



EVERYDAY HEROES. EXTRAORDINARY HOPE.

2014 ANNUAL REPORT



Parkinson Society Canada
Soci t  Parkinson Canada

Parkinson's Disease

A chronic, degenerative, neurological disease resulting from a reduction of dopamine in the brain. It affects about 100,000 Canadians. There is no cure.



Our Vision

A better life with a brighter future for Canadians living with Parkinson's today. A world without Parkinson's tomorrow.

Our Mission

Parkinson Society Canada is the national voice of Canadians living with Parkinson's. Our purpose is to ease the burden and find a cure through advocacy, education, research and support services.

Core Values

Parkinson Societies in Canada work together as a pan-Canadian network guided by the following values:

- | **People with Parkinson's first**
- | **Creativity**
- | **Collaboration**
- | **Transparency**
- | **Compassion**
- | **Empowerment**

These values reflect the way we interact with each other and in the formulation of all policies, decision making and consultation processes.

Hope. Reach. Impact.

Whether you spend a year, a month or a day with a person with Parkinson's, you will be inspired. Indeed, each person's journey with Parkinson's disease is as unique as their brain. And what they all have in common is an admirable strength of spirit, determination and courage shown in the face of adversity. Simply put, these are our heroes. That's why throughout 2014, we paid tribute to these everyday heroes who demonstrate extraordinary hope that one day the secrets of Parkinson's disease will be unlocked and we may put an end to this life altering disease.

What is also undeniable about life with Parkinson's is that change and transition are the norm. And what we have also learned is that those who are flexible and adaptable have the best outcomes in managing their disease. That life lesson is relevant to Parkinson Society Canada as we evolve and transform our organization to best serve the Parkinson's community in Canada.

There is strength in unity. Through partnerships and alliances, we have become stronger in our ability to deliver on our mission as the national voice for Canadians with Parkinson's. Throughout this report, you will learn about the impact that we have made through trusted

relationships with researchers in the scientific community, health care professionals, our pan-Canadian network of regional Parkinson Societies, and coalitions with champions who advocate for change. None of which would be possible without the ongoing financial support of incredible individuals, corporations and foundations.

Over the past five decades, we have remained steadfast in our focus to hold people with Parkinson's at the heart of all we do. We are grateful to our donors, supporters, volunteers and employees who enable us to bring hope by delivering world-class education, research, advocacy and support programs to individuals and families in communities coast to coast to coast. We look forward to building on these strengths while the quest for a cure continues.



L) **Joyce Gordon** President and CEO
R) **Jean-Pascal Souque** Chair, Board

Inspire Hope

ADVOCACY IN ACTION

In light of our leadership role and long-standing membership in Neurological Health Charities Canada, Parkinson Society Canada (PSC) was pleased to be part of the announcement of the findings from the four-year, \$15 million National Population Health Study on Neurological Conditions. The study provides our first Canadian, evidence-based, overview of Parkinson's disease and its impacts, as well as clear indications of the gaps in care, data and research. We will use this information to advocate for government policies that improve the lives of people with Parkinson's and their families.



Dr. Chris Simpson, President of the Canadian Medical Association, left, meets with Joyce Gordon, President and CEO of Parkinson Society Canada to discuss a National Seniors Strategy for Canada.

BY THE NUMBERS

Results of the National Population Health Study on Neurological Conditions reveal the Parkinson's population over the age of 65 will double by 2031 at a rate of **10 Canadians diagnosed daily.**

Thousands of Canadians living with Parkinson's, along with Parkinson's researchers and clinicians, stepped forward and participated in this ground-breaking study. They shared their experiences and insights and ultimately made an impact on government policy. They are all our heroes.

We have established a group of "Parkinson's Ambassadors," people living with the disease or those caring for them. Our ambassadors present the real face of Parkinson's at meetings and events with elected officials and public servants. Along with facts, figures and logic, our aim is to work **with** governments and other stakeholder groups to improve the quality of life for everyone affected by Parkinson's disease.

To kick off Parkinson's Awareness Month on April 1, 2014, Parkinson Society Canada staff and volunteers with our National Advocacy Committee met in Ottawa with 21 Members of Parliament and policy makers from all three federal parties, including: the Minister of Health's staff, both opposition health critics, the Minister of State (Seniors), both opposition seniors critics and members of the health committee.

