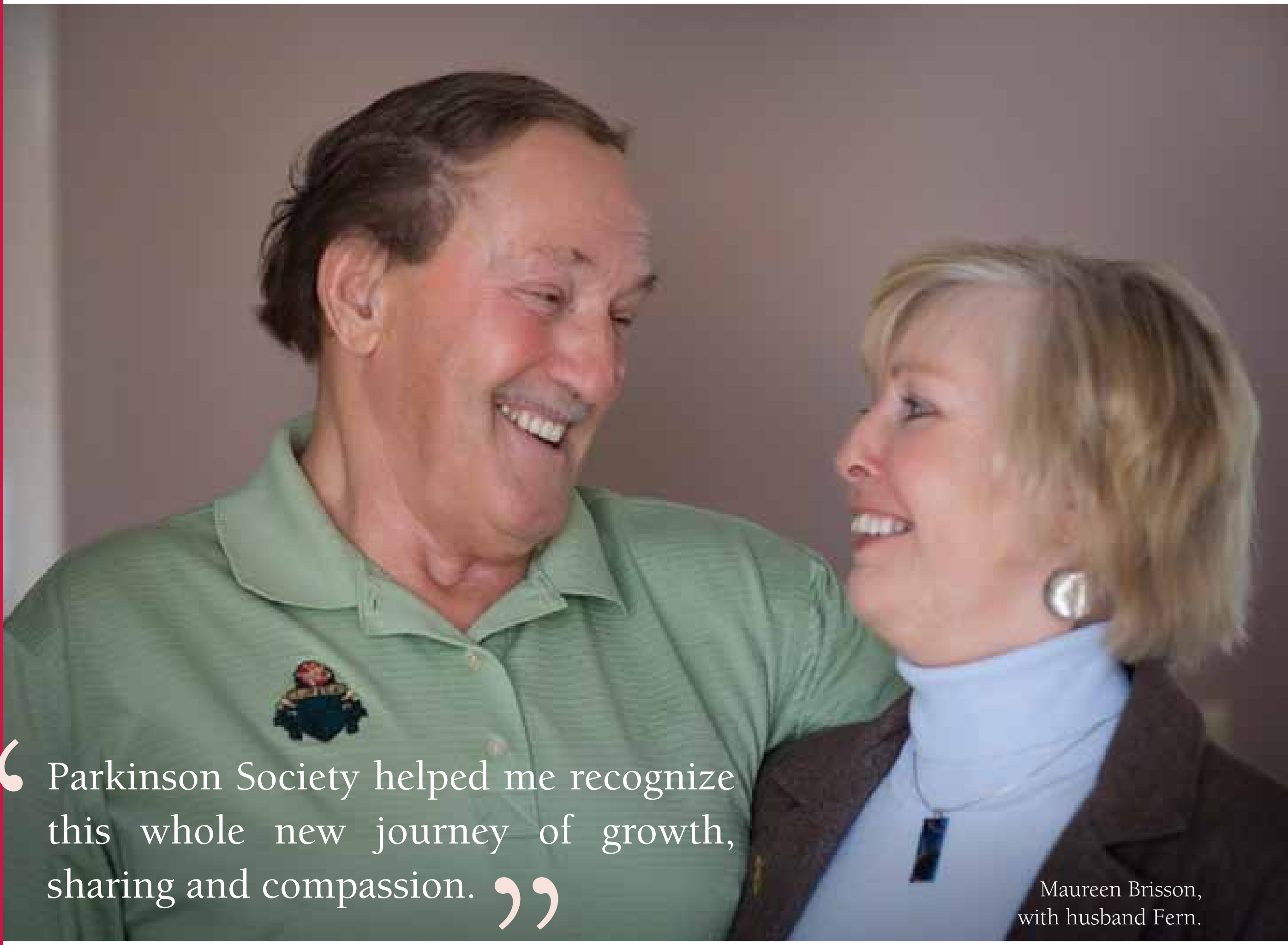
Parkinson Society Canada

# 2008 ~ 09 ANNUAL REPORT

## Meeting the needs of Canadians with Parkinson's



> "Parkinson Society helped me recognize this whole new journey of growth, sharing and compassion."

