SUPPORTING CANADIANS WITH PARKINSON'S
SINCE/DEPUIS 1965
AU SERVICE DES CANADIENS ATTEINTS DE PARKINSON

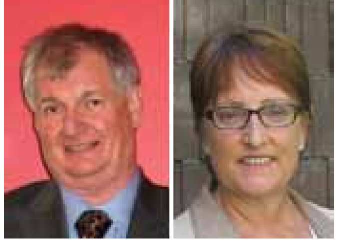
2009–2010 ANNUAL REPORT

STRENGTHENING CONNECTIONS

Parkinson Society Canada
Société Parkinson Canada

» Strengthening Connections

Parkinson Society British Columbia	604.662.3240
The Parkinson's Society of Alberta	780.342.8993
Parkinson Society of Southern Alberta	403.243.9901
Parkinson Society Saskatchewan Inc.	306.966.1348
Parkinson Society Manitoba	204.786.2637
Parkinson Society Central & Northern Ontario	416.227.1200



Message from the Board Chair & CEO

This year marks Parkinson Society Canada's 45th year of supporting Canadians with Parkinson's. As the only Canadian charity dedicated to providing education, support, advocacy and research for Canadians living with Parkinson's, we have grown from a few grassroots groups in scattered cities across Canada into a collaborative federation extending from coast to coast.

Over the past year, we strengthened Parkinson Society Canada by developing and signing a federation agreement with our regional partners setting out common principles and defining our roles, responsibilities and financial relationships. The acceptance and signing of this document increases our opportunities for enhanced service delivery, shared learning and leadership and improved efficiencies.

Parkinson Society Canada's board of directors moved to a new governance model to ensure people with Parkinson's have a voice in decision-making, through representation and active participation on the board. Our members also approved new bylaws in compliance with the new Canada Not-for-profit Corporations Act.

Individually and through membership in Neurological Health Charities Canada, Parkinson Society Canada continued to build relationships with key government policy makers and worked to secure funding for a national population-based study to determine the depth and breadth of brain disease in Canada. We were invited to work with the Canadian Medical Association to develop a patient-centred charter.

Parkinson Society Canada will represent Canada at the 2010 World Parkinson's Congress in Glasgow, Scotland. Participating in this international forum for the latest scientific discoveries, medical practices and caregiver initiatives and will bring renewed energy to fulfil our mission.

With assistance from our regional partners, we funded 30 research projects across Canada, noticing increased interest in psychosocial research exploring non-motor symptoms and quality of life issues that affect people with Parkinson's.

A highlight of the year involved getting a Parkinson's medication that was becoming less available, back on the shelf, after our prolonged discussions and follow-up with government, manufacturers and distributors.

Electronically, we used the Internet to promote our new Test Your Parkinson's IQ education piece, acquiring over 3 million impressions, and to reach younger audiences via Facebook and Twitter.

In the fiscal year, 2009-10, we continued to fund education programs, support services, research and advocacy, while managing to reduce administrative costs by two percent. With the support of caring Canadians we exceeded our target for direct mail gifts and broke our previous record for funds raised in SuperWalk.

We are grateful for the commitment, generosity and goodwill of our volunteers, partners, donors and staff who help us fulfil our mission.

Bruce Ireland	Joyce Gordon
Bruce Ireland Chair	**Joyce Gordon** President & CEO

Parkinson Society Southwestern Ontario	Parkinson Society Ottawa	Société Parkinson du Québec	Parkinson Society Maritime Region	Parkinson Society Newfoundland & Labrador	Parkinson Society Canada
519.652.9437	613.722.9238	514.861.4422	902.422.3656	709.754.4428	1.800.565.3000

SUPPORT, EDUCATION & AWARENESS

Connecting people living with Parkinson's to the help and information they need...

...235 chapters and support groups across Canada

"Most of the changes I've experienced due to Parkinson's have been difficult. Parkinson Society Canada has supported me as I deal with these changes. There are days when I've felt lost, overwhelmed, and self-conscious. But I haven't felt alone."

—Doug Martens, Member of the River East Movers and Shakers, a Parkinson's disease support group in Winnipeg, Manitoba

...Get it on Time

- developed an information program to help hospital and care facility staff understand that when people with Parkinson's don't receive their medications on time, their Parkinson's gets out of control and they can become very ill

"The [hospital] staff didn't understand how I could be fine one minute and not be able to move the next. They didn't make the link that I needed my (Parkinson's) drugs."

