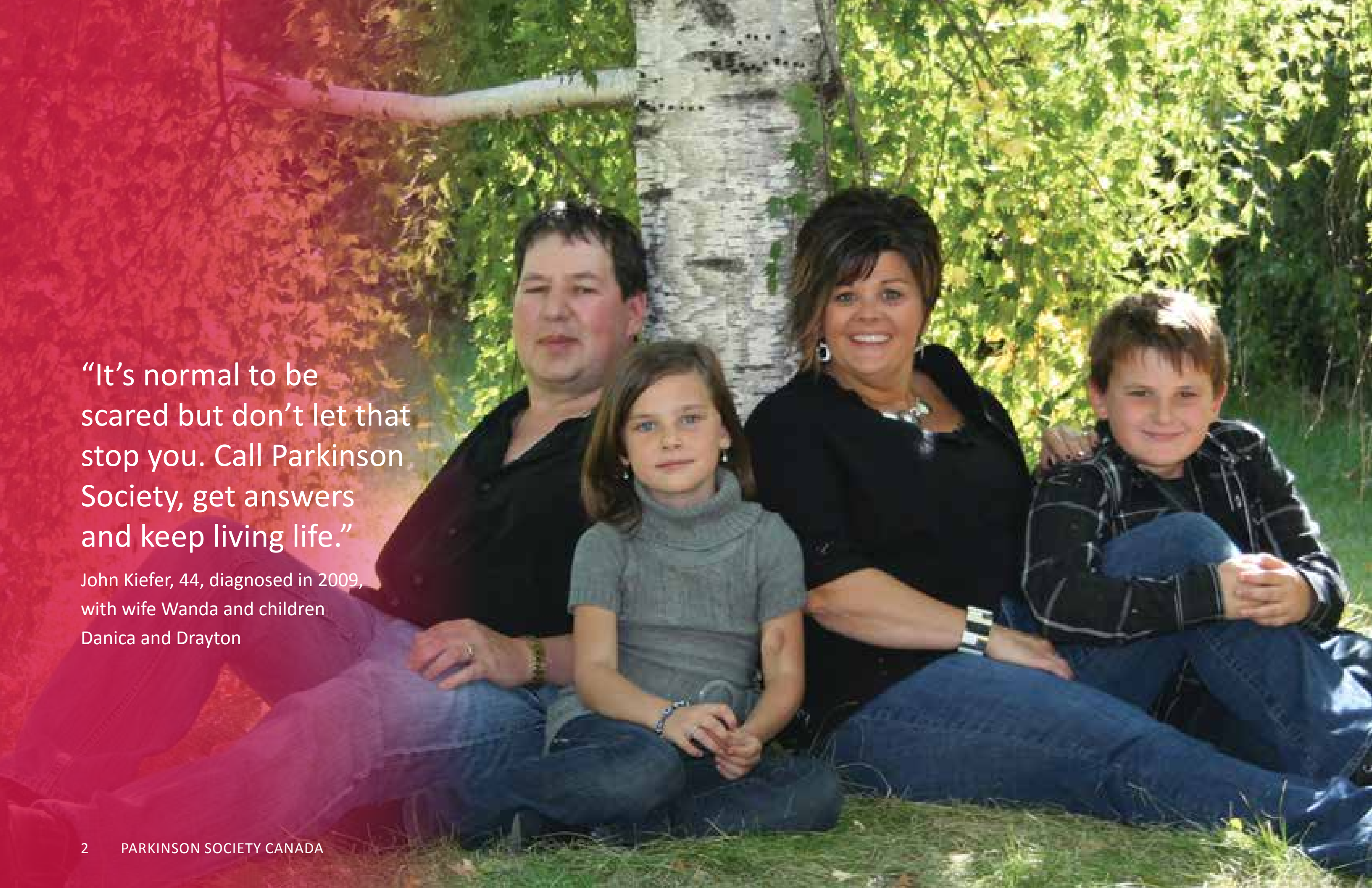
Parkinson Society Canada
Société Parkinson Canada

Leading Our Community Through Collaboration

2013 ANNUAL REPORT



“It’s normal to be scared but don’t let that stop you. Call Parkinson Society, get answers and keep living life.”

John Kiefer, 44, diagnosed in 2009, with wife Wanda and children Danica and Drayton

Leading Our Community Through Collaboration

Parkinson Society Canada works together with a network of partners to provide support for daily living complemented by extensive resources and information, in person, in print and online for the Parkinson's community, while continuing the global quest for a cure.