Maureen Brisson,
with husband Fern.

Parkinson Society Canada
Société Parkinson Canada

# Message from the Board Chair & CEO

Over the past year, Parkinson Society Canada and our 12 regional partners adopted a nation-wide strategic plan and focused our efforts on building capacity to better serve the needs of Canadians with Parkinson's.

Extending our reach using technology, we posted more education materials online, promoted online giving for SuperWalk, our signature fundraising event, converted Parkinson Post into an e-publication and created a Facebook page to communicate with the Parkinson's community. Working collaboratively with our regional partners, we developed position statements on priority topics. During April, Parkinson awareness month, we extended our media outreach into several ethnic communities, so that the messages of the national advertising and public awareness campaigns could reach thousands more Canadians. These moves all served to strengthen our position as the national voice of Canadians living with Parkinson's.

As an individual organization and as a member of Neurological Health Charities Canada (NHCC), Parkinson Society Canada is now firmly established as a credible and capable leader in the neurological community. We are among the first to be called when Parkinson's and other neurological diseases are in the news. In addition to our membership in the NHCC, we have forged innovative research and program partnerships with organizations such as Public Health Agency of Canada, Canadian Institutes of Health Research, Health Canada and Canadian Coalition for Genetic Fairness to maximize our efforts and achieve common goals. We also advocated for changes in public policy on behalf of Canadians with Parkinson's and their families.

Thanks to our higher profile and the positive relationships we have forged, we have seen an increase in the number of research grant applications we receive and the quality and excellence of the grant submissions. In 2008-2009, we supported 26 research projects across Canada.

In the face of the worldwide economic downturn, we have managed to hold steady. Supporters and communities across Canada helped set new fundraising records. In the past year, 84% of our receipted income went towards easing the burden and finding a cure.

As we head into our 45th year, we hope to count on the continued dedication, generosity and support of our volunteers, donors and staff across Canada. We thank you for assisting us in achieving our mission — providing education, support services, advocacy and research.

Bob Ashuk
Chair
Parkinson Society Board

Joyce Gordon
President & CEO
Parkinson Society Canada

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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) 342-8993
Toll Free: (888) 873-9801
Fax: (780) 342-8969
www.parkinsonalberta.ca

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

Parkinson Society Saskatchewan Inc.
Phone: (306) 966-1348
Fax: (306) 966-8030
www.parkinson.ca

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

Parkinson Society Central and Northern Ontario Region
Phone: (416) 227-1200
Toll Free National: (800) 565-3000
Fax: (416) 227-1520
www.cno.parkinson.ca

Parkinson Society Southwestern Ontario
Phone: (519) 652-9437
Toll Free Ontario: (888) 851-7376
Fax: (519) 652-9267
www.parkinsonsociety.ca

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

La Société Parkinson du Québec
Phone: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
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

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

# Education & Awareness

In 2008-2009, we made great strides in raising the profile of Parkinson's disease in Canada through numerous education and awareness initiatives.

Highlights included:

- developing position statements on four priority topics: Medical Advice; Non-endorsement; Drugs approved by Health Canada be on provincial formularies and Stem Cell Research;
- publishing *Progression of Parkinson's disease* and *10 Steps to help you cope* information sheets for those recently diagnosed;
- realizing a significant increase in calls to our National Information and Referral Centre, particularly during April, when we saw a 75% increase in calls over the last year. Over 50% of the requests now come via the website, www.parkinson.ca;
- increasing traffic to the redesigned bilingual website — over 91,000 hits during the year. Visits to Donate Now were up 49% and visits to Support and Education increased by 32%. There was a spike of 10,950 hits to the English site and 985 to the French site, in April. Visitors are also using the national website to access their regional Parkinson Societies.

