well as clear indications of the gaps in care, data and research.

Key findings of the study regarding Parkinson's disease include the following:

- The number of Canadians over 40, living with Parkinson's disease, will *increase* by 65%, from 99,000 in 2016 to 163,700 by 2031.
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As the number of people living with Parkinson's grows, the need for support services and the complexity of issues faced by those living with this highly individual condition increases as well. We have an **urgent** need to address these gaps in order to improve quality of life for people living with Parkinson's and we need your help to do this.

We are proud of the work that we do in these areas, and our members have told us that our efforts are making a difference. Our 2014 membership survey indicates that 88.45% of clients rate our services as very good or excellent while 85.98% indicated that our client services team met all of their expectations during their most recent interaction. An example of the general tone of comments:

“As a person with Parkinson's (1-3 years) my contact with the PSCNO is invaluable.... I have this disease and find the Parkinson's community is exceptional. I am proud to be part of it.”

Your Event: You Can Help

Research and support services are just two of our four pillars. Money raised through events like yours helps fund support services, education, advocacy and research. PSCNO prides itself on being responsive to the needs of the communities we serve and we appreciate your support in helping to fulfill them, and in supporting our vision of a better life and a brighter future for Canadians living with Parkinson's today, a world without Parkinson's tomorrow.

In support of your event, we're happy to fulfill the needs of your donors, to support and promote your initiatives and to ensure that your hard work has impact. If you'd like to discuss opportunities to make a more specific impact with your fundraising based on the information provided or other concerns, we welcome an opportunity to ensure that your fundraising has meaning.

Thank you for your support.

Following Up

If you have any questions related to the contents of this document or about your event in general, please do not hesitate to contact us.

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