Parkinson Society Canada
Société Parkinson Canada

2006/2007
Annual Report

Research

Parkinson Society Canada (PSC) is the largest non-government funder of Parkinson's research in Canada and our research investment is growing. Over the past five years, PSC has invested over $5.2 million into basic research fellowships, clinical movement disorders fellowships, pilot project grants, and new investigator awards, across Canada.

Ultimately, we are searching for a cure, however discoveries that lead to improved treatment and/or a better understanding of the disease stand to significantly affect the quality of life for Canadians living with Parkinson's today. As such, PSC funds both basic and clinical research.

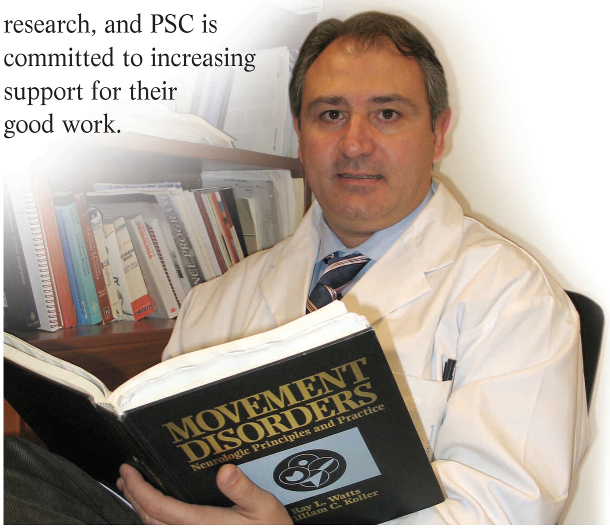
Each year, PSC receives approximately 50 applications for research funding and historically, the number of qualified proposals far exceeds the availability of funds. We are actively working to raise additional dollars to close this gap.

Our Scientific Advisory Board, made up of the most talented neuroscientists and physicians in Parkinson's disease, use the highest standard of adjudication and a peer-reviewed process to guide our research investments.

Over the past year, PSC awarded more than $1.2 million to 19 vital research projects including:

- **Pilot Project Grant:** Brian E. Staveley (Friedman Pilot Project), St. John, NL.
- **New Investigator Award:** Julie Messier, Montreal, QC; Quincy J. Almeida, Waterloo, ON.
- **Basic Research Fellowship:** Karim Mukhida, Dalhousie, NS; Elissa M. Strome, Vancouver, BC.
- **Clinical Movement Disorders Fellowship,** Andrew Borys, (Boehringer Ingelheim CMD) Winnipeg, MB

This is an exciting time in Parkinson's research as the pace of discovery is accelerating. Canadian scientists are of the best in the world, particularly in the area of Parkinson's research, and PSC is committed to increasing support for their good work.



Education

A Trusted Source

As the first point of contact for many newly diagnosed individuals and family members, PSC has become a trusted source of information and support for the entire Canadian Parkinson's community.

Over the past year, we have developed the Health Care Professionals Forum and developed a new national website. Both projects provide easier access to resources and more information about Parkinson's disease.

Health Care Professionals Forum

The Forum encourages open communication between health care professionals (i.e. nurses, occupational therapists, physiotherapists, social workers) for the overall benefit of Canadians with Parkinson's. Through this virtual network, health care professionals are able to share information and further the understanding of Parkinson's disease treatment, day-to-day management, non-motor symptoms, and related conditions.

The Forum enables professionals to post messages on a variety of issues and to receive responses quickly from colleagues around the world. Participants can post questions and responses, discuss issues and gain insights from colleagues.

New Website www.parkinson.ca

The development of a new national website means PSC is better able to provide information to Canadians with Parkinson's. This one-stop source of information helps them get answers, make decisions, and live successfully with Parkinson's disease.

The user-friendly site provides the most current information about Parkinson's disease, helps visitors find support in their regions, and provides the latest information on what is happening in the Parkinson's community. The Parkinson's In the News section is regularly updated with information about new treatments, new drugs, changes in legislation, and new initiatives for people with Parkinson's.

