

# PARKINSON SOCIETY CANADA

Annual Report 2007 / 2008



Parkinson Society Canada  
Soci t  Parkinson Canada

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## President and Board Chair's Message

2007-2008 was a year of coming together to guide decision-making and to set priorities to enable us to meet the growing needs of Canadians living with Parkinson's.

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

At Parkinson Society Canada (PSC), volunteers and staff committed countless days to work through our internal planning process under the direction of the Implementation Team. Through interviews and face-to-face contact, we reached out to over 200 people with Parkinson's, care partners, medical professionals, and other stakeholders to help define what we focus on and how we work. This consultative process culminated with the National Summit in November of 2007, where stakeholders clarified our mission, vision and values. By all accounts, the Summit was a pivotal experience in finding ways to do things better for the benefit of Canadians living with Parkinson's.

The meeting of the Parkinson Research Alliance, established in the spring of 2007, and coordinated with support from PSC, marked the first time that researchers and clinicians gathered for a national meeting dedicated to Parkinson's disease. In January of 2008, the group came together for a second time at the University of Ottawa. Again, PSC played an active role in funding and participating in the two-day meeting that focused on both scientific research and clinical issues. In addition to the invaluable exchange of knowledge and information, one of the most exciting outcomes of the meeting was the group's commitment to develop a Canadian consensus statement on Parkinson's disease. This document is much needed to further the Parkinson's agenda and advocate more effectively for better treatment, care and supports for Canadians with Parkinson's. The Parkinson's Research Alliance will meet again in January of 2009.

In our unrelenting quest to use donor dollars wisely, PSC has worked over the past year to embrace technology as a tool to improve efficiency. All aspects of our research program were moved on-line, including the review and scoring process undertaken by the Scientific Advisory Board. We began the transition of Parkinson Post from a traditional magazine to an e-publication (first issue November 2008), and we have continued to use the Internet to build our virtual National Advocacy Network. These transitions will allow more flexibility, better communication and greater efficiency as we work to ensure that we continue to meet the needs of all stakeholders.

As a result of the work of so many within the Canadian Parkinson's community, we are getting stronger. At PSC, we benefit every day from the valued contribution of volunteers and the loyal support of donors. To all those who have given so much this year, thank you. We are exceedingly grateful.



**Bob Ashuk**, Chair  
National Board of Directors



**Joyce Gordon**, President & CEO  
Parkinson Society Canada

## Advocacy

This year, the National Advocacy Committee expanded to welcome representatives from Alberta, Saskatchewan, the Maritimes and Newfoundland and Labrador. With a truly pan-Canadian perspective, the committee identified four areas for advocacy work and a key objective for each:

**Research:** secure funding for a national epidemiological study of neurological disease;

**Quality of Care:** influence the quality of health care, support and services that Canadians living with Parkinson's receive;

**Awareness & Education:** expand PSC's National Advocacy Network to include a representative from every federal electoral riding;

**Public Policy:** identify and influence key policy issues directly affecting Canadians living with Parkinson's.

This is an ambitious mandate, but one that is possible because of the work undertaken over the past two years. PSC is now recognized as a leader within the charitable and neurological fields. We have built strong relationships with key influencers and policy-makers. We have engaged politicians and decision-makers in our work. We've asked for their advice and now we're putting it into action.

The number one recommendation we've heard is to collaborate with other like organizations for greater impact. To this end, PSC convened a meeting of health charities representing 12 neurological conditions in January 2008. In the end, every organization agreed to work together under the banner 'Neurological Health Charities Canada' (NHCC). The collaboration



*The Honorable Tony Clement, Canadian Minister of Health meets with Joyce Gordon, President and CEO, Parkinson Society Canada (both centre front row) and members of the NHCC.*

was launched in June with one clear message to federal policy makers - the NHCC is advocating for the development of a National Brain Strategy, one that addresses both neurological and psychiatric conditions of the brain, with the first step being a national study of neurological disorders.

