200

200 Years
Understanding Parkinson's Disease

Annual Report 2017

Parkinson Canada

Message from the Chair

In 1817, Dr. James Parkinson made a magnificent discovery. In 2017, we advanced a bold vision. **We are looking outward at possibilities.**

As your Board of Directors, we strive to both challenge and support the organization to be bolder, reach further and achieve more. To prepare for the increasing demands facing the Parkinson's community in Canada, our growth needs to be more than linear. We remain nimble and flexible in identifying opportunities that will help us achieve our strategic plan. Partnerships are absolutely critical for our success and the realization of our vision to be in a position to invest $10 million annually in research by 2035.

Today, my passion and focus is on collaboration and developing deeper relationships, leading to a stronger, more connected organization. Leveraging partnerships will guide us along a positive trajectory towards growing funds and increasing commitments to research, along with expanded services and targeted education opportunities for our diverse stakeholders.

Research and knowledge sharing are also key. That's why Parkinson Canada is driving the Canadian Parkinson Network (CPN), a new frontier in research collaboration, in terms of discovery and funding solutions.

Fundamental business disruption has arrived across many sectors and the charitable sector is not immune. As your Chair, I am particularly proud of the expertise and commitments shared by our Board members, as we challenge our business model , review our governance structure and lead the Canadian Parkinson Network. We are open to new horizons and recognize we cannot deliver on our vision entirely on our own.

It's gratifying to know how far we've come in uniting the Parkinson's community. I am grateful to my Board colleagues, and Parkinson Canada donors, supporters, volunteers, and employees who enable us to deliver on our promise of hope.

One day, we will welcome a world without Parkinson's disease.

Judi Richardson, Chair
Parkinson Canada Board of Directors

Message from the CEO

For more than 50 years, Canadians seek our support to live better with Parkinson's while we **search for a cure.**

Our focus remains on delivering operational excellence with one voice. In 2017, our second year as Parkinson Canada, we continued to build one brand from the six entities that unified into one pan-Canadian charitable organization the previous year.

With our teams of paid and unpaid staff, we bring our vision to life and are building an enduring foundation for our day-to-day operations, by:

- **Creating a central hub:** launched one-stop for stakeholders through the new website, one toll-free phone number, and one central Information and Referral Network for enquiries.
- **Evolving our culture of collaboration:** increased emphasis on service delivery in the field through partnerships, additional community staff and access to programs and resources across the country.
- **Delivering evidence-based resources:** *Medications to Treat Parkinson's Disease* book and *Parkinson's Disease: An Introductory Guide* are in their second printing.
- **Partnering with experts:** led by Dr. David Grimes, authors reviewed evidence to develop the second edition of *Canadian Guidelines on Parkinson's Disease*, addressing gaps like palliative care.
- **Streamlining operations:** an enhanced and integrated Customer Relationship Management database enables centralized gift processing and communication preferences.

Our increased profile has resulted in the highest number of research grant applications received; investigators are learning about the Parkinson Canada Research Program which is moving novel science forward, while building system capacity through clinical fellowships, to finding better treatments and improve quality of life. We continue to leverage our investment in research.

We went to Parliament Hill seeking matching funds and support for the Canadian Parkinson Network, which includes a biobank and patient registry. The network will benefit multiple research sites across the country through access to samples and data.

We continue to be the lead on the Canadian Action Plan for the Brain with Neurological Health Charities Coalition, which resulted in Parkinson's disease and three other neurological conditions being included in the annual Canadian Chronic Disease Surveillance System (CCDSS).

We consulted with key stakeholders including donors, clients, health professionals, and the public through an Ipsos survey. Thank you for sharing your experiences; this will shape our work for the next three to five years.

On behalf of Parkinson Canada, I would like to thank each of you who lend a hand in making our vision a reality. I am grateful for the generosity of our donors. With you, we are making Parkinson's matter. I look forward to the day when the headline reads, "A cure for Parkinson's."

We simply can't wait another 200 years.

Joyce Gordon, CEO
Parkinson Canada

Sprague Plato, standing, speaks at the Parliamentary breakfast about his journey with Parkinson's, following diagnosis 12 years ago at age 58. He is a Parkinson Canada Board member, Chair of the Government Relations and Advocacy Committee, and active ambassador. Also pictured (from left): Dr. Oury Monchi, MP Joël Lightbound, Daphne FitzGerald, past Chair, Parkinson Canada Board of Directors.