—Rajeed, 70, person with Parkinson's

...New information sheets

- **Parkinson's Medications…What you need to know!:** empowering people with Parkinson's with a checklist for noting changes in symptoms to discuss with the doctor

- **Stem cell Research and Parkinson's disease:** a description of the different types of stem cells, a summary of the status of stem cells in Parkinson's research and a caution against information on the Internet that is not based on scientific evidence

...Ensuring the availability of treatments

- alerted a drug manufacturer, Health Canada and the federal government to the fact that a critical Parkinson's medication was in short supply across Canada, urging them to establish a more permanent supply and assisting healthcare professionals in prescribing alternative medications in the meantime

...Making positive connections with the Parkinson's community, media and the general public

- raised awareness of the non-motor symptoms of Parkinson's with our new Test Your Parkinson's IQ information card and through other initiatives
- launched a new initiative in partnership with Parkinson Society Central & Northern Ontario to reach out to corporate Canada by opening the Toronto Stock Exchange

- created events and opportunities for donors to meet with researchers and learn firsthand how their gifts are benefiting people with Parkinson's
- connected media with people to interview
- helped people with Parkinson's tell their "stories from the front" and share their personal experiences of how compulsive behaviour, a side-effect of some Parkinson's medications, has affected their lives for CTV's W5
- profiled researchers and discussed their areas of expertise such as new drug treatments and imaging techniques, the basic science of genetics and biomarkers that offer new hope for people with Parkinson's
- kept pace with the changing world of communications by reaching out to newer audiences electronically while retaining our commitment to provide print publications such as Research Highlights
- connected website visitors quickly and efficiently to the information they seek, by continually updating our website with new information, and by making navigation easier; increased traffic to the Support and Education web pages during March/April by 100 percent
- doubled subscribers to *e*-ParkinsonPost to 6,000 in less than a year

ADVOCACY

Connecting people with Parkinson's to the highest levels of government, giving them a voice...

- worked with the Parliamentary Subcommittee on neurological conditions to keep Parkinson's issues in the spotlight; members of the Canadian Parkinson's community are scheduled to testify before the subcommittee in October 2010
- as a founding member of Neurological Health Charities Canada (NHCC), urged the federal government to implement a national brain strategy that will, among other priorities, address the needs of Canadians with Parkinson's and their families
- served on the implementation committee for the first national population health study of neurological conditions in Canada, ensuring that Parkinson's disease is included in 16 of the 18 research initiatives; the results, co-led by the NHCC and the Public Health Agency of Canada, to be released in 2013
- through membership in the Canadian Coalition for Genetic Fairness, alerted policy makers to the need to protect the privacy of genetic information
- co-chaired the newly established National Surveillance Committee for Neurological Conditions (run by the Public Health Agency of Canada)

"On average, patients have not discussed half of their non-motor symptoms with a physician. Most of them are treatable. That's why it's so important that they be detected."
—Dr. Ron Postuma, Assistant Professor, Department of Neurology, McGill University and Staff Neurologist, Montreal General Hospital

Even small discoveries can have a big significance and can really drive research forward.

In 2009-10, Parkinson Society Canada, the largest non-government funder of Parkinson's research in Canada, invested $1.3 million in its National Research Program and supported 30 projects across Canada.

RESEARCH

Parkinson Society Canada's funded researchers are making the connection between...

...Non-motor symptoms and their contribution to disability in Parkinson's disease

- improving detection and management of non-motor features of Parkinson's disease — depression, sleep disorders, constipation, loss of sense of smell — and the development of a knowledge translation outreach strategy

...Chewing gum and improved swallowing ability

- sensorimotor priming for improved swallowing function in people with Parkinson's disease — a one-year pilot project testing how long improvements in swallowing and secretions last if patients chew gum several hours a day

...Loss of sense of smell and possible earlier diagnosis of Parkinson's

- clinical trial of a diagnostic procedure for early stage Parkinson's disease — a one-year pilot project coupling a new form of diagnostic imaging with a scratch-and-sniff test

"By the time Parkinson's shows up clinically, about 60-70% of dopamine neurons are already lost. The damage is largely irreparable. If we can diagnose earlier, we can begin treatment earlier"
—Dr. Harold Robertson, Professor Emeritus of Pharmacology and Scientific Director and Co-Founder of the Brain Repair Centre, Dalhousie University

DONALD CALNE LECTURE

Connecting people with Parkinson’s to the best and brightest minds...