Partnerships are just one of the ways we will realize our advocacy objectives. We also need help from individuals across Canada. The most effective way to communicate with elected representatives is through constituents – the people that voted them into office. With a complete and thriving grass-roots advocacy network, Members of Parliament will become more aware of the issues that are important to Canadians living with Parkinson's and their families. Awareness is the first step to creating change and as we identify policy issues that need attention, we need your help in motivating your Member of Parliament to act!

Over the past year, we've seen the power of grass-roots advocates in action. Our hope is that over the coming year, we will expand the network to cover all 308 ridings across Canada.

**Awareness is the first step to creating change.**

## Donald Calne Lecture

Parkinson Society Canada honoured 2007 Donald Calne Lectureship recipient Dr. Anthony E. Lang in Ottawa on January 18, 2008. Welcomed by Dr. Anne Louise Lafontaine, Chair of Parkinson Society Canada's Research Policy Committee, Dr. Lang was formally introduced by the 2006 recipient, Dr. A. Jon Stoessl.

Dr. Lang delivered an address entitled "Beyond the Decade of the Brain: Challenging Conventional Wisdoms about Parkinson's Disease". Speaking to an audience of over 150 scientists, health care professionals and members of the Canadian

Parkinson's community, Dr. Lang positioned his comments about Parkinson's disease in relationship to the U.S. initiative "Decade of the Brain (1990-2000)" – highlighting happenings since, demonstrating progress and emphasizing controversies that exist in the field of Parkinson's disease. Dr. Lang encouraged people to find new answers by thinking differently about Parkinson's disease. A DVD of Dr. Lang's lecture is available at [general.info@parkinson.ca](mailto:general.info@parkinson.ca).

This event was held in partnership with Parkinson Society Ottawa and made possible with the support of Solvay Pharma.



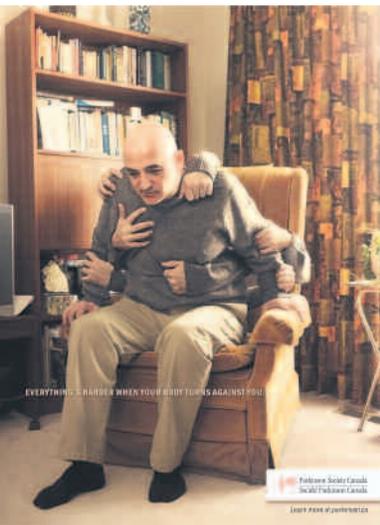
*Dr. Anthony Lang (right) recipient of the 2007 Donald Calne Lectureship with Dr. Jon Stoessl (left) past recipient of the award and Chair of the Scientific Advisory Board.*



*Brian FitzGerald, a person with Parkinson's, asks Dr. Lang a question about his research.*

**Dr. Lang encouraged people to find new answers by thinking differently about Parkinson's disease.**

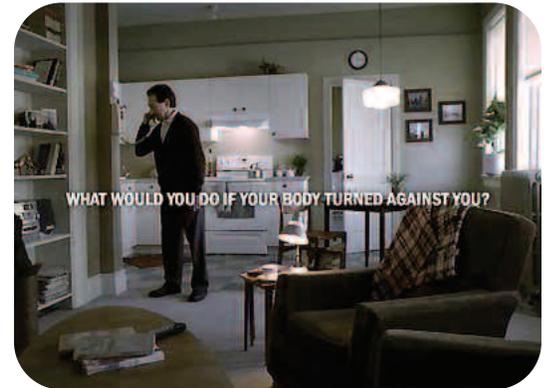
## Education and Awareness



This past April, PSC responded to feedback from Canadians with Parkinson's by launching the first national advertising campaign to create awareness about Parkinson's disease in many years. The campaign was a collaboration of many talented and committed people. TAXI 2, one of the top ad agencies in the country, donated its time and expertise to create a message that was both controversial and real, shocking the public into seeing the truth behind Parkinson's disease.