Support

CACOP Clinical Assistance Community Outreach Program

PSC awarded 10 Clinical Assistance grants and seven Community Outreach grants totalling $610,000 over a two year period including:

- **Clinical Assistance Grant:** Movement Disorders Program Foothills Hospital, Calgary AB
- **Clinical Assistance Grant:** Parkinson's Disease and Movement Disorder Clinic Ottawa Civic Hospital (K. Bearg Clinical Assistance Grant)
- **Community Outreach Grant:** The Maritime Parkinson Clinic, Halifax (CIBC Community Outreach Grant)
- **Community Outreach Grant:** Baycrest Centre for Geriatric Care (The Brian Hennick Community Outreach Grant)

Support Groups on the Rise

As the first point of contact for many newly diagnosed Canadians, providing quality information and somewhere to go for assistance are the cornerstones of support. The numbers tell the story; last year 1,600 people requested assistance through our toll free National Information & Referral Service, and more than 3,500 individuals benefited from over 230 support groups coast-to-coast.

Support groups are community-based networks of people living with Parkinson's. Some cater specifically to Young Onset or Care Partners but overall, they are a place to share experiences, to learn how to live well with Parkinson's, and to gain insight from others who may have faced similar challenges.

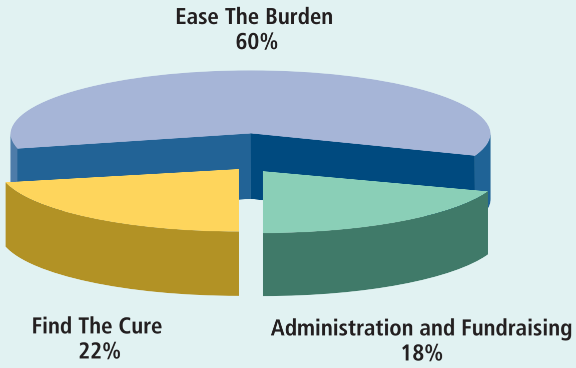
These services enable PSC to fulfill our mandate, to continue to provide support services and access to care for Canadians with Parkinson's. Unfortunately, the number of Canadians with Parkinson's is expected to rise significantly over the next 10 years. As the need escalates, PSC services will continue to adapt to accommodate the changing needs and unique experiences of Canadians with Parkinson's and their loved ones.

Volunteers

Volunteers are the backbone of our success and they assist in advocacy efforts, in leading support groups, organizing fundraisers, writing newsletters, serving as members of the board. The reasons are many: some are battling Parkinson's themselves, some are Care Partners, some have a parent, sibling or friend with Parkinson's. For most, it is a passion for Parkinson's and the belief in the work that PSC does that keeps volunteers committed.

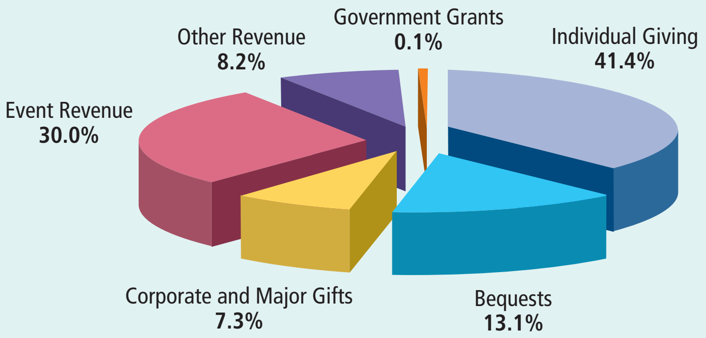
Parkinson Society Canada and Regional Partners Charitable Information Returns (T3010)*

as a % of receipted dollars



*Percentages are based on Parkinson Society Canada and its 12 regional partners.

Parkinson Society Canada Sources of Revenue*



*Percentages are based on consolidated financial information as of fiscal year ended May 31, 2007 from Parkinson Society Canada, Southwestern Ontario, Central and Northern Ontario, Newfoundland and Labrador, and Manitoba

SuperWalk

SuperWalk is the largest annual fundraising event that brings the Parkinson's community together with a common purpose: to raise funds for research that will lead to a cure and to support people living with Parkinson's. In 2006, SuperWalk raised $1.97 million with over 11,000 walkers taking part.

Everyone knows someone living and dealing with Parkinson's disease and SuperWalk provides an opportunity for individuals to do something about it.

SuperWalk has grown significantly since its very humble beginnings in 1990, when seven people affected by Parkinson's disease got together to walk. Today, more than 80 communities participate from coast-to-coast, and over the past 16 years, SuperWalk has raised more than $10 million to fund vital research, education, support and advocacy.

For more information about SuperWalk, visit www.superwalk.com.

Awareness

People with Parkinson's tell us that the quality of their lives improves when those around them understand the disease and its symptoms. They often need a helping hand and a kind word to help them through difficult situations – those that are only made worse with the added stress of intolerance and lack of understanding.

