

2012 Annual Report



Parkinson Society Canada
Soci t  Parkinson Canada

Parkinson's is...

a chronic degenerative neurological disease resulting from a reduction of dopamine in the brain. It affects over 100,000 Canadians.

There is no cure.

Symptoms include: resting tremor, slowness of movement, stiffness or rigidity of muscles, difficulty with balance and walking, changes in voice volume and speech, difficulty with fine movements, such as handwriting, tendency to shuffle with decreased arm swing when walking. Non-motor symptoms include depression, swallowing difficulties, sleep disturbances and changes in cognition.

Knowledge is power over Parkinson's

Knowledge of symptoms, treatment and where to find support can help people manage their Parkinson's. We're here for you. Call 1-800-565-3000 or visit www.parkinson.ca

Vision

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

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.

Values

All Parkinson Societies in Canada work together as a cross-country 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.

Cover photo: Parkinson Society Central & Northern Ontario spokesperson Saphia Khambalia with grandfather diagnosed with Parkinson's disease.



Dr. Matthew J. Farrer presented the Donald Calne lecture in Vancouver, B.C. in October, 2012.

Message from our CEO and Chair

THIS HAS BEEN A YEAR OF “PARKINSON’S WITHOUT BORDERS” AND PARKINSON SOCIETY CANADA (PSC) HAS ACHIEVED MANY IMPORTANT MILESTONES THANKS TO OUR GENEROUS DONORS. WE ARE HONOURED TO BE PART OF A CANADA-WIDE NETWORK THAT PUTS CANADIANS WITH PARKINSON’S FIRST. WE CONTINUE TO OPTIMIZE THE WAY WE WORK WITH OUR PARTNERS TO ENSURE WE HAVE A GREATER COLLECTIVE IMPACT.

Parkinson Society Canada launched the first ever Canadian Guidelines on Parkinson’s disease, endorsed by the Canadian Neurological Sciences Federation. Broadly transferring knowledge contained within the Guidelines to physicians and health professionals will ensure more consistent evidence-based treatment for people with Parkinson’s no matter where in Canada they live. Since the launch in June 2012, more than 80,000 physicians and health professionals have been introduced to the Guidelines.

Information contained in the Guidelines enables PSC and our network of partners across Canada to develop and deliver educational programs and services on the front-line educating individuals, caregivers, health professionals and the public about living well with Parkinson’s, based on the best evidence and the latest research available.

In 2012, Parkinson Society Canada and its regional partners proudly supported 33 new grants, fellowships and student awards with a new investment of \$1,713,208 from the National Research Program over the next two years.

The most successful Parkinson SuperWalk event to date took place in more than 100 communities

raising \$3.24 million for the National Research Program, as well as providing much needed funding for local programs and services.

As part of our work as a founding member of Neurological Health Charities Canada (NHCC), in 2012 we advocated at the national level for investment in programs and services to benefit families living with Parkinson’s. We have made great strides working alongside our NHCC partners and the Canadian Coalition for Genetic Fairness to seek protection for Canadians and to bring forward for second reading Bill S-218, an act to prohibit and prevent genetic discrimination. At the same time, work continued on many projects within the National Population Health Study on Neurological conditions and results will be shared in 2014.

Governance continues to be a top priority for the Board of Directors. In 2012, the Board made the decision to begin work toward achieving accreditation with the Imagine Canada Standards Program, a designation that takes certification to the highest level in five key areas: Board Governance, Financial Accountability and Transparency, Fundraising, Staff Management and Volunteer Involvement.

As we prepare to host the 3rd World Parkinson Congress in Montreal, Canada in October 2013, we hope you will find out more about our programs and continue to join us on our journey of providing hope for today and building a world without Parkinson’s tomorrow.

We are grateful for the contributions of thousands of volunteers, individual, corporate and foundation supporters. Your support means that we are there each day for individuals and families as we guide them to live their best possible Parkinson’s experience.



A handwritten signature in black ink that reads "Joyce Gordon".

Joyce Gordon,
President and CEO



A handwritten signature in black ink that reads "Bruce Ireland".

Bruce Ireland,
Chair, Board

Highlights from 2012

PARKINSON SOCIETY CANADA IS A MEMBER OF A NETWORK OF PARTNERS ACROSS CANADA THAT PUTS CANADIANS WITH PARKINSON'S FIRST, DEVELOPING NATIONAL EDUCATION PROGRAMS, INVESTING IN CUTTING-EDGE RESEARCH AND DELIVERING FRONT-LINE SUPPORT SERVICES AND EDUCATION. HERE ARE SOME WAYS DONORS HELPED US MAKE A DIFFERENCE IN 2012:

We launched the first ever Canadian Guidelines on Parkinson's disease and related website so that health professionals in Canada now have a better understanding of Parkinson's and a tool to help treat their patients.