Gaggi Media, a media planning agency, secured pro-bono air time and print space so that the ad could appear on television, social media networks, billboards, physician office TV screens, as well as in the Globe and Mail and in magazines including Walrus, Canadian Nurse, Outdoor Canada, Homemakers and Canadian Living. The response was overwhelming. The media value of what PSC has received to date is \$250,000.

The goals of the campaign were clearly defined: to raise awareness about the Parkinson's experience, to dispel myths associated with the disease, and to set the stage to raise more funds for research and support services. Canadians with Parkinson's shared their insights with the creative team so they could convey the struggle that people with Parkinson's experience daily.



The message is powerful and attention grabbing, and obviously resonated with the general public – resulting in 25% more visits to the PSC website during the campaign.

In addition to traditional media, the ad was aired on social networking websites and search engines including Google, Facebook, Yahoo, and YouTube. The ads were picked up by numerous Parkinson's disease websites, medical and scientific blogs and transcended traditional health related websites as advertising and marketing sites commented on both the artistic and marketing merits of the ad. The ad was listed as one of the top 10 ads on the Internet during the month of April.

To view the ad campaign, visit [www.parkinson.ca](http://www.parkinson.ca) and click on the Media Centre.

**The goals of the campaign were clearly defined: to raise awareness about the Parkinson's experience, to dispel myths associated with the disease.**

## Support Services

In March 2008, PSC Board approved a Framework for Education and Support Services. The framework outlines general principles for service delivery for the national organization including values and philosophy.

With this in place our goal is to provide consistent quality of service across the country, providing opportunities for Canadians with Parkinson's to enhance their knowledge in order to make informed decisions; supporting them to meet their daily challenges; and helping them to find and gain access to quality health care and community services.

The National Information and Referral Centre, made possible through the generosity of Manulife Financial, is an essential service that is first point of contact for information and referral to regional support. Monthly contact through our toll free 1-800 line and through email remains consistent, with over half of inquiries coming through e-mail.

Our priority in delivering education and support services will be to identify those core services that must be accessible to all Canadians based on the standard of best practice. To this end we will work collaboratively with our regional partners to provide the best service possible. PSC is increasingly being contacted by those with other Parkinson's conditions and so we must expand our services to meet these needs. We are also doing more to address the progression of Parkinson's and to identify issues concerning end-of-life care.

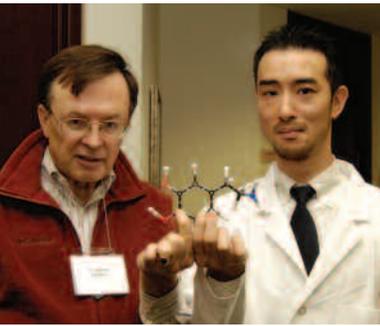
Canadians living with Parkinson's need consistent messages on topics of concern to them and so our commitment is to provide credible, up to date information related to the care and management of Parkinson's. In order to speak with one voice, we are working with our regional partners to identify which issues are most important and we are developing position statements on topics such as stem cells, access to drugs, pesticides and alternative therapies.



*Symposia like the one held in Calgary help improve the quality of care for people with Parkinson's disease.*

**Our goal is to provide consistent quality of service across the country.**

## Research



*Dr. Gordon Hardacre, a person with Parkinson's (left) and Dr. Satoshi Suo, 2007 PSC Basic Research Fellowship recipient (right), hold up a model of a Dopamine molecule.*

### PSC Scientific Advisory Board

Dr. A. Jon Stoessl, Chair  
 Dr. Pierre J. Blanchet  
 Dr. Therese Di Paolo  
 Dr. Edward Fon  
 Dr. Alan Goodridge  
 Dr. Doug Hobson  
 Dr. Mandar Jog  
 Dr. Susan Fox  
 Dr. Michel Panisset  
 Dr. Oksana Suchowersky  
 Dr. Joseph Tsui

Investing in research is a cornerstone of what we do at PSC. The search to uncover more effective treatments, and ultimately a cure, is the single biggest priority for the over 100,000 people living with Parkinson's disease across Canada.