Dr. Andres Lozano, distinguished neurosurgeon, professor and RR Tasker Chair in Functional Neurosurgery at the University of Toronto presented this year’s Donald Calne Lecture, bringing his audience up to date on advances in deep brain stimulation surgery (DBS). Dr. Lozano, the first surgeon in North America to perform DBS, also gave an overview of the new surgical approaches being tried such as transplantation of dopamine-producing cells into the brain, stem cell therapy, gene therapy and trophic factors therapy. Dr. Lozano hinted at even more experimental approaches and techniques such as spinal cord stimulation and shining a special light into the brain to activate or silence neurons. His presentation on advances in the treatment of Parkinson’s in surgery and prospects for the future can be viewed at www.parkinson.ca.

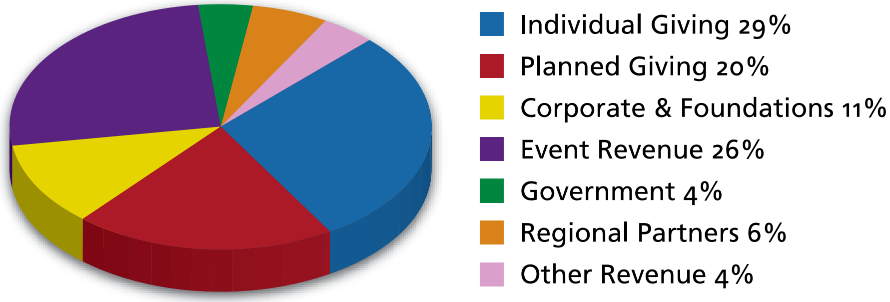
> “As neurosurgeons we are interested in seeking out misbehaving cells by mapping the brain and looking for them. Just as in real estate, the three most important things are location, location, location. We spend a lot of time figuring out where to go and getting individual neurons to reveal their secrets to us.”
>
> —Dr. Andres Lozano, Neurosurgeon, Toronto Western Hospital

PARKINSON RESEARCH ALLIANCE

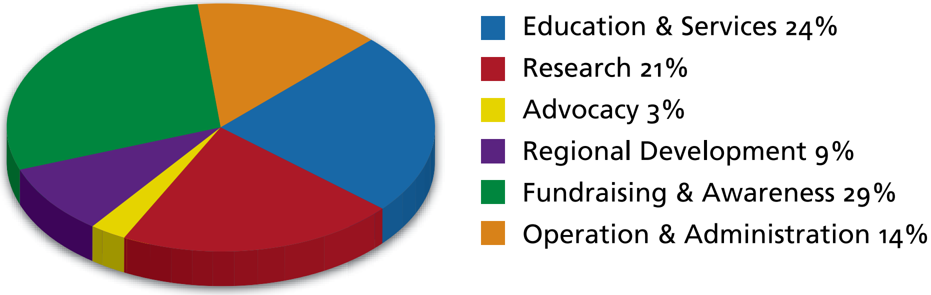
Connecting Canada’s leading neurologists, neuroscientists and movement disorder specialists with each other as they continue to...

- share information on their progress in research
- work on developing the first clinical practice guidelines for the diagnosis and treatment of Parkinson’s disease in Canada

Parkinson Society Canada Sources of Revenue



Parkinson Society Canada Use of Resources



Based on audited financial statements as of fiscal year ended May 31, 2010

RAISING FUNDS

Connecting people with Parkinson's to the hope for a future without Parkinson's...

...Parkinson SuperWalk

"I know that a cure may not come in my time but I'd like to think that it's coming in the future and that my efforts can be a part of that."
—Bob Nicholls, Co-founder of the Alliston, Ontario Parkinson SuperWalk, Bob, 61, has been living with Parkinson's for 18 years

"Our whole lab plans to participate in the SuperWalk. It sounds like a fun event."
—Parkinson Society Canada Grant Recipient Dr. Naomi Visanji, Neuroscientist and Post-Doctoral Fellow, University of Toronto

...Living With Parkinson's

"Imagine, getting a black belt in karate while in your late fifties, while living with Parkinson's. To me, that's the power of positive thinking. When it comes to Parkinson's, think positive, just like my Dad. You can make a difference!"
—Lauren Collins, Degrassi: The Next Generation

"My dear wife, Marion, aged 86, has been battling Parkinson's for 18 years and has been a patient in a nursing home for the past two years. Due to good care, the will to live, nursing, medications, etc. she's holding her own. You will be interested to know that a substantial gift to the Society, to which we are indebted, will come your way from her will and estate. I do thank you and will continue to support your good work as long as I live."
—William F., Caregiver

Parkinson Society Canada supporters gave:

- $2.7 million in SuperWalk
- over $1.5 million in bequests
- $445,000 in corporate and foundation gifts
- over $1.375 million in direct mail gifts, exceeding our goal