We educated Canadians on important topics such as Physical Activity and Parkinson's, and developed a new resource and tracking chart to encourage regular activity.

We partnered with experts like Dr. Oury Monchi to deliver new information on topics such as Cognitive Impairment and Parkinson's disease, reaching greater audience using web-based technology.

We empowered thousands of Canadians to help manage their daily life with Parkinson's disease through advocacy, education and referrals to support in their communities.

We connected more than 50,000 of our over 100,000 web visitors to support in their community. In 2012, we responded to 25% more inquiries through the Information and Referral Centre.

In 2012, Parkinson Society Canada and its regional partners proudly supported 33 new grant, fellowships and student awards with a new investment of \$1,713,208 over the next two years. Including the 15 research awards in their second year, the National Research Program is currently committed to investing \$2,367,153. We make discovery research a priority. PSC funded projects result in improved understanding of the causes of Parkinson's and lead to finding pathways to better treatments.

We funded Clinical Fellowships to ensure more trained Parkinson's specialists in the future. Since 1981, more than \$21 million has been invested in over 400 research grants, fellowships and awards. We partnered with organizations like the Canadian Institutes for Health Research to leverage that funding into additional projects. We helped translate knowledge from discoveries to develop and distribute new resources such as Dr. Ron Postuma's *Guide to the Non-Motor Symptoms* or Parkinson's (for patients) and the companion *Physician's Guide to Non-Motor Symptoms of Parkinson's*.

Parkinson's issues figured prominently in the federal Health Committee's report entitled *Focusing on the Brain: An Examination of Neurological Diseases in Canada*, which was tabled to parliament in late June. Parkinson Society Canada ensured throughout the 11 hearings which began in 2010 and ended in the spring, Parkinson's issues were well represented through witness' testimony. In the report, many favorable recommendations were made which could positively impact the Parkinson's community including:

- The Government of Canada consider using the results of the National Population Health Study on Neurological Diseases in collaboration with the provinces and territories, as the basis of a pan-Canadian strategy for neurological diseases.
- The Public Health Agency of Canada include neurological conditions within its Canadian Chronic Disease Surveillance System.

- The Government of Canada consider establishing a Centre of Excellence for neurodegenerative conditions through its Networks of Centres of Excellence Program.

Through the Canadian Coalition for Genetic Fairness, Parkinson Society Canada, with active support from the Parkinson's community, helped bring genetic protection front and centre on the Hill. Private Member's Bill C-445, introduced on October 1, 2012 by NDP Member of Parliament Ms. Libby Davies (East Vancouver), elevated discussion in parliament about the possibility of adding genetic characteristics to the Human Rights Act to help end genetic discrimination in Canada.

We responded to the call and provided thousands of free information packages and referrals to resources for those newly diagnosed with Parkinson's.

We awarded the Donald Calne Lectureship to Dr. Matthew Farrer, Professor in the Department of Medical Genetics and Director of the Centre for Applied Neurogenetics in the Brain Research Centre at University of British Columbia (UBC), in Vancouver, BC.

We prepared to welcome the global Parkinson's community to the 3rd World Parkinson Congress in Montreal, October 1-4, 2013.

We operated Parkinson SuperWalk events in 95 communities to celebrate families and raise awareness. In 2012, Canadians coast to coast contributed \$3.24 million.



The Young Onset Support Group, Winnipeg, Manitoba



Walter Gretzky diagnosed with Parkinson's, with Chris Maciejowski

Regional Partner Updates

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO 2012 HIGHLIGHTS

- New programs developed, thanks to people naming Parkinson Society Central & Northern Ontario in their will and donating stock.
- The Hope in Bloom tulip campaign raised a record \$125,000 with 200 volunteers
- Over 1,500 guests attended 9 major education sessions in small and large communities including a 3-part speaker series and session targeted to health care professionals; events held in Barrie, Peterborough, Burlington, Sudbury and Toronto.
- Parkinson SuperWalk participants in the region raised a record \$920,000.
- Secured Ontario Trillium Foundation funding for a communications specialist to increase awareness and reach out to more Ontarians in need.
- City News television anchor Saphia Khambalia, whose grandfather has Parkinson's, became regional spokesperson for Central & Northern Ontario, helping to raise awareness.
- The second Hope on Display Calendar showcased creative expressions of people touched by Parkinson's; 8,000 copies were distributed.
- 5,556 requests to our Information & Referral line were answered.