In our efforts to improve health care for all Canadian seniors, we are a member of the Alliance for a National Seniors Strategy, led by the Canadian Medical Association. As an advisor to the Alliance we have been focusing our work on the home care needs of seniors – now and in the future. With the Parkinson's population over the age of 65 set to double, the need to address such issues cannot wait. The Alliance expects to announce a seniors strategy framework in spring 2015 and is seeking public endorsement in its *Demand A Plan* campaign and website.



Joyce Gordon, centre, with Minister of Health Rona Ambrose and attendees at National Study announcement in September.

SHAPING GOVERNMENT POLICY

Federal government recognizes the public health impact of Parkinson's disease and related conditions and will add them to the national chronic disease framework.

Parkinson Society Canada, members of the Parkinson's community and lead researchers took part in discussions to help build a National Dementia Strategy.

Parkinson Society Canada's President and CEO testified on the need for genetic fairness legislation in Canada to the Senate's Standing Committee on Human Rights.

INVESTING IN RESEARCH THAT MAKES AN IMPACT

Parkinson Society Canada and its regional partners have great expectations for the 29 grant, fellowship and student awards funded to advance our knowledge of Parkinson's, a complex disease. One of the most promising of this year's recipients is Jean-François Trempe, assistant professor at McGill University, who received a New Investigator Award.

Trempe wants to solve the puzzle of Parkinson's through basic understanding about the way the disease works. He is studying the structure and shape of PINK1, a protein that plays a critical role in familial Parkinson's disease. Learning the shape of this protein could eventually help researchers develop a drug to repair the protein when it is damaged, to help it do its intended job of keeping brain cells healthy.

The National Research Program has funded more than 450 research awards, totaling more than \$24 million since 1981. In 2014 more than \$2 million was used to fund 40 research awards, including 11 research grants now in their second year. Funding of more than \$1.6 was awarded in this grant cycle to support new Parkinson's research projects over the next two years.

Parkinson Society Canada (PSC) is the only national health charity that specifically funds Parkinson's research in Canada; funding research that investigates most aspects of the disease, including: causes, complications, cognitive impairment, biomarkers, neuroprotection and quality of life. We focus our funding on innovative projects, and basic science that might lead to further

“ Medical history tells us that whenever we get the structure of a molecule, it gives us so many ideas on how to fix it,” says Trempe. “There is a saying that a picture is worth a thousand words – a structure is worth a thousand experiments.”

JEAN-FRANÇOIS TREMPE, PhD
RECIPIENT OF THE
NEW INVESTIGATOR AWARD

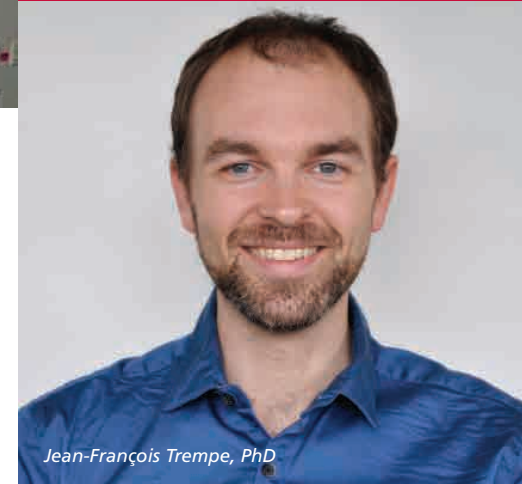
study; and improve our understanding of Parkinson's disease and how to treat it. Over time the investments made have generated many breakthroughs in the understanding of Parkinson's disease and those breakthroughs have been internationally acknowledged.

The National Research Program is promoted at events and conferences such as: the Canadian Association for Neuroscience conference in Montreal in May. The Donald Calne lecture, hosted by PSC and presented by an outstanding Parkinson's researcher, was delivered by Dr. Ali Rajput of Saskatchewan at the same conference.

BY THE NUMBERS

Eight final research project reports submitted in 2014 yielded **7 publications, 11 abstracts and 21 presentations.**

Our high-calibre research advances the collective knowledge towards a cure.



Jean-François Trempe, PhD

MORE CAN BE DONE

An additional 43 projects requiring \$2,048,155 were deemed scientifically worthy, yet went unfunded. One of these projects could have sparked a breakthrough. We need to raise more money to fund more research.

RESEARCH IN HAND

PSC-funded research resulted in the development of new resources for the under-served population of 12,000-14,000 Canadians with Young Onset Parkinson's disease (YOPD): YOPD – Advice to Physicians and YOPD – Advice for Those Newly Diagnosed.