By increasing the general public's understanding of the Parkinson's experience, entire communities will become more sensitive to the needs of Canadians with Parkinson's.

Over the past year, new efforts to increase relevant awareness of Parkinson's included:

- An awareness campaign broadcast in grocery stores across the country and in corporate office towers in three major Canadian cities.
- The launch of *Stories from the Front,* public service announcements involving people with Parkinson's is part of a national awareness campaign, to be broadcast on television.
- Providing 12 regional offices with materials and strategies to increase communication, to support local awareness efforts, and local fundraising efforts, and to reach out to people with Parkinson's.

Parkinson Society Canada National Office

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Fax: (416) 227-9600 www.parkinson.ca

Parkinson Society Canada works with 12 regional offices across the country:

Parkinson Society British Columbia
Phone: (604) 662-3240
Toll Free (BC only): (800) 668-3330
Fax: (604) 687-1327
www.parkinson.bc.ca

Victoria Epilepsy and Parkinson's Centre Society
Phone: (250) 475-6677
Fax: (250) 475-6619
www.vepc.bc.ca

The Parkinson's Society of Alberta
Phone: (780) 482-8993
Toll Free: (888) 873-9801
Fax: (780) 482-8969
www.parkinsonalberta.ca

The Parkinson's Society of Southern Alberta
Phone: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
www.parkinsons-society.org

Saskatchewan Parkinson's Disease Foundation
Phone: (306) 966-1348
Fax: (306) 966-8030
E-mail: spdf@sasktel.net

Parkinson Society Manitoba
Phone: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 786-2327

PSC Central and Northern Ontario Region
Phone: (416) 227-1200
Toll Free National: (800) 565-3000
Fax: (416) 227-1520

PSC Southwestern Ontario Region
Phone: (519) 652-9437
Toll Free Ontario: (888) 851-7376
Fax: (519) 652-9267
www3.sympatico.ca/pf.swo

Parkinson Society Ottawa
Phone: (613) 722-9238
Fax: (613) 722-3241
www.parkinsons.ca

Parkinson Society Quebec
Phone: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

Parkinson Society Maritime Region
Phone: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468
Fax: (902) 422-3797
www.parkinsonmaritimes.ca

Parkinson Society Newfoundland and Labrador
Phone: (709) 754-4428
Toll Free (NL): (800) 567-7020
Fax: (709) 754-5868

Advocacy

Advocating for Change

Established in June 2005, the National Advocacy Committee's role is to identify key issues of concern to Canadian families with Parkinson's, and to work on their behalf to influence decision-making that will benefit all Canadians living with Parkinson's disease.

To this end, the committee has worked to establish relationships with elected federal representatives and bureaucrats; to present a compelling case for support to the Government; to develop a national network of community-based advocates; and, to provide support to regions as they develop their local advocacy programs.

Recognizing that the strength of our case was hindered by the lack of Canadian data about Parkinson's, the advocacy committee commissioned the development of a framework for a national research study about all aspects of Parkinson's disease in Canada. Such a study will answer many questions about the incidence and overall impact of Parkinson's, nationally and regionally, and provide a much-needed roadmap to guide future investment and policy development. A team of researchers at McGill University set about developing this framework in September 2006. The final report was presented to the Minister of Health and the Minister of Finance in May 2007, along with a request for financial support of $5 million to fund the study.

While this important work was underway, the advocacy committee turned its attention to strengthening our foundation of support at Parliament Hill. In October 2006, CEO Joyce Gordon made a presentation to the Standing Committee on Finance and in November 2006, volunteers met with almost 50 Members of Parliament. These meetings provided the opportunity to educate decision-makers about the Parkinson's experience; to connect specific Members of Parliament to their constituents living with Parkinson's; and, to generate support for the national research study.

Our immediate goal is to secure financial support for the national research study. To date, we do not have a commitment from the government however we continue to work to this end.

Critical to this process has been the development of the National Advocacy Network. This grass-roots network is made up of individuals who act as the local Parkinson's representative to their Member of Parliament. These folks offer a very effective and direct line of communication to their representative, and together, can create a groundswell of activity across the country. Over the past year, this group has been helpful in raising awareness about the Parkinson's experience and the needs of our community. As a result of letter-writing and face-to-face meetings, we can confidently say that many federal decision-makers have a more accurate and empathetic understanding of Parkinson's disease today.

The committee's goal is to have local advocates identified in 150 of the 308 federal ridings by December 31, 2007. Anyone interested in joining the National Advocacy Network is invited to express their interest by email to advocacy@parkinson.ca.