PARKINSON SOCIETY MANITOBA (PSM) 2012 HIGHLIGHTS

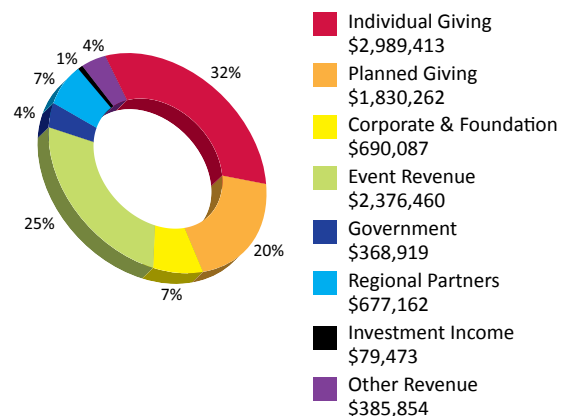
- Successfully achieved and exceeded planned program growth, the final step in a plan adopted by the PSM Board of Directors in 2009, doubling the overall program delivery since the adoption of its Program and Services plan.
- Launch of the Young Onset Support group.
- Record attendance of 190 people at the Winnipeg Regional Conference.
- Establishment of a Westman Office in Brandon to serve western Manitoba.
- Hosted 1st Annual Westman Conference drawing over 70 people.
- Regularly serving over 225 people each month through support groups, a growth of approximately 100 people per month over the past few years.
- Experienced record financial results in 2012 mirroring the growing impact PSM is having through its broader range of services across the province; most notably driven by the four Parkinson SuperWalk events (Brandon, Gimli, Morden, and Winnipeg) which raised over \$227,000 smashing the previous record of \$152,000.

PARKINSON SOCIETY SOUTHWESTERN ONTARIO (PSSO) 2012 HIGHLIGHTS

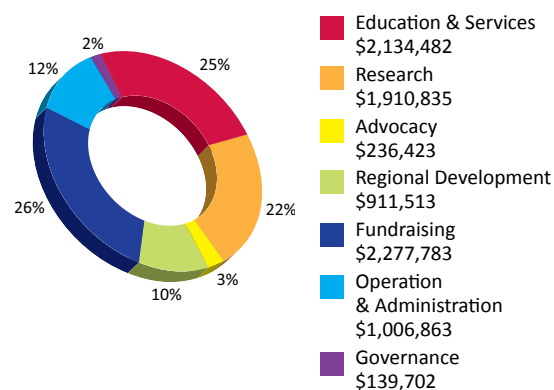
- Parkinson's awareness events in April included:
 - ~ Young Onset Workshop;
 - ~ Communications & Cognition;
 - ~ Community Presentation;
 - ~ Medical Partner Celebration.
- Received a grant to pilot an exercise program with VON.
- Both spring and fall Regional conferences were sold out.
- 13 Parkinson Superwalk events raised \$460,000. Walter Gretzky, who has Parkinson's, participated in a Lip Dup YouTube video promoting Superwalk.
- Launched an online forum with two discussion groups: a Young Onset Forum, which is part of a research project and a Public Forum.
- Partnered with Alzheimer Society and St. Joseph's Health Care to host a general practitioners Education Trilogy dinner and distributed the *Canadian Guidelines on Parkinson's Disease*.

Financials

PARKINSON SOCIETY CANADA SOURCES OF REVENUE



PARKINSON SOCIETY CANADA USE OF RESOURCES



ADDITIONAL INFORMATION

- Parkinson Society Canada figures include the National office and three unincorporated regional partners: Parkinson Society Southwestern Ontario; Parkinson Society Central & 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 Alberta Society,

PARKINSON SOCIETY CANADA CONDENSED CONSOLIDATED STATEMENT OF FINANCIAL POSITION AS AT DECEMBER 31, 2012

ASSETS

Current Assets

Cash and Investments	\$3,421,992
Accounts receivable	711,824
Prepaid expenses	<u>194,916</u>
	4,328,732
Long Term Investments	2,164,542
Property and Equipment (Net)	<u>129,638</u>
Total Assets	<u>6,622,912</u>

LIABILITIES

Accounts Payable and Accrued Liabilities	502,509
Deferred Contributions	<u>1,145,855</u>
	1,648,364