Extend our Reach

REACHING OUT TO INCREASE AWARENESS

Parkinson Society Canada reaches out to inspire hope, share knowledge, increase awareness and connect the Parkinson's Community within Canada and around the world.

BY THE NUMBERS

Visits to Parkinson.ca increased more than **70%** (more than 225,000 unique visitors accessing

more than **1 million** page views), up from 121,000 visitors in 2013.

More than **8,000 people** have joined the online conversation with Parkinson Society Canada and Parkinson SuperWalk on Facebook and Twitter. That's more than double the number in 2013.

The ParkinsonClinicalGuidelines.ca website for health professionals received **10.5% more visitors** in 2014 through effective promotion at conferences, editorial content and social media.

Our bilingual, digital newsletter *e-Parkinson Post/e-L'Actualité Parkinson* was published five times and distributed to about **12,000 individuals** in the Parkinson Community, mainly in Canada.

Our social media channels on YouTube, Twitter and Facebook feature interviews, advocacy "calls-to-action," upcoming events, research news from around the world, as well as tips for people living with the disease and their care partners and fund raising ideas. Comments and blogs offer further conversations and insight.

Our national website www.parkinson.ca, available in English and French, provides information and resources to the Parkinson Community across Canada. Popular resources include the *Non-Motor Guide to Parkinson's*, and information on exercise and the progression of Parkinson's disease. The Research section of our site has been updated to include an online funding application to streamline our funding process and profiles of all of our currently funded researchers.

Our Parkinson Awareness Month campaign featured interviews, advertisements and stories from people living with Parkinson's and caregivers. And in October a seven-page article *A Guide to Parkinson's Disease* was produced for *Good Times* (a retirement magazine).

We remain the "go-to" organization for the media whenever Parkinson's is in the news. In August, we responded to numerous media enquiries surrounding the death of Robin Williams, providing evidence-based information on the link between depression and Parkinson's. Additional content on the topic was posted on the PSC website.

Strengthen our Impact

“ Although our community only has the services of one neurologist, we’ve recently had four new customers diagnosed with Parkinson’s. I took this online learning module to review any new treatments. It was also very valuable when I was preparing a lesson on Parkinson’s treatments for my nursing students. I’ll be recommending the program to them.”

JOANIE GOURDE-BELLAROSE, PHARM. D.

An online learning module about Parkinson’s for health professionals takes participants through several case studies.

BY THE NUMBERS

More than
3,000

health care professionals and individuals participated in our 2014 webinar offerings – **600** when they were first broadcast and more than **2,500** online at their convenience.

EDUCATION THAT IMPACTS CARE

We continue supporting our mission by ensuring easy access to credible training information, translating knowledge for the public and health professionals so that people with Parkinson’s get optimal care. Some highlights from 2014 include:

Expert webinar series: Four, one-hour webinars based on the *Canadian Guidelines on Parkinson’s Disease* (CGPD) were presented to primary care physicians and allied health professionals active in the early identification and referral of Parkinson’s patients. More than 260 health care professionals participated in the “live” webinars and more than 2,000 website visitors have accessed the archived webinars to date.

Online learning module: The first accredited online learning module available in English and French was launched in November. The focus of the module, accredited by the College of Family Physicians of Canada, is to educate health professionals on best practices for treatment and disease management for diagnosed patients, including motor and non-motor symptoms of Parkinson’s. More than 200 health professionals have taken the course.

Parkinson’s guidelines for pharmacists: We published an article entitled the *Parkinson’s Disease Guidelines for Pharmacists* in the May/June 2014 issue of the *Canadian Pharmacists Journal*. The publication has a readership of more than 4,600 nationwide. People with Parkinson’s disease have the highest rate of prescription drug use compared to other neurological conditions. By connecting with community pharmacists we are helping to ensure their ability to better support both patients and physicians in the ongoing management of Parkinson’s medications.



Canadian Pharmacists Journal

Public webinar on the newest Parkinson’s treatments: Dr. Anthony Lang, lead researcher on the Duodopa trial, and Dr. David Grimes, lead researcher on the Neupro trial were the expert speakers in a one-hour, public webinar on new Parkinson’s treatments, and their use. More than 300 people participated and the presentation continues to be accessible through www.parkinson.ca.