# Support

Parkinson Society Canada is the leading organization providing support to Canadians living with Parkinson's.

Our 235 chapters and support groups across the country serve people with Parkinson's and families in their own communities.

Our volunteer-led support groups are safe places where people with Parkinson's and caregivers can:
- exchange ideas;
- share experiences;
- learn from guest speakers;
- learn from each other;
- discover helpful strategies for living with the disease.

Viola Chan (centre) with her circle of support from Parkinson Society British Columbia.

> "It was the beginning of a new life. I joined a support group and found understanding people who gave me all the help I needed to find my balance once again."

## *A fighter's story*

When I was diagnosed with Parkinson's disease in June 1999, two years after the first symptoms, the doctor's confirmation completely defeated me. I took on a negative attitude, felt sorry for myself and became consumed by the disease. I refused all medication, isolated myself and sank slowly into depression, dreaming of the day when it would all be over.

Then, in autumn 2000, I got in touch with the President of Parkinson Society Québec. It was the beginning of a new life. I joined a support group and found understanding people who gave me all the help I needed to find my balance once again. Thanks to their information and concern, I surrendered myself to meeting a neurologist who told me from our first encounter, "We will age together, and we will age well". I agreed to take the medication for my condition and found quality of life once again.

By helping regularly at the monthly meetings, I have come out of my isolation and made the choice to remain alive. I volunteer and, rather than concentrate on my losses, I offer my talents and strengths and help other people overcome their ordeal by sharing my experience.

Lise Michaud, Chair,
Board of Directors,
Parkinson Society, Quebec City Area

# A caregiver's story

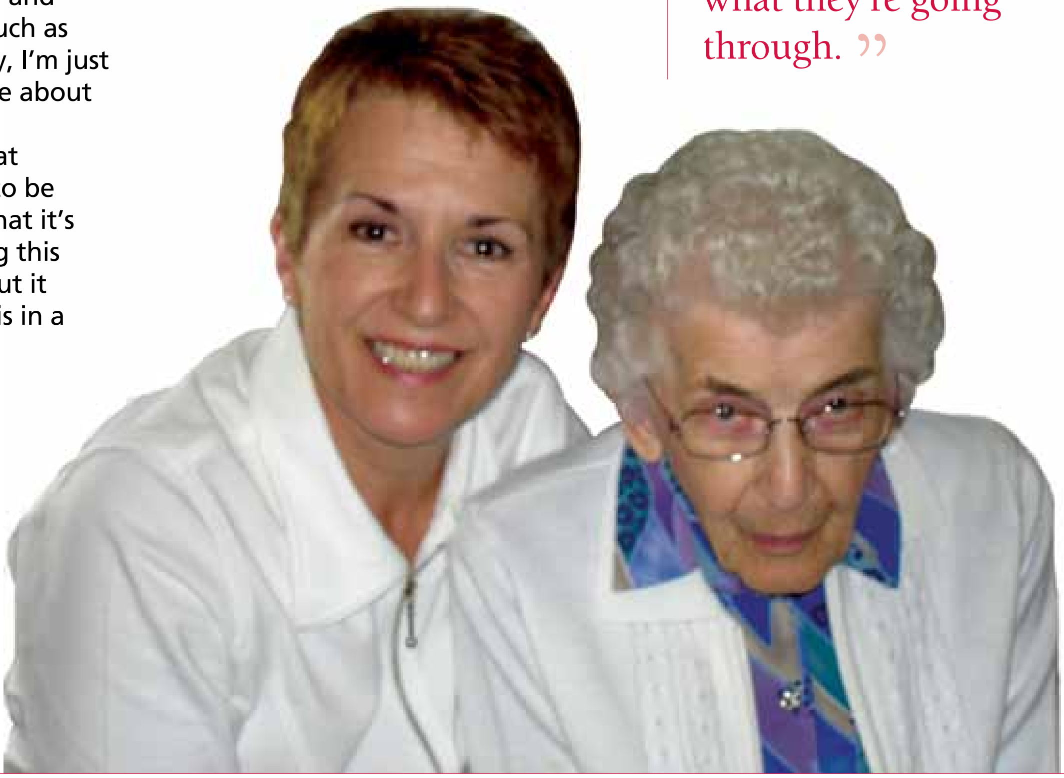
When my mother was diagnosed over 10 years ago, she was functioning on her own and independent. But as her Parkinson's progressed, I felt I didn't know how to help her, so I looked in the phone book to see if I could get connected with a support group. That was about five years ago.