NET ASSETS

Unrestricted net assets	4,775,581
Invested in Property and Equipment	129,638
Restricted net assets	57,329
Endowments	<u>12,000</u>
	4,974,548
Total Liabilities and Net Assets	<u>6,622,912</u>

Parkinson Society Saskatchewan, Parkinson Society Ottawa, Parkinson Society Maritime 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

PARKINSON SOCIETY CANADA CONSOLIDATED INCOME STATEMENT FOR THE TWELVE MONTHS ENDING DECEMBER 31, 2012

REVENUE

Individual Giving	\$2,989,413
Events	2,376,460
Planned Giving	1,830,262
Corporate Donations	690,087
Government funding for population health study	368,919
Investment Income	79,473
Other	<u>385,854</u>
	8,720,468

EXPENSES

Research, Services & Education, Regional Development, Advocacy	4,948,240
Fundraising	2,277,783
Operating and Administration	<u>1,146,565</u>
	8,372,588

Support from Incorporated Regional Partners	677,162
Support to Incorporated Regional Partners	<u>(245,013)</u>
	432,149
Excess of Revenue over expenses	<u>\$780,029</u>

partners. The support to regional partners in the Consolidated Income Statement of \$245,013 is included in the \$911,513 in the Use of Resources graph under Regional Development.

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



2012 Parkinson SuperWalk

Over 14,000 participants, volunteers, donors and sponsors in 95 communities joined together to raise \$3.24 million to fund local support programs and services for Canadians living with Parkinson's.

“One of the amazing things about Parkinson Society Canada is not just the wealth of information they provide, but the people you meet. The support and encouragement I have received from others has helped guide me through my first year of diagnosis.”

Blair Sigurdson, co-founder, Young Onset Support Group and captain of the Young Onsets SuperWalk team



MONEY RAISED FROM PARKINSON SUPERWALK

British Columbia	\$591,938.98
Alberta	\$345,234.21
Saskatchewan	\$82,874.24
Manitoba	\$229,316.80
Southwestern Ontario	\$463,275.92
Central & Northern Ontario	\$922,959.17
Ottawa	\$170,080.78
Quebec	\$213,533.98
Maritimes	\$153,759.97
Newfoundland & Labrador	\$70,810.51

Total: \$3.24 million Canada-wide

THANK YOU TO OUR NATIONAL SPONSORS



CORPORATE AND FOUNDATION SUPPORTERS

Parkinson Society Canada gratefully acknowledges support from the following major corporate and foundation supporters in 2012:

Abbott Canada
The Walter J. Blackburn Foundation
Cenovus Employee Foundation
Brant Community Foundation
Bridge Medical Communications
Garden Centre Group Co-op Corporation
The Lawrason Foundation
London Community Foundation
The Mayvon Foundation
Neelands Refrigeration Limited
Nestlé Canada Inc.
North Waterloo Farmers Mutual Insurance Company
Novartis Pharma Canada Inc.
The Plunkett Foundation
Sifton Family Foundation
Teva Canada Innovation
Zwig Family Foundation

Parkinson Society Canada (PSC) is the national voice of Canadians living with Parkinson's. From diagnosis to discovery, since 1965 PSC has been there at every point along the Parkinson's journey providing education, advocacy and support services to individuals and health care professionals. The National Research Program funds innovative research to test new ideas that are vital in the global search for better treatments and a cure. Contact PSC to find out more about programs, events and services available near you and to volunteer. To join Parkinson SuperWalk, the largest cross-Canada event in support of Parkinson's, visit www.parkinsonsuperwalk.ca.

1.800.565.3000, www.parkinson.ca
www.parkinsonclinicalguidelines.ca



Parkinson Society Canada is a member of Imagine Canada's Ethical Code Program. We are one of only 400+ charities in Canada to meet the Code's fundraising and financial accountability standards.

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.

Members

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

SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board, a volunteer panel of respected experts from the Parkinson's scientific community across Canada, participates in 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. Richard Camicioli, University of Alberta
Dr. Matthew Farrer, University of British Columbia
Dr. Bin Hu, University of Calgary
Dr. Zelma Kiss, University of Calgary
Dr. Wayne Martin, University of Alberta
Dr. Martin McKeown, University of British Columbia
Dr. Janis M. Miyasaki, University of Toronto
Dr. David Park, University of Ottawa
Dr. Ron Postuma, McGill University
Dr. Harold Robertson, Dalhousie University
Dr. Michael Schlossmacher, University of Ottawa
Dr. Anurag Tandon, University of Toronto
Dr. Louis-Eric Trudeau, University of Montreal

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