SHARED OBJECTIVES MAKE US STRONGER FROM COAST TO COAST TO COAST

Shared values, objectives and a single strategic plan, enables Parkinson Society Canada and our partner societies across the country to align our efforts for maximum impact. Planning together helps us to speak with a strong, unified voice on behalf of all Canadians affected by Parkinson's. Working together means we can deliver consistent programs and services across the country in the most efficient and effective manner.

For example, a bilingual *Support Group Facilitator Manual* was created by and for regional partners. The manual is customizable, so that regions can modify sections to include local references. The manual serves as a guide for anyone starting a support group or taking on a leadership role in an established group. It can also be used by support group members to enhance their understanding of the support group process and the requirements for keeping a group functioning well. It also details the role of a local chapter in offering information and support to Canadians living with Parkinson's (as well as other related disorders and Parkinson's conditions), their care partners and family members.

HELPING PEOPLE LIVE THEIR BEST LIFE WITH PARKINSON'S DISEASE

Peter Davison is a gifted motivational speaker. He's lived the life of an adventurer, facing many challenges as a marathon runner and high-altitude trekker. He's made the grueling trip to Mount Everest's base camp. Then, at the age of 45, he was diagnosed with Parkinson's disease.

At first Peter struggled with the news, reacting with denial and shame. But as he started to tell people, their supportive and loving responses affected him deeply. Through a local partner of Parkinson Society Canada, Peter found a place where people understood what he was going through, and he was able to find support and information about the disease.

While he faces new challenges from Parkinson's disease every day, Peter maintains his positive and courageous outlook on life. Peter is now 55, happily married to Andrea and dad to two preschoolers.

“ Without Parkinson Society Canada, having Parkinson's can be a very lonely place. The Society is creating community on the journey of hope, healing and finding a cure. Without it people are isolated and struggling to find hope.”

PETER DAVISON

PERSON LIVING WITH YOUNG-ONSET PARKINSON'S DISEASE

From our toll-free National Information and Referral phone line, to online and printed resources, we serve thousands of people with Parkinson's each month, along with their loved ones, who approach Parkinson Society Canada seeking credible information, referrals to local resources and empathetic support.

Our regional partners across the country operate more than 250 chapters and support groups delivering services Canadians living with Parkinson's and their care partners need to live their best life. With the Parkinson's population over 65 set to double by 2031, our resources will be severely stretched to handle the increasing demands. Donor support is needed more than ever to continue to serve our clients well, and to ensure increased funding for high-calibre research.

“ I received the 'Parkinson Package' . . . The pamphlets and articles were very informative and made me feel a lot more comfortable with my new diagnosis. It still is a little frightening, but I want to thank you for being so kind and steering me in the right direction. Our first conversation on the phone really put me at ease. You surely are an expert at what you do . . . ”

NEWLY DIAGNOSED CLIENT



Peter and Andrea Davison and their two children Hannah and Vance.

YOU MAKE IT POSSIBLE

PARKINSON SUPERWALK 2014

More than 14,000 participants, volunteers, donors and sponsors in more than 100 communities across the country joined together to raise \$2.9 million to fund local support programs and services for Canadians living with Parkinson's and for research towards a cure.

THANK YOU TO OUR NATIONAL PARKINSON SUPERWALK SPONSORS:



Many Parkinson SuperWalk participants walk together in support of a family member.



BY THE NUMBERS

More than
50%

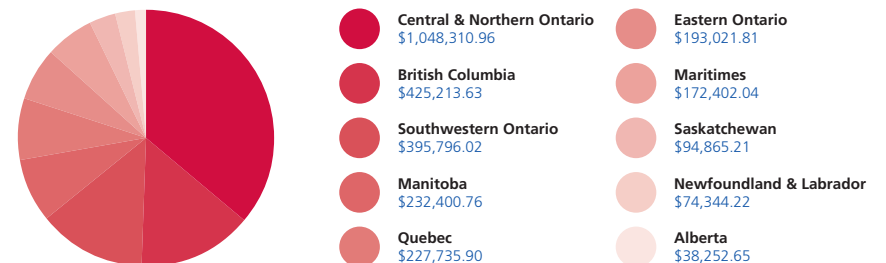
of Parkinson SuperWalk donations were made online. That's more than **20,000** donations totalling \$1.5 million of the \$2.9 raised Canada-wide.

Everyday hero Amanda Mulder, 23, hobbled through **Parkinson SuperWalk** in London, Ontario while on crutches, in remembrance of her grandfather John Steenbergen, who lived with Parkinson's. He died in 2013 at 80 years of age.