For me, the number one reason for being in a support group is the education – the fact that you learn how to cope with the disease and how to help the person as much as you can, as a caregiver. Today, I'm just so much more knowledgeable about Parkinson's.

Right now, my Mom's throat and swallowing are starting to be affected but I have learned that it's the Parkinson's that is causing this so I'm able to talk to her about it and help her. Also, my Mom is in a home now, and when she is having difficulties, I feel confident that I can talk knowledgeably to the healthcare staff and sometimes even give them information.

But education is just one part of it. The support group has become a major part of my life because everyone there understands what I'm going through and I understand what they're going through. Just having that connection is very comforting.

> “The support group has become a major part of my life because everyone there understands what I'm going through and I understand what they're going through.”

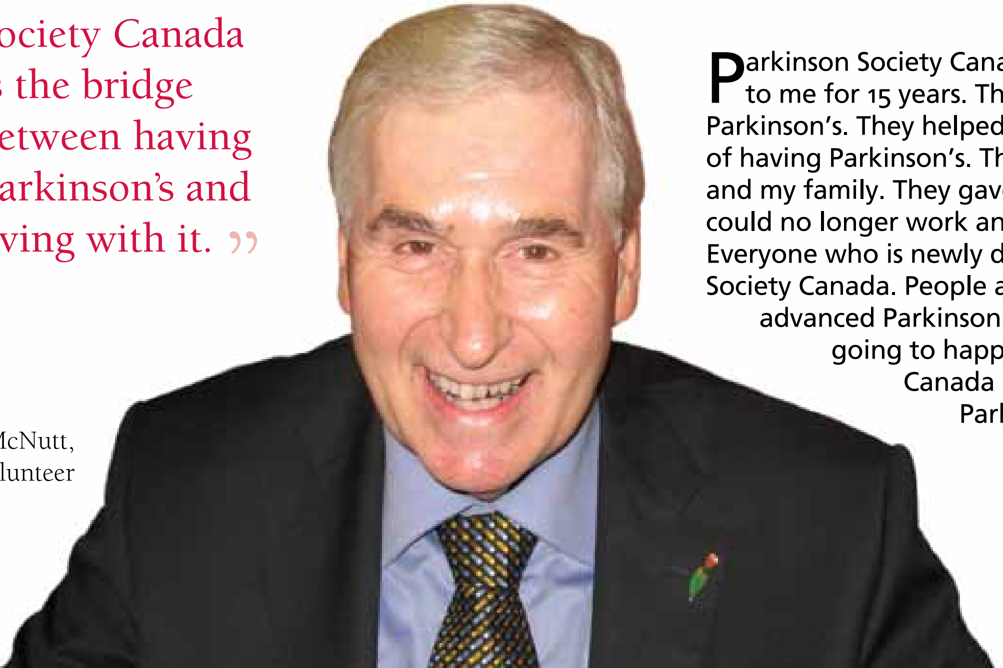


Caregiver Betty Lou Earl (left) with her mother Cecilia, is grateful for ongoing support from Parkinson Society Saskatchewan.

# A volunteer's story

> “Parkinson Society Canada is the bridge between having Parkinson's and living with it.”

Parkinson Society Canada has been providing service to me for 15 years. This is where I learned about Parkinson's. They helped me through the first years of having Parkinson's. They provided support for me and my family. They gave me something to do when I could no longer work and made good use of my time. Everyone who is newly diagnosed needs Parkinson Society Canada. People are scared when they see advanced Parkinson's. They wonder if this is going to happen to them. Parkinson Society Canada is the bridge between having Parkinson's and living with it.