A Voice for Change

Parkinson Canada advocates on issues that affect the Parkinson's community at all levels of government. Along with nearly 200 dedicated **volunteer ambassadors**, we present your concerns to politicians and decision-makers to bring a unified voice for brain health for all Canadians. Many ambassadors are diagnosed with Parkinson's, or are a caregiver. They are passionate about making a difference for all Canadians affected by Parkinson's. Consider joining the movement and find out how you can become a Parkinson Ambassador to continue this important work. With one voice, we are making a difference!

Highlights of our contributions in 2017:

- **Access to medications:** Surveying our community we sent submissions to Canadian Agency for Drugs and Technologies in Health and to the Institut national d'excellence en santé et en services sociaux; as a result Movapo received a positive recommendation and is in the provincial funding review process. Duodopa was approved on a case-by-case basis in Nova Scotia as a result of a letter writing campaign executed by our ambassadors.
- **Genetic fairness:** Through our work with the Canadian Coalition on Genetic Fairness the Genetic Non-Discrimination Act became law. It prohibits any person from requiring individuals to undergo a genetic test or disclose the results of a genetic test as a condition of providing goods or services, or entering into or continuing a contract.
- **Medical marijuana** (cannabis) is legally accessible in Canada for medical purposes. To date, science-based evaluation has not conclusively demonstrated that marijuana can directly benefit people with Parkinson's; more research is needed and the new Parkinson Canada position statement reflects this.
- On May 4, 2017, Parkinson Canada held a Parliamentary breakfast and advocacy day on Parliament Hill. The breakfast was sponsored by MP Joël Lightbound (who at the time was the Parliamentary Secretary to the Minister of Health). Many notable guests were in attendance including MPs, Senators, and Minister Karina Gould. The focus was on Parkinson Canada's initiative, the **Canadian Parkinson Network (CPN).** The goal of the CPN is to better coordinate world class Parkinson's research happening across Canada that would create transformational

change for people with Parkinson's and their caregivers to live well in their communities through effective use of health, social and economic resources.

The Canadian Parkinson Network will include:

- a patient registry with comprehensive clinical information
- a database with information from diagnostic (imaging tests, MRI, PET scans), anatomical (neuroimaging, sleep, behavioural and neuropsychological information) and functional measurements
- a biobank, i.e. patient biomaterials such as blood samples and DNA for genetic studies

Porridge for Parkinson's (Toronto)

Porridge for Parkinson's began in Vancouver in 2001 when **Marg Meikle**, a former CBC radio host, developed Parkinson's disease at the early age of 43. With this as the impetus she started a breakfast event in her home to raise money for Parkinson's research. The event was a huge success. Now her legacy lives on throughout the country including in Toronto where the Porridge for Parkinson's committee raised more than $200,000 in 2017. To date, their breakfast event has contributed more than $750,000 to the Parkinson Canada Research Program.

Dr. Alexandre Boutet of the University of Toronto (University Health Network) received a **Porridge for Parkinson's Graduate Student Award in Honour of Isabel M. Cerny.** For many people with Parkinson's disease who undergo deep brain stimulation (DBS), the treatment can appear nothing short of miraculous. Dr. Boutet, currently completing his doctorate in neuroscience, has seen some individuals take as long as a year to adjust to the implant. Boutet is addressing this problem with another powerful technology, the imaging system known as functional magnetic resonance imaging (fMRI). This specialized MRI technique allows a strong magnetic field to compose a useful picture of blood flow, which also reveals those brain cells that are activated at any given moment. Depending on the type of stimulus — such as when an individual is reading, speaking, or listening to music — different parts of the brain "light up" accordingly in an fMRI image.

Dr. Cricia Rinchon, also of University of Toronto (University Health Network) received a **Porridge for Parkinson's Graduate Student Award in Honour of Delphine Martin.**

Patients with moderate to advanced Parkinson's disease can be treated with deep brain stimulation (DBS). The mechanisms of DBS are not fully understood, but the excitability and reorganization of groups of neurons (termed plasticity) likely play important roles. Excitability and plasticity of the brain area responsible for voluntary movement, primary motor cortex (M1), can be studied by administering transcranial magnetic stimulation (TMS) to the scalp. Dr. Rinchon will investigate a potentially more effective method of inducing plasticity by pairing subthalamic nucleus (STN) DBS and repetitive TMS (rTMS). These findings will improve our understanding of the mechanisms underlying DBS, and further develop combining DBS with cortical stimulation as a potential therapeutic strategy for Parkinson's disease.