A 2013 highlight was our extensive involvement in World Parkinson Congress, hosted by Canada for the first time. We welcomed more than 3,000 attendees from around the world: the scientific community, people with Parkinson's and their family members, health professionals and the public. Canadian pride was reflected in the hearts and activities of the Parkinson's community in the months leading up to and following this week-long gathering in Montreal.

Throughout this annual report you will read about our work during 2013. We continue to build partnerships at a national level with like-minded organizations focusing on common goals. We are a member of Health Charities Coalition of Canada, working on issues related to health policy and research to improve quality of life for the Canadians. We also continued our leadership role with Neurological Health Charities Canada (NHCC). NHCC was instrumental in leading funded initiatives like the National Populations Health Study of Neurological Conditions. Through these collaborations we have moved neurological health issues front and centre for policy makers, as ambassadors in the crusade against Parkinson's disease.

Parkinson Society Canada is proud of the ways we work better, together, in communities coast to coast. We are proud of the Canadian spirit that drives our advocacy efforts which will lead to future success. Through your generous support we continue to serve Canadians living with Parkinson's. We encourage you to stay connected with us in person, visit our website or join the conversation on social media to find out more about Parkinson programs and services in your community. Thank you for joining us to make a world of difference.

Joyce Gordon,
President and CEO

Bruce Ireland,
Chair, Board

Partnering with Health Professionals to Improve Care and Treatment

Parkinson Society Canada (PSC) continues to unfold its multi-phased educational strategy targeted to family physicians and health care professionals across a variety of specialties. That's because the best Parkinson's care is delivered through a multi-disciplinary, team approach. Our initiatives build on the launch of the first *Canadian Guidelines on Parkinson's Disease (CGPD)* in 2012. We want to ensure family physicians make referrals to neurologists, and allied health specialists, early. We have partnered with physicians, introducing the guidelines across many specialties, under the guidance of our Medical Advisory Committee.

In November, PSC delivered an accredited workshop to primary care physicians at the annual Family Medicine Forum. Participants learned to apply the guidelines in their everyday practice through clinical case scenarios.

Dr. Jon Stoessl, Director, Pacific Parkinson's Research Centre and National Parkinson Foundation Centre of Excellence and contributing author to the CGPD, and Dr. Paul Randall, a family physician, led the session which received positive feedback. We will continue to share this knowledge at similar sessions, targeted to physicians, nurses and specialists. More than 13,000 visitors have accessed the guidelines website and downloaded almost 10,000 copies of 15 different resources (English and French combined).

Dr. Barbara Connolly, Assistant Professor, McMaster University

DID YOU KNOW?
Over 8,000 visitors learned about Swallowing and Diet and Nutrition in Parkinson's disease through new online resources

Partnering with Researchers to Improve Living with Parkinson's

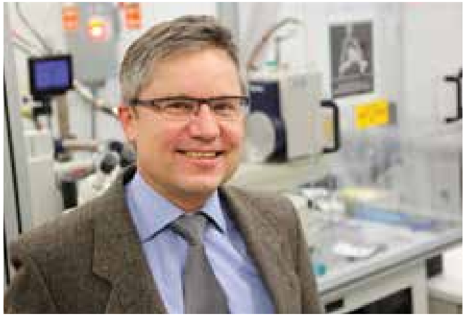
Each year, Parkinson Society Canada and our partners invest in discovery stage research where investigators test new theories and pursue promising new leads. The National Research Program funds researchers at the beginning of their careers in order to foster the next generation of Parkinson's scientists in Canada. When we learn more about the causes, progression and complications, we can find better treatments for Parkinson's today. Here are some research successes in 2013:

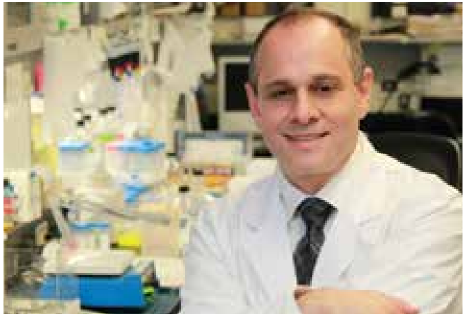
Cutting edge research leads to improving quality of life and opens doors to new drug therapies.

In 2013, a Parkinson Society Canada funded project led to the discovery of a three dimensional structure of the protein Parkin by Dr. Kalle Gehring at Dr. Edward Fon's lab at the Montreal Neurological Institute. This discovery has allowed the scientists to design mutations in Parkin that make it better at recognizing damaged mitochondria and therefore possibly provide better protection for nerve cells. These findings open doors to new drug therapies that could slow the progression of Parkinson's. The research was published in the leading journal Science.