Robert McNutt,
Volunteer

# Advocacy

The Honourable Leona Aglukkaq, Minister of Health for Canada, and members of Neurological Health Charities Canada (NHCC) celebrate the announcement of $15 million for a national neuro strategy. NHCC is comprised of 16 national neurological charities.

In the coming year, we will continue expanding the national advocacy network and work on identifying and developing new strategic partnerships.

Parkinson Society Canada's advocacy initiatives are focused on ensuring that government decision-makers not only understand the issues facing Canadians living with Parkinson's but also factor these issues into their policy, program and investment decisions, so that the impacts on Parkinson's can be minimized. In the past year, we made considerable progress in this area:

**The collective advocacy efforts of the Canadian Parkinson's community helped:**

- educate federal candidates through election advocacy activities;
- support the growth of a strategy to address genetic discrimination;
- secure $15 million to fund a national epidemiological study of neurological conditions in Canada, including Parkinson's disease, through the NHCC.

**Across the country, regional advocacy efforts have also helped:**

- secure $450,000 to develop an Ontario Neurological Strategy;
- present new data about the impact of Parkinson's disease to government leaders in Manitoba;
- advance the efforts of the Better Pharmacare Coalition in British Columbia;
- author and launch Parkinson's Disease: A Policy Perspective, a new policy document targeted at MLAs in Alberta.

## Donald Calne Lecture

Internationally renowned neuroscientist Dr. J. William Langston was the recipient of the 2008 Donald Calne Lectureship. Dr. Langston is the founder, CEO and Scientific Director of the Parkinson's Institute in Sunnyvale, California. His discovery of the link between a synthetic form of heroin and parkinsonism helped revolutionize the entire field of Parkinson's research. A video of Dr. Langston's presentation on new developments in Parkinson's research can be viewed at www.parkinson.ca.

Dr. William Langston,
2008 Donald Calne Lectureship

## Parkinson Alliance Meeting in Calgary

Researchers from across Canada shared ideas and information at the Parkinson Alliance meeting in Calgary, in January 2009.

Meeting highlights included:

- presentations on their progress in Parkinson's research from Dr. Heidi McBride on mitochondrial function; Dr. Susan Fox on the multiple roles of 5-HT in Parkinson's disease; Dr. Nicholas Dupré on screening candidate genes for Parkinson's disease in a specific population; Dr. David Park on DJ-1 using the MPTP model involvement of the mitochondrial function; Dr. Alex Rajput on essential tremor and Parkinson's disease / tremor in clinical pathological and biochemical studies; Dr. Mandar Jog on Neuroelectrodynamics; Dr. Ron Postuma on sleep and Parkinson's disease / disease prediction and heterogeneity; Dr. Sam Weiss on neural stem cells;
- a review of clinical guidelines from other countries, in preparation for creating Canadian consensus guidelines or clinical practice guidelines for the management and treatment of Parkinson's disease;
- discussion of the possibility of applying for a National Centres of Excellence grant.

As the largest non-government funder of Parkinson's research in Canada, Parkinson Society Canada has invested more than $16.8 million in Parkinson's research, granting over 300 fellowships, grants and new investigator awards, since 1981.

Parkinson Society Canada supported 26 research projects across Canada in 2008-2009.

In July 2008, Parkinson Society Canada committed a total of $946,950 in funding over the next two years, in addition to the $433,333 already committed to fund year two of awards from the 2007-2009 cycle.

This year's Psychosocial Research Grant, co-funded by the Canadian Institute of Health Research, Institute of Neurosciences, Mental Health and Addiction was awarded to Dr. Veronique Bohbot, Assistant Professor, Clinical Research at the Douglas Hospital Research Centre. Dr. Bohbot lectures in the Departments of Psychology and Neurosciences at McGill University.

Parkinson Society Canada research awards presentation in Ottawa.