Two other grateful recipients this year who received funding with thanks to the Porridge for Parkinson's (Toronto) event are **Dr. Simon Wing** of McGill University and **Anita Abeyesekera** of Western University.

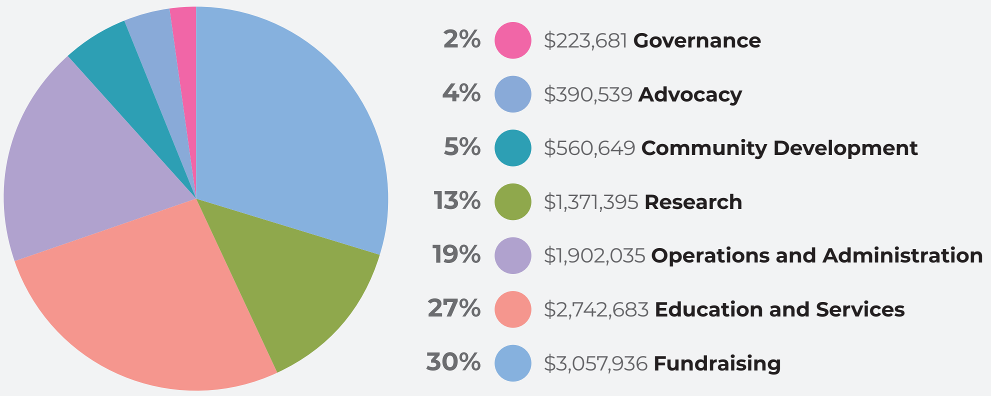
Together, we will find a cure.

Statement of Financial Position

as at December 31

	2017	2016
Assets		
Current Assets		
Cash	$457,190	$731,541
Short-term Investments	2,929,650	3,885,258
Accounts Receivable	502,001	586,921
Prepaid Expenses and Other Assets	152,638	184,111
	4,041,479	**5,387,831**
Investments	6,262,745	5,880,035
Property and Equipment	102,403	103,173
Total Assets	**$10,406,627**	**$ 11,371,039**
Liabilities		
Accounts Payable and Accrued Liabilities	697,011	695,539
Deferred Contributions and Deferred Research Contributions	230,515	490,296
	927,526	**1,185,835**
Net Assets		
Unrestricted	8,905,536	9,625,243
Invested in Property and Equipment	102,403	103,173
Internally Restricted Research Reserve	241,162	226,788
Endowment Funds	230,000	230,000
	9,479,101	**10,185,204**
Total Liabilities and Net Assets	**$10,406,627**	**$11,371,039**

Use of Resources

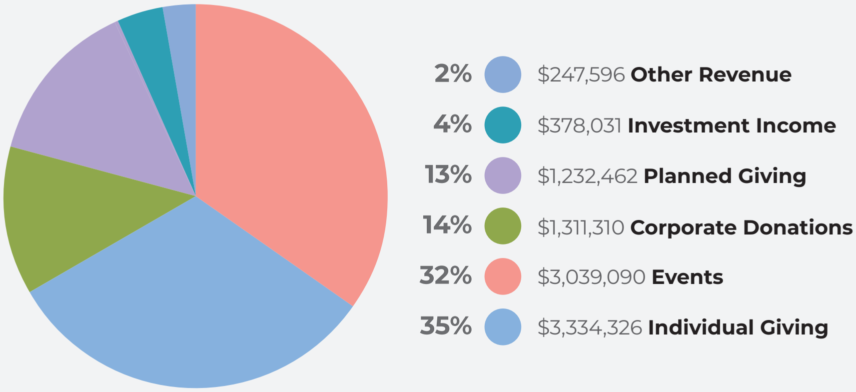


Income Statement

For the Twelve Months Ending December 31, 2017 and 2016

	2017	2016
Revenue		
Individual Giving	$3,334,326	$3,145,337
Events	3,039,090	2,418,894
Corporate Donations	1,311,310	1,566,594
Planned Giving	1,198,062	3,915,280
Investment Income	378,031	212,945
Contribution from The Charles Playfair and Dora Burke Playfair Fund for Research	34,400	75,248
Other	247,596	208,022
Total Revenue	**9,542,815**	**11,542,320**
Expenses		
Research, Advocacy, Education and Support Services	5,065,266	4,902,134
Fundraising	3,057,936	2,758,499
Operations and Administration	2,125,716	1,926,229
	10,248,918	**9,586,862**
(Deficiency) Excess of Revenue over Expenses	**$(706,103)**	**$1,955,458**