Growing the number of Parkinson's specialists in Canada through targeted investment in fellowships

Dr. Barbara Connolly, Assistant Professor, McMaster University, opened a clinic just two years after receiving the Nora Fischer Movement Disorders Fellowship award. Trained in Toronto under Dr. Anthony Lang, Dr. Connolly now provides her world-class skills and expertise to patients in the Hamilton, Ontario area, where Parkinson's specialists were in short supply.





Top: Dr. Kalle Gehring. Below: Dr. Edward Fon.

DID YOU KNOW?
PSC committed $1,758,839 in 2013 to support 22 new grants, fellowships and student awards for research projects in Canada over the next two years, including 13 awards in their second year

Learning from the Experts

Dr. Virginia M.-Y. Lee, Professor at the University of Pennsylvania School of Medicine, was the 2013 Donald Calne Lecture award recipient. Dr. Lee spoke about "New insights into the mechanisms of Parkinson's disease progression." Her groundbreaking research on the etiology and pathogenesis of alpha-synuclein, tau, TDP-43, and other misfolded disease proteins in the pathobiology of neurodegenerative diseases like Parkinson's and Alzheimer's diseases has been heralded by her peers. Dr. Lee's recent work, specifically on alpha-synuclein, has generated global excitement among other researchers in related fields. The Donald Calne Lectureship Award is presented each year to a distinguished neuroscientist of international reputation, whose work is primarily in the area of Parkinson's disease.

Find out more about the funded researchers and their projects at www.parkinson.ca/research.

Dr. Virginia M.-Y. Lee, right, Donald Calne lecturer 2013, with Julie Wysocki, Director, National Research Program.

Partnering with our Network to Support Canadians with Parkinson’s

Our knowledge grows dramatically with each decade and, while there is much more to discover, great strides are being made to understand how we can help Canadians with Parkinson’s better manage and cope with their symptoms. We work with a network of partners that provides support for daily living and education conferences, complemented by extensive resources in print and online. This year we expanded our resources to include information about Multiple System Atrophy (MSA) and Parkinson-related conditions, like Parkinson Supranuclear Palsy (PSP). We continue to extend our reach to support Canadians and connect with them through education and services delivered coast to coast.

DID YOU KNOW?
More than 7,000 copies of the Canadian Guidelines on Parkinson’s Disease were distributed in Canada in 2013

Growing Importance of Canada’s Parkinson’s Community to the Global Parkinson’s Movement

Our network of Parkinson Society partners across Canada was instrumental in ensuring that a record number of Canadians – over 1,000 delegates - attended the third World Parkinson Congress in Montreal in October 2013. Contributions from Canadians experts included sessions with Dr. Michael Schlossmacher, Dr. Matt Farrer, Dr. Anne-Louise Lafontaine, Dr. Michel Panisset and event co-Chair, Dr. Jon Stoessl. Poster presentations ranged from highly scientific findings to topics about daily living, including a poster on a program to educate law enforcement personnel about the signs and symptoms of Parkinson’s. Congress also included a new informal peer support component, the first Buddies Program, matching international travellers with Canadians with similar interests so delegates had a built-in support system to minimize anxiety while away from home.

Elevating Parkinson’s Issues

- Parkinson Society Canada led the World Parkinson Congress’ first international policy forum specifically on Parkinson’s to raise the disease as a global health priority. Over 50 delegates including government policy staff from Canada, Europe, Mexico and the United States and Europe attended the forum. It is anticipated this initiative will be expanded for the next World Parkinson Congress in 2016.
- Parkinson Society Canada is proud to be an active member of The Canadian Coalition for Genetic Fairness. Genetic fairness was featured in the 2013 Throne Speech in the fall as a new priority for the Government of Canada. In addition, Bill S-201, an Act to prohibit and prevent genetic discrimination (the Genetic Non-Discrimination Act) was introduced in the Senate and moved into second reading in April, 2013.
- In July 2013, Parkinson Society Canada made its first Patient Evidence Submission to the Canadian Agency for Drugs and Technology in Health (CADTH). More than 600 members of the Parkinson’s community participated in a bilingual online survey. Feedback was incorporated in the submission which will be used to help determine whether Neupro is recommended to publicly-funded federal, provincial and territorial drug plans for inclusion on their respective formularies. The full submission can be accessed on our website at parkinson.ca.
- The completion of the National Population Health Study of Neurological Conditions (NPHSNC or “the Study”) brings an end to NHCC’s formal partnership and funding agreement with the federal government. Findings will guide and influence the work we do on behalf of the 100,000 Canadians living with Parkinson’s who are among the millions of Canadians struggling with the stigma and daily living challenges of brain disease. As a leading partner of the NHCC coalition, PSC looks forward to the release of the Study, marking an important opportunity to more fully understand the depth and breadth of Parkinson’s disease and other neurological conditions in Canada. With this insight, we can better meet the needs of this aging, expanding population.