"He had Parkinson's disease for 10 years and I saw how hard it was on him" says Amanda. "I hope that one day this disease will be non-existent. Seeing my grandfather having to deal with the challenges that a Parkinson's diagnosis presents, broke my heart every day, and if I can help even in the slightest to make sure no one else has to face those challenges, I will do whatever I can."

Amanda raised \$570 towards Parkinson research and support by participating in **Parkinson SuperWalk** and getting the generous support of her family and friends.

MONEY RAISED FROM PARKINSON SUPERWALK \$2.9 MILLION RAISED ACROSS CANADA



To join **Parkinson SuperWalk**, the largest cross-Canada event in support of Parkinson's, visit www.parkinsonsuperwalk.ca.

PARKINSON SOCIETY CANADA

CONDENSED CONSOLIDATED STATEMENT OF FINANCIAL POSITION

AS AT DECEMBER 31

	2014	2013
ASSETS		
Current Assets		
Cash and Investments	\$3,808,097	\$2,757,694
Accounts receivable	596,745	612,401
Prepaid expenses	106,124	114,361
	<u>4,510,966</u>	<u>3,484,456</u>
Long Term Investments	2,511,431	2,338,492
Property and Equipment (Net)	88,643	101,730
Total Assets	<u><u>7,111,040</u></u>	<u><u>5,924,678</u></u>
LIABILITIES		
Accounts Payable and Accrued Liabilities	470,579	489,898
Deferred Contributions	541,007	755,607
	<u>1,011,586</u>	<u>1,245,505</u>
NET ASSETS		
Unrestricted net assets	5,931,978	4,503,283
Invested in Property and Equipment	88,643	101,730
Restricted net assets	66,833	62,160
Endowments	12,000	12,000
	<u>6,099,454</u>	<u>4,679,173</u>
Total Liabilities and Net Assets	<u><u>\$7,111,040</u></u>	<u><u>\$5,924,678</u></u>

PARKINSON SOCIETY CANADA

CONSOLIDATED INCOME STATEMENT

FOR THE TWELVE MONTHS ENDING DECEMBER 31

	2014	2013
REVENUE		
Individual Giving	\$2,856,801	\$2,737,010
Events	1,938,619	1,993,876
Planned Giving	1,707,037	960,915
Corporate Donations	866,101	752,171
Government funding for population health study	231,539	472,888
Contribution from The Charles Playfair and Dora Burke Playfair Fund	234,000	301,825
Investment Income	158,284	128,171
Other	139,512	160,052
	<u>8,131,893</u>	<u>7,506,908</u>
EXPENSES		
Research, Services & Education, Regional Development, Advocacy	4,364,473	5,099,170
Fundraising	2,212,880	1,978,405
Operations and Administration	1,078,780	1,039,072
	<u>7,656,133</u>	<u>8,116,647</u>
Support from Incorporated Regional Partners	1,095,068	1,103,478
Support to Incorporated Regional Partners	(150,547)	(157,673)
	<u>944,521</u>	<u>945,805</u>
Excess of Revenue over expenses	<u><u>\$1,420,281</u></u>	<u><u>\$336,066</u></u>

FINANCIALS

Additional information

Parkinson Society Canada figures include the National office and two unincorporated regional partners: Parkinson Society Central and Northern Ontario and Parkinson Society Manitoba.

The consolidated financial report does not include the financial activities of the Society's incorporated regional partners: Parkinson Society British Columbia, Parkinson Society Saskatchewan, Parkinson Society Southwestern

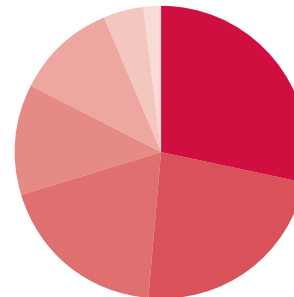
Ontario, Parkinson Society Eastern Ontario, Parkinson Society Maritimes Region, Parkinson Society Quebec, and Parkinson Society Newfoundland & Labrador.

Regional Development: Parkinson Society Canada has a nationwide mandate to ensure excellence in client programs and services for people with Parkinson's and their families. We do this by supporting the ongoing growth and development of regional partners.