Sources of Revenue



Revenue	**Expenses**	**Net Deficit**
$9,542,815	$10,248,918	$(706,103)

Everyday HEROES Extraordinary HOPE

PARKINSON SUPERWALK®

Parkinson SuperWalk Raises Heroes and Hope

People living with Parkinson's were joined by family and friends, healthcare professionals, dedicated volunteers, and researchers across the country. Residents of Toronto contributed heavily to the success of the 27th annual Parkinson SuperWalk, an event which has raised more than $37 million since the first walk in 1990 was launched by 15 volunteers marching up Bathurst Street in Toronto.

"These funds help us to positively make a difference in the lives of those living with Parkinson's, their caregivers and healthcare professionals. We are investing in education today, and research that offers hope for a future without Parkinson's. For these individuals, a cure can't wait," says **Joyce Gordon**, CEO, Parkinson Canada

To mark this year's landmark fundraising total and in the spirit of "shining a light" on the accomplishment, the CN Tower was lit up in blue and red, the walk colours, at dusk on Wednesday, September 13.

Parkinson Canada takes a moment after the walk to shine a light on Everyday Heroes across the country that showcase the resiliency and strength of spirit in their daily lives. In 2017, the organization acknowledged Wadena, Saskatchewan's **Ardyce Glessing**.

Ardyce was chosen from over 100 nominees as the year's National Hero. Ardyce has not let her Parkinson diagnosis in 2008 change her life or relationship with family and friends. She reflects, "When someone has Parkinson's the whole family and everyone who loves them do too. We must not dwell on what we can't do and be thankful for **what we can**."

+ Parkinson SuperWalk is operated in BC by Parkinson Society British Columbia, under license.

Noteworthy Facts

$2.25 million+

4,000 fundraising walkers in 2017

10,000 participants

27 years

25 RESEARCHERS FUNDED
for 2017-2019 research cycle

$1.64 MILLION
committed to research

46
PRESENTATIONS
delivered to
Healthcare Professionals


2017 National Hero
Ardyce Glessing

PARKINSON AMBASSADORS MAKING A DIFFERENCE

Five years ago at the age of 36, **Natasha McCarthy** of PEI was surprisingly relieved to find out she had young onset Parkinson's disease (YOPD). It took 15 months for her doctor and specialist in New Brunswick to make the diagnosis. In the Maritimes, a group of about 25 people with YOPD or newly diagnosed with PD, meets monthly via videoconference. Natasha has been active as a Parkinson Ambassador, meeting with MPs about genetic fairness legislation, which has since passed in the House of Commons. In addition, she was an official blogger for the World Parkinson Congress 2016 in Portland, Oregon and today has almost 140,000 readers. Natasha finds writing the blog is therapeutic and brings her comfort. McCarthy explains her approach to the unique challenges of YOPD this way: "You and Parkinson's are going to be together for a very long time. It's going to be a long, hard road, if you decide to lie down and give up. It's best to take charge and concentrate on what you can do, not what you can't."

The Parkinson Canada Research Program

Engaging scientists to make Parkinson's a priority

As of September 2017, Parkinson Canada and its partners are proud to support 25 new grants, fellowships and student awards. These new awards represent a total of $1,323,369 committed to support new projects in Canada over the next two years. Including the 8 research awards in their second year, and the 25 new projects, the Parkinson Canada Research Program is currently committed to investing $1,643.369.

The new awards include:

- **10 Pilot Project Grants**
- **3 New Investigator Awards**
- **3 Basic Research Fellowships**
- **1 Clinical Movement Disorders Fellowship**
- **1 Clinical Research Fellowship**
- **7 Graduate Student Awards**

The Donald Calne Lectureship

Parkinson Canada awards the Donald Calne Lectureship to a distinguished neuroscientist of international reputation, whose work is primarily in the area of Parkinson's disease. The esteemed recipient gives a speech on the state of Parkinson's research. In 2017, the lecture was given in conjunction with the 21st International Parkinson's Disease and Movement Disorders Congress.