As the largest non-government funder of Parkinson's research in Canada, PSC continually strives to increase our annual research investment. Identifying innovative partnerships that allow us to stretch our research dollars further is a key strategy in putting more researchers to work.

To this end, PSC partnered with the Canadian Institutes of Health Research's Institute of Neurosciences Mental Health and Addiction to fund psychosocial research grants and doctoral awards.

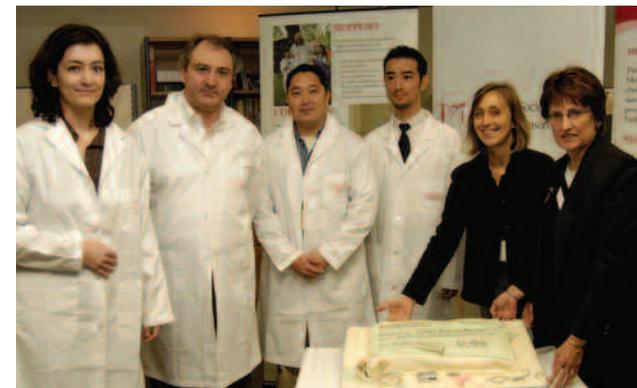
Since 1981, PSC has invested more than \$14.7 million in Canadian Parkinson's research, granting over 300 basic research fellowships, clinical movement disorder fellowships, pilot project grants, and new investigator awards.

In July 2007, PSC committed a total of \$1,123,281 in funding in addition to the \$417,500 committed to fund year two of awards from the 2006-2008 cycle. In 2007-2008, PSC supported 25 research projects across Canada. In addition, PSC introduced a new category of award to encourage young scientists at the start of their career, to focus on Parkinson's projects, providing a minimum of \$45,000 directly to graduate students each year.

In the early 1990's, PSC established the Clinical Assistance and Community Outreach Program (CACOP) to provide financial support to clinical and/or academic neurologists to offset the cost of nurses to assist in the care of Parkinson's patients in clinics across Canada. To date, PSC has provided funding in excess of \$3 million; for fiscal 2007-2008, the funding was \$305,000. The responsibility for managing and funding this program shifted to PSC's Regional Partners on June 1, 2008.



*Ottawa-based researchers were presented with a cheque for \$266,000 from Parkinson Society Canada.*



*Researchers in Toronto receive a cheque in the form of a cake for \$379,000 from Parkinson Society Canada.*

**Investing in research is a cornerstone of what we do at PSC.**

## Parkinson Society Canada National Office

4211 Yonge Street, Suite 316,  
Toronto, ON M2P 2A9.  
Phone: (416) 227-9700,  
Toll Free: (800) 565-3000,  
Fax: (416) 227-9600 [www.parkinson.ca](http://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](http://www.parkinson.bc.ca)

### Victoria Epilepsy and Parkinson's Centre Society

Phone: (250) 475-6677  
Fax: (250) 475-6619  
[www.vepc.bc.ca](http://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](http://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](http://www.parkinsons-society.org)

### Saskatchewan Parkinson's Disease Foundation

Phone: (306) 966-1348  
Fax: (306) 966-8030  
[www.parkinson.ca](http://www.parkinson.ca)

### Parkinson Society Manitoba

Phone: (204) 786-2637  
Toll-Free: (866) 999-5558  
Fax: (204) 786-2327  
[www.parkinson.ca](http://www.parkinson.ca)

### PSC Central and Northern Ontario Region

Phone: (416) 227-1200  
Toll Free National: (800) 565-3000  
Fax: (416) 227-1520  
[www.cno.parkinson.ca](http://www.cno.parkinson.ca)