Photo: The inaugural World Parkinson Congress Policy Forum was held in Montreal, Canada with approximately 50 delegates attending including government policy staff from Canada, Europe, Mexico and the United States. Also in attendance were leaders from international Parkinson societies, Parkinson ambassadors, and representatives from industry. The event was moderated by Jeffery Simpson, National Affairs Columnist for The Globe and Mail.


RESS
FORUM
ON

DID YOU KNOW?
More than 3,500 people have joined the online conversation with Parkinson Society Canada and Parkinson SuperWalk on Facebook and Twitter

PARKINSON
SUPERWALK
parkinsonsuperwalk.ca

Parkinson SuperWalk 2013

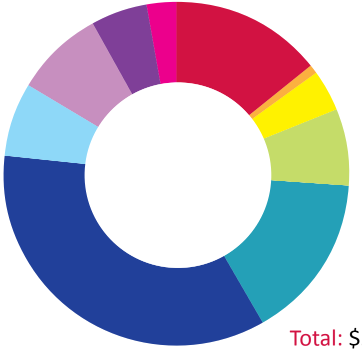
Over 14,000 participants, volunteers, donors and sponsors in 95 communities joined together to raise $2.76 million to fund local support programs and services for Canadians living with Parkinson's.

"Parkinson Society Canada was there for me and my mother so that we could be better care givers to my father, especially during his difficult days. I'm glad we can pass this gift on to other families," said Patricia Peterson, Edmonton, daughter of the late Dr. Frank Peterson.

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

MONEY RAISED FROM PARKINSON SUPERWALK



🟥	British Columbia	$391,912.46
🟧	Alberta	28,787.47
🟨	Saskatchewan	102,859.85
🟩	Manitoba	198,481.65
🟦	Southwestern Ontario	429,056.67
🟦	Central & Northern Ontario	967,486.19
🟦	Eastern Ontario	193,126.92
🟪	Quebec	228,932.19
🟪	Maritimes	145,539.39
🟥	Newfoundland & Labrador	$74,957.02

Total: $2.76 million raised across Canada

Photo: Proceeds from Parkinson SuperWalk fund educational resources, support services, rearcg and advocacy efforts provided by Parkinson Society Canada and its regional partners.
Photo credit https://mjand.co

THANK YOU TO OUR NATIONAL SPONSORS

TEVA Canada Innovation

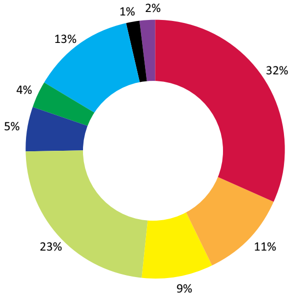
NATUREGG NATUROEUF

Roots

DID YOU KNOW?
More than 130,000 unique visitors accessed over 870,000 pages of information on parkinson.ca, our bilingual website

Financials

PARKINSON SOCIETY CANADA SOURCES OF REVENUE



🟥 Individual Giving
$2,737,010

🟧 Planned Giving
$960,915

🟨 Corporate & Foundation
$752,171

🟩 Event Revenue
$1,993,876

🟦 Government
$472,888

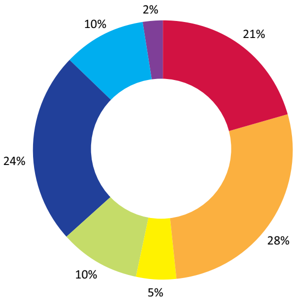
🟩 Contribution from The Charles Playfair and Dora Burke Playfair Fund
$301,925

🟦 Regional Partners
$1,103,478

⬛ Investment Income
$128,171

🟪 Other Revenue
$160,052

PARKINSON SOCIETY CANADA USE OF RESOURCES



🟥 Education & Services
$1,722,212

🟧 Research
$2,287,101

🟨 Advocacy
$423,475

🟩 Regional Development
$824,055

🟦 Fundraising
$1,978,405

🟦 Operation & Administration
$851,869

🟪 Governance
$187,203

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

PARKINSON SOCIETY CANADA CONDENSED CONSOLIDATED STATEMENT OF FINANCIAL POSITION AS AT DECEMBER 31, 2013

ASSETS	
Current Assets	
Cash and Investments	$2,757,694
Accounts receivable	612,501
Prepaid expenses	114,361
	3,484,556
Long Term Investments	2,338,492
Property and Equipment (Net)	101,730
Total Assets	**5,924,778**
LIABILITIES	
Accounts Payable and Accrued Liabilities	489,898
Deferred Contributions	755,607
	1,245,505
NET ASSETS	
Unrestricted net assets	4,503,383
Invested in Property and Equipment	101,730
Restricted net assets	62,160
Endowments	12,000
	4,679,273
Total Liabilities and Net Assets	**$5,924,778**