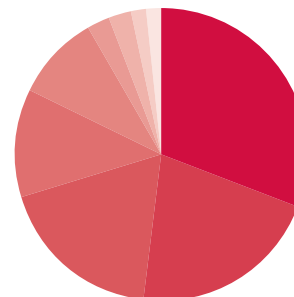
The Support to regional partners in the Consolidated Income Statement of \$150,547 (2013 - \$157,673) is included in the Use of Resources graph under Regional Development.

According to Canada Revenue Agency guidelines, fundraising activities that are under 35% as percentage of revenue are considered reasonable.

PARKINSON SOCIETY CANADA USE OF RESOURCES



PARKINSON SOCIETY CANADA SOURCES OF REVENUE



Revenue \$9,226,961
Expenses \$7,806,680
Net Revenue \$1,420,281

THANK YOU TO OUR DONORS

A Parkinson's diagnosis has a profound impact on the lives of individuals, entire families and whole communities. We are working diligently to create an optimistic future that will address some of the most urgent problems faced every day by those living with Parkinson's. But we can't get there without the help and support of our amazing donors and sponsors. We are grateful for your unwavering support.

We'd like to thank the tens of thousands of Canadians like you, who have made such an important and valued decision to join us, by investing in our collective efforts. In particular, many of you dug deep at the end of the year and made contributions to our donation-matching appeals to a far greater extent than we expected. The result of these welcome holiday gifts was a year-end surplus for Parkinson Society Canada to continue to invest in helping all Canadians living with Parkinson's and to continue the search for a cure.

**YOU ARE OUR EVERYDAY HEROES.
AND YOU INSPIRE EXTRAORDINARY HOPE IN US ALL!**

In 2014 Parkinson Society Canada added a new, online, third-party fundraising tool, where interested Canadians can access resources and create personal fundraising web pages to support their community-based fundraising efforts. Visit <http://donate.parkinson.ca/community> for more details.

THANK YOU TO ALL OF OUR DONORS

**Parkinson Society
Canada received 54,513
gifts this year from
our donors.**

LEAVING A LEGACY

**More than \$1.6 million
was received from
34 donors who included
a gift in their Will or
made another planned
gift to Parkinson
Society Canada.**

**We sent out 2,270 cards
(printed and digital) to
families and friends
after a donation was
made in someone's
honour or memory.**

**COMMUNITY
FUNDRAISING**
IN SUPPORT OF
PARKINSON SOCIETY CANADA

PARKINSON SOCIETY CANADA NATIONAL BOARD OF DIRECTORS

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Hassan Pirnia, Treasurer	Jawad Kassab
Judi Richardson, Secretary	Rudy Knight
Joyce Barretto	Muneeb Yusef
Julie Cafley	

RESEARCH POLICY COMMITTEE

The Research Policy Committee is a standing committee of the Parkinson Society Canada Board of Directors. Its mandate is to advise the Board on the most effective means to promote research into the cause(s), management and eventual cure of Parkinson's disease.

Dr. Pierre J. Blanchet, Chair	Dr. Philip Hébert	Dr. Anne-Louise Lafontaine
Dr. Edward Fon	Dr. Douglas Hobson	Dr. Daniel Levesque
Dr. Mark Guttman	Dr. Wendy Horbay	

SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board, a volunteer panel of respected experts from the Parkinson's scientific community across Canada, conducts a rigorous peer review process to determine scientific excellence and relevance to Parkinson's disease. This ensures that Parkinson Society Canada funds research that is novel, important and scientifically sound.

Dr. Edward Fon, Chair, McGill University	Dr. Janis M. Miyasaki, University of Alberta
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NATIONAL ADVOCACY COMMITTEE

Joyce Barretto, Chair	Chris Groot	Morgan Wheeldon
Yvon Trepanier, Co-Chair	Wendy Horbay	Muneeb Yusuf
Megan Boyle	Sprague Plato	
Joan Gibson	Tony Pugh	

Parkinson Society Canada received accreditation under Imagine Canada's national Standards Program. The Standards Program is a Canada-wide set of shared standards for charities and non-profits to demonstrate their compliance in five fundamental areas: board governance; financial accountability and transparency; fundraising; staff management; and volunteer involvement. It helps organizations mitigate risk by ensuring that staff and volunteers understand and meet their legal, financial and fiduciary responsibilities. PSC is one of just over 150 organizations in Canada to obtain this highest accreditation standard.



Charitable registration number: 10809 1786 RR0001



Parkinson Society Canada

Soci t  Parkinson Canada

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