### PSC Southwestern Ontario Region

Phone: (519) 652-9437  
Toll Free Ontario: (888) 851-7376  
Fax: (519) 652-9267  
[www.parkinsonsociety.ca](http://www.parkinsonsociety.ca)

### Parkinson Society Ottawa

Phone: (613) 722-9238  
Fax: (613) 722-3241  
[www.parkinsons.ca](http://www.parkinsons.ca)

### Parkinson Society Quebec

Phone: (514) 861-4422  
Toll Free: (800) 720-1307  
National francophone line  
Fax: (514) 861-4510  
[www.parkinsonquebec.ca](http://www.parkinsonquebec.ca)

### Parkinson Society Maritime Region

Phone: (902) 422-3656  
Toll Free (NS, NB & PEI):  
(800) 663-2468  
Fax: (902) 422-3797  
[www.parkinsonmaritimes.ca](http://www.parkinsonmaritimes.ca)

### Parkinson Society Newfoundland and Labrador

Phone: (709) 754-4428  
Toll Free (NL): (800) 567-7020  
Fax: (709) 754-5868  
[www.parkinson.ca](http://www.parkinson.ca)

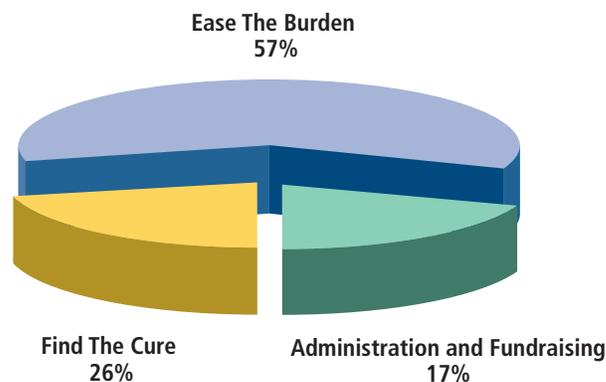
## Raising Funds

Parkinson Society Canada faces a clear challenge. The number of people with Parkinson's is projected to increase over the next 20 years. As demand grows and the number of baby boomers over the age of 60 increases dramatically, the need for more and better services increases. The demand for a cure and the need to identify causes increases. The need to be financially sustainable is urgent. The time to meet these challenges is now. Our fundraising efforts over the past year have been focused on developing initiatives to meet present and future demands.

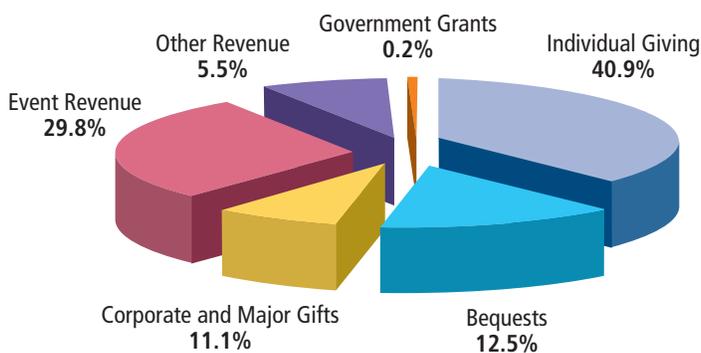
PSC benefits from a strong and loyal base of donors who demonstrate support for our work time and time again. We benefit from a strong foundation of fundraising programs including direct mail, monthly giving and our annual SuperWalk event. Supported by 12,000 walkers in over 80 communities, SuperWalk raised \$2.1 million in 2007.

New areas of focus for the fundraising team include the recently launched Family Fund, in addition to initiatives in major gifts and planned giving. Finding innovative ways to attract new donors is an ever-present challenge. However we see real promise in on-line giving initiatives and in reaching out to the families and friends of the over 100,000 Canadians who have Parkinson's today.

### Parkinson Society Canada Charitable Information Return (as a % of received dollars)



### Parkinson Society Canada Sources of Revenue\*



\*Percentages are based on financial information as of fiscal year ended May 31, 2008.