PARKINSON SOCIETY CANADA CONSOLIDATED INCOME STATEMENT

FOR THE TWELVE MONTHS ENDING DECEMBER 31, 2013

REVENUE	
Individual Giving	$2,737,010
Events	1,993,876
Planned Giving	960,915
Corporate Donations	752,171
Government funding for population health study	472,888
Contribution from The Charles Playfair and Dora Burke Playfair Fund	301,925
Investment Income	128,171
Other	160,052
	7,507,008
EXPENSES	
Research, Services & Education, Regional Development, Advocacy	5,099,170
Fundraising	1,978,405
Operating and Administration	1,039,072
	8,116,647
Support from Incorporated Regional Partners	1,103,478
Support to Incorporated Regional Partners	(157,673)
	945,805
Excess of Revenue over expenses	**$336,166**

ADDITIONAL INFORMATION

- Parkinson Society Canada figures include the National office and two unincorporated regional partners: Parkinson Society Central and 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 Society Saskatchewan, Parkinson Society Southwestern Ontario, Parkinson Society Eastern Ontario, Parkinson Society Maritimes 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 partners. The Support to regional partners in the Consolidated Income Statement of $157,673 is included in the $824,055 in the Use of Resources graph under Regional Development.

Board listings

PARKINSON SOCIETY CANADA NATIONAL BOARD OF DIRECTORS

Bruce Ireland, Chair, Ontario
Jean-Pascal Souque, Vice-Chair, Ontario
Lucie Lachance, Secretary, Quebec
Steve Bower, Treasurer, Alberta
Joyce Barretto, Ontario
Sherri Brand, Ontario
Dan Cooney, Alberta
Daphne FitzGerald, Ontario
Wenday Horbay, Ontario
Philip Hebért, Ontario
Jawad Kassab, Ontario
Rudy Knight, Nova Scotia
Tony Pugh, British Columbia
Judi Richardson, British Columbia

SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board, a volunteer panel of respected experts from the Parkinson's scientific community across Canada, conducts 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

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

NATIONAL ADVOCACY COMMITTEE

Joyce Barretto, Co-chair – Ontario
Yvon Trepanier, Co-chair, Ontario
Grant Cranston, Ontario
Chris Groot, British Columbia
Tony Pugh, British Columbia
Morgan Wheeldon, Nova Scotia

MEDICAL ADVISORY COMMITTEE

David Grimes, Chair, MD, FRCPC, Ottawa
Lynsey Bartlett, MD, MSc, CCFP, Ottawa
Karen Cronin, MD, CCFP, Downsview
Philip Hebért, BA MA MD PhD FCFPC, Toronto
W.R.Wayne Martin, MD, FRCPC, Edmonton
Andrea Moser, MD, MSc, CCFP, FCFP, Toronto
Ron Postuma, MD, MSc, Montreal, Quebec
Paul Randall, MD, CCFP, FCFP, King City
Kerrie Schoffer, BA, MD, FRCPC, Halifax

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.

OUR VISION

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

OUR 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.

CORE VALUES

All Parkinson Societies in Canada work together as a cross-country network guided by the following values:

- People with Parkinson’s first
- Collaboration
- Compassion
- Creativity
- Transparency
- Empowerment

These values reflect the way we interact with each other and in the formulation of all policies, decision making and consultation processes.

Parkinson Society Canada
Société Parkinson Canada

4211 Yonge Street, Suite 316, Toronto ON M2P 2A9
TEL 1.800.565.3000
Charitable registration number: 10809 1786 RR0001
parkinson.ca
parkinsonclinicalguidelines.ca

@ParkinsonCanada

Parkinson Society Canada received accreditation under Imagine Canada’s national Standards Program. The Standards Program is a Canada-wide set of shared standards for charities and nonprofits to demonstrate their compliance in five fundamental areas: board governance; financial accountability and transparency; fundraising; staff management; and volunteer involvement. It helps organizations mitigate risk by ensuring that staff and volunteers understand and meet their legal, financial and fiduciary responsibilities. PSC is one of just over 100 organizations in Canada to obtain this highest accreditation standard.