Pictured (l-r): *Dr. Wayne Martin, Professor Emeritus, University of Alberta; Dr. Andrew Lees, 2017 award recipient; Dr. Donald Calne, for whom the Canadian award was established in 2002; Dr. Ali Rajput, 2014 recipient; Dr. Anthony E. Lang, 2008 recipient; and Dr. A. Jon Stoessl, 2006 recipient.*

The Trillium Grow Grant

Parkinson Canada invited Ottawa-area residents to attend its public Research Forum and community celebration to hear Drs. Ron Postuma and Silke Cresswell. Pictured from left, Joyce Gordon, Parkinson Canada CEO; new community development coordinator Margaux Wolfe whose role, along with two others, was funded by a three-year Trillium Grow Grant; James Puddicombe, a volunteer with the Ontario Trillium Foundation; special guest Ottawa Centre MPP Yasir Naqvi; and Debbie Davis, VP Mission, Parkinson Canada; at the grant presentation ceremony.

Since 1981

528 RESEARCH PROJECTS FUNDED

OVER $27M INVESTED

1,035 Healthcare Professionals completed online learning modules

13,900 PEOPLE attended education events

341,468 people **visited parkinson.ca**

up 40% from 2016

516 SUBSCRIBERS
HAD **115,516** VIEWS
on our YouTube channel

5,968
FOLLOWERS ON TWITTER
up 77% from 2016

5,000+ COPIES
of *Parkinson's Disease: An Introductory Guide* were distributed

New resources in 2017:

Medications to Treat Parkinson's Disease is a new professional resource from Parkinson Canada, written by Tejal Patel, BScPharm, PharmD, from University of Waterloo. The booklet outlines how different medications work, the side effects and helpful tips about adjusting medication. The publication includes self-monitoring tools such as calendars and surveys that can be filled out and discussed at medical appointments. Canadians can access this resource in French and English, online at parkinson.ca.

Parkinson's Disease: An Introductory Guide is a new book developed and authored with the McGill University Health Centre Patient Education Office. The Guide will help people living with Parkinson's, their caregivers and healthcare professionals to better understand the disease. It describes the illness, changes in the body over time, treatment and care options, and possible health problems. As a practical introduction to Parkinson's disease, it provides information about:

- *Symptoms of Parkinson's and how to spot them*
- *Treatment and care options*
- *Tips and strategies to take charge of one's health*
- *Possible problems to watch out for*
- *When and where to find more help*

This guide was made possible with the support of Parkinson Canada, the Canadian Institutes of Health Research, and the Fonds de la recherche en santé du Québec.

PARKINSON CANADA COMMUNITY EDUCATION EVENTS

Pictured (l-r): *Marc Pittet, Director, Parkinson Canada Board; Julie Wysocki, Director, Parkinson Canada Research Program; Dr. Julius Anang, St. Boniface Clinic and Dr. Sean Udow, University of Manitoba.*

Parkinson Canada hosted major community education events in Winnipeg, Manitoba featuring Dr. Julius Anang who presented *Parkinson's Disease Treatments* and Dr. Sean Udow, who presented his *Educate PD* project which will better inform patients and clinicians on difficult aspects of Parkinson's during office visits.

Dr. Udow and Dr. Anang received clinical fellowships from Parkinson Canada, and both now practice in Winnipeg. Dr. Anang co-authored *Parkinson's Disease: An Introductory Guide*. More than 5,000 copies of this comprehensive resource were distributed in 2017 thanks to generous support from donors.

Parkinson Medications and You

Parkinson Canada hosted a bilingual symposium in partnership with the Cummings Center in Montreal, Quebec for 135 participants. Expert presenter Dr. Tejal Patel, a clinical pharmacist and lead author of *Medications to Treat Parkinson's Disease*, reviewed how various therapies work, how to adjust dosing, and which drug interactions and side effects to watch for. Paola Campana, a physiotherapist at the Institut universitaire de gériatrie de Montréal, explored the positive impact of physical training on medication use and motor skills at early and intermediate stages of Parkinson's. The event concluded with a panel where individuals discussed their experiences about different aspects regarding medication use and physical activity.

1,878 PEOPLE accessed 6 webinars and 6 podcasts

26,916 SUBSCRIBERS received our newsletters

THANK YOU TO OUR DONORS!

64,225 donors in 2017 gave **88,687 donations**

44 planned gifts were received from estates

1,460 donors give monthly

1 Parkinson Canada partnered with the Davis Phinney Foundation to bring ***The Victory Summit***® educational event for people living with Parkinson's to Toronto, Canada in 2017. Thanks to generous sponsors and local partners, participants attended at no cost. The Toronto event included an exhibit hall with complementary therapies, local resources and national organizations. The Victory Summit® event provides essential tools and resources that inspire people with Parkinson's to live well each day.