**Total Grants: $1,429,333**

Parkinson Society Canada research awards presentation in Toronto.

# Raising Funds

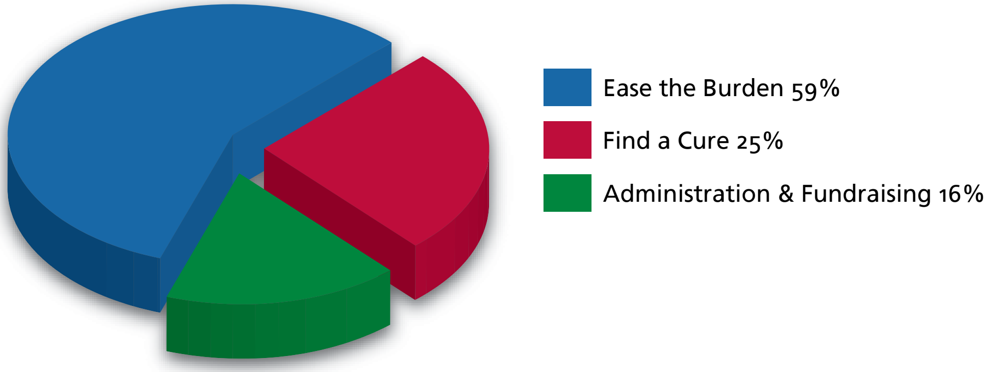
**Volunteers**
804 volunteers
16,853 volunteer hours

**Research**
26 research projects
Over $1 million paid out
Since 1981, $15.6 million in grants

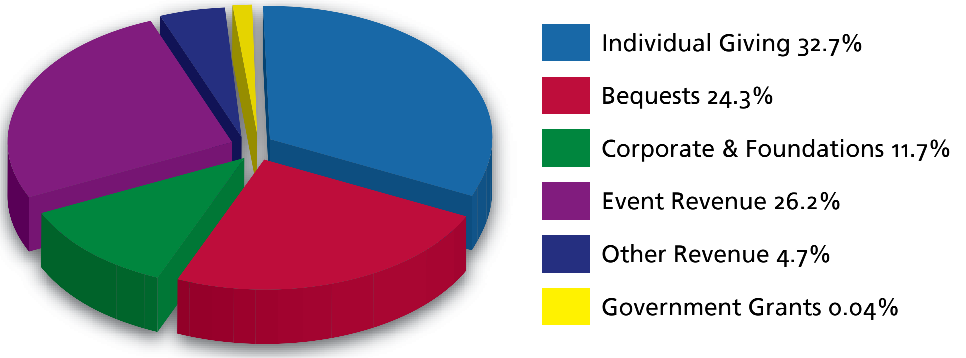
**Support Services**
235 Chapter and Support Groups

Seven-year-old Michaelea Silver raised over $2,000 in SuperWalk for Parkinson's 2008.

**Parkinson Society Canada Charitable Information (receipted dollars)**



**Parkinson Society Canada Sources of Revenue***



* Percentages are based on financial information as of fiscal year ended May 31, 2009.

We fund our education programs, support services, advocacy, and research with the contributions and donations of our donors. Over the past year, Parkinson Society Canada supporters have remained loyal and committed, even in the face of a downturn in the economy. We salute them.

Parkinson Society Canada supporters

- raised $2.2 million, making SuperWalk an outstanding success; a record 12,000 walkers participated in 85 communities, coast to coast
- contributed over $1.6 million in bequests to the planned giving program
- donated over $1.4 million in direct mail gifts, and through their generous gifts, enabled us to create three new research grants:

  The Garden Centre Group Co-op New Investigator Award
  Harrison McCain Foundation – Graduate Student Award
  IBM Employees Charitable Fund – Graduate Student Award

Their continued support will assist us in meeting the needs of the increasing numbers of Canadians who will develop Parkinson`s as our society ages.

**1.800.565.3000**
**www.parkinson.ca**