2 **New hope to halt compulsive gambling.** Up to 20 percent of people who take a class of drugs called dopamine agonists to treat their stiffness, tremor or freezing in place, develop impulse control problems such as compulsive gambling. At the University of British Columbia, behavioural neuroscientist **Catharine Winstanley,** pictured right, uses animal models to test drugs that block a protein called GSK3, which is linked to those impulse problems. If successful, her research will remove a major stumbling block to using a successful medication to treat the symptoms of Parkinson's disease.

3 ***Dancing with Parkinson's*** is a program hosted by the National Ballet School, Parkinson Canada and community partners to provide an engaging way to be physically active and reduce social isolation through movement. People with Parkinson's with a range of ability and mobility enjoy participating in this inspiring therapy that teaches movement targeted to manage certain aspects of Parkinson's. Spouses and friends are welcome to join, making the experience even more enriching.

4 Parkinson Canada hosted a public education session on Parkinson's disease and depression, featuring ***Andy Barrie and his journey with Parkinson's,*** as well as medical expert **Dr. Mateusz Zurowski** and social worker **Janice Stober**. Depression affects more than 40% of people with Parkinson's.

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Dr. Angela Roberts, Northwestern University
Ms. Sharon Yardley, Pacific Parkinson's Research Centre, Vancouver Coastal Health – UBC

The Research Policy Committee (RPC) and Scientific Advisory Board (SAB) are two separate volunteer committees. The chair of the SAB also serves on the RPC to ensure continuity.

Scientific Advisory Board

The annual research program application review process is undertaken by the Scientific Advisory Board (SAB) of Parkinson Canada. These volunteers employ a proven, multidisciplinary peer-review system in their annual review of applications, which provides for the highest quality of objective adjudication.

Dr. Ron Postuma, Chair, McGill University
Dr. Silke Appel-Cresswell, University of British Columbia
Dr. Frédéric Calon, Université Laval
Dr. Robert Chen, Krembil Research Institute (University Health Network)
Dr. Bin Hu, University of Calgary
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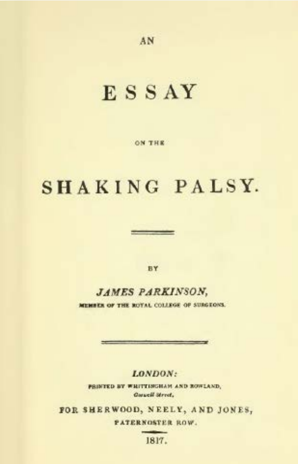

AN
ESSAY
ON THE
SHAKING PALSY.

BY
JAMES PARKINSON,
MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

LONDON:
PRINTED BY WHITTINGHAM AND ROWLAND,
Goswell Street,
FOR SHERWOOD, NEELY, AND JONES,
PATERNOSTER ROW.
1817.

Dr. James Parkinson was an English surgeon, apothecary, geologist, palaeontologist, and political activist, best known for his 1817 work, *An Essay on the Shaking Palsy*. He was the first to describe "paralysis agitans", a condition that would later be renamed Parkinson's disease by Jean-Martin Charcot. Now 200 years later, there is a large body of knowledge and countless researchers working to unravel its mysteries and find a cure.

There's help and hope at Parkinson Canada

STRONG CHARITIES. STRONG COMMUNITIES.
ACCREDITED
SINCE 2013
IMAGINE CANADA

Here for You

You just found out you have Parkinson's, and the whole family is anxious. Who do you turn to? Parkinson Canada offers Information and Referral as one of many core services available across the country. Individuals can call **1 800 565 3000** or connect by email at info@parkinson.ca. In 2017, we responded to thousands of contacts for help. You and your family will have questions from the moment of diagnosis, and at many points along the way as the disease progresses. We're here for you no matter what, whether you are newly diagnosed, or you are facing difficult conversations such as when you may not be able to drive a vehicle or staying safely at home is no longer an option. You may deal with issues of employment, caregiving, insurance, taxes, or assistive devices. We can connect you with information and community support, activity programs and local support groups. The health professionals who treat you turn to Parkinson Canada to learn more themselves, and for education and resources for their patients.

Parkinson Canada

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Parkinson.ca | ParkinsonClinicalGuidelines.ca

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