

Review 2016

● Stories of Hope, Health and Happiness



Blake Bell
Parkinson SuperWalk
National Hero, 2016

 Parkinson Canada
2016 Annual Report

A Year in

Message from the Chair and CEO

Working as ONE to deliver help and inspire hope

When Parkinson's disease comes into a person's life and their home, it changes everything. We've been changing too. The January 2016 union of six Parkinson's organizations into one Parkinson Canada shows that we are taking the bold steps needed to grow our capacity to reach more people with Parkinson's effectively and efficiently. This is more important than ever given that the number of people with Parkinson's is growing by more than 25 people each day.

In this unity is strength. Throughout this report, you will find examples of how your generosity helps transform the lives of thousands of Canadians living with Parkinson's disease. You will also find examples of the impact we are having as *the* source of credible information about Parkinson's in Canada. Health care professionals increasingly turn to our clinical guidelines for accurate treatment information and refer their patient to our programs and services.

On these pages, you will find stories of how connecting with Parkinson's Canada improves the lives of people living with Parkinson's from support groups to webinars and from taking part in SuperWalk to supporting local Parkinson community fundraising efforts.

Thank you for being a big part of our story. We are grateful to our donors, supporters, volunteers and employees who enable us to bring hope by delivering world-class education, research, advocacy and support programs to individuals and families in communities coast to coast to coast. We look forward to building on these strengths while the quest for a cure continues.



Daphne Fitzgerald
Chair, Parkinson Canada



Joyce Gordon
CEO, Parkinson Canada

Advocacy

153 Parkinson's Ambassadors volunteered in communities across Canada to have their voices heard on issues important to them. This represents a **growth of 42 per cent** in our Ambassador Network.

In 2016, we called for action on:

- Federal legislation to prohibit and prevent **genetic discrimination**.
- **Improved access to medication**, particularly coverage of Duodopa® for people with advanced Parkinson's in BC and Nova Scotia. In Manitoba, Duodopa® became available on a case-by-case basis.
- Improved understanding through new position statements informing our community about **Medical Marijuana (Cannabis) and Parkinson's** and the new, federal **Medical Assistance in Dying** legislation.
- Improved assistance for **caregivers** in Ontario through respite services, education and tax relief.

If you are living with Parkinson's, are a caregiver, or just want to help, you can be a voice for Canadians with Parkinson's.

Research

The Parkinson Canada Research Program funds research into the causes, and improved treatments for people with Parkinson's, to improve their quality of life. Research increases our understanding of Parkinson's disease, and related disorders, moving us closer to a cure.

The impact of our investment in discovery-stage research multiplies beyond the initial funding. New funding comes from other organizations such as government agencies that further invest in Canadian scientists based on proven early results. *See infographic on back for more statistics.*

Researcher	Parkinson Canada Initial Grant	New Leveraged Funding
Dr. David Park	\$45,000	\$641,836
Dr. Ali Salahpour	\$89,340	\$426,151
Dr. Martin Duennwald	\$45,000	\$522,225
Dr. George Robertson	\$45,000	\$392,000
Dr. Marc Ekker	\$45,000	\$330,193
Total Funding	\$269,340	\$2,312,405

Financials

Balance Sheet	December 2016	Opening Balance January 1, 2016
Assets		
Current		
Cash	\$731,541	\$1,380,998
Short-term Investments	3,885,258	4,008,483
Accounts receivable	586,921	646,502
Prepaid expenses and other	184,111	108,524
	<u>5,387,831</u>	<u>6,144,507</u>
Investments	5,880,035	2,932,534
Property and equipment	103,173	97,371
	<u>5,983,208</u>	<u>3,029,905</u>
Total Assets	<u>11,371,039</u>	<u>9,174,412</u>
Liabilities		
Current		
Accounts payable and accrued liabilities	695,539	596,025
Deferred contributions	490,296	348,641
	<u>1,185,835</u>	<u>944,666</u>
Net Assets		
Unrestricted	9,625,243	7,689,406
Invested in property and equipment	103,173	97,371
Internally restricted research stability reserve	226,788	212,969
Endowment Funds	230,000	230,000
	<u>10,185,204</u>	<u>8,229,746</u>
Total Liabilities and Net Assets	<u>\$11,371,039</u>	<u>\$9,174,412</u>

Income Statement For the Twelve Months Ending Saturday, December 31, 2016

Revenue	
Individual Giving	\$3,145,337
Planned Giving	3,915,280
Corporate donations	1,566,594
Contribution from the Charles Playfair and Dora Burke Playfair fund for Research	75,248
Events	2,418,894
Investment Income	212,945
Other Revenue	208,022
	<u>11,542,320</u>
Expenses	
Fundraising	2,758,499
Operating and administration	2,020,439
Research, advocacy, education and support services	4,807,924
	<u>9,586,862</u>
Overall Surplus (Deficit)	<u>\$1,955,458</u>

Everyday Heroes

Blake Bell

First National Hero finds *SuperWalk* is part of his healing process.

Blake Bell became Parkinson SuperWalk's first National Hero, winning the title in a nationwide contest based on nominations. Bell's colleagues, friends and family called him an "inspiration," and praised his warm and positive attitude.

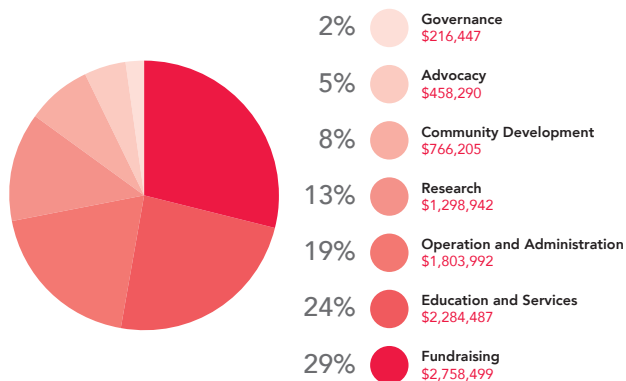
"I admit I cried after reading the nominations I received and learning that I was named the National Hero. That's not how I think of myself, I simply want to treat people well, and trust that they'll do the same for me."

Bell first took part in Parkinson SuperWalk in 2015 and decided to share his Parkinson's with people who did not know about his condition.

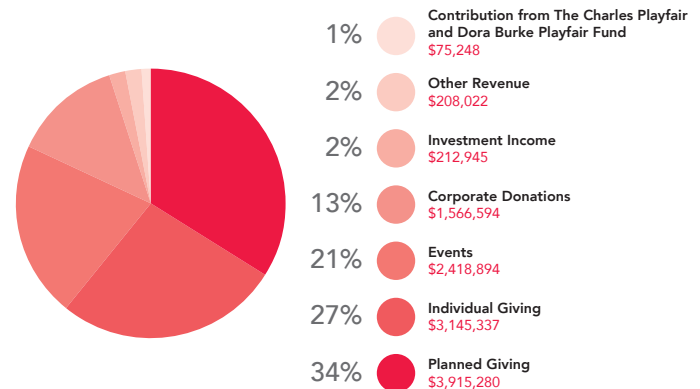
"I got overwhelming support from friends and family. In many ways, participating in *Parkinson SuperWalk* has been a part of my healing process."



Use of Resources



Sources of Revenue



You make it possible

60,019 donors in 2016 gave 81,555 donations
58 planned gifts received from estates
1,095 monthly donors

Revenue
\$11,542,320

Expenses
\$9,586,862

Net Revenue
\$1,955,458

Lows in Motion event raises funds and hope



Congratulations to the more than 6,000 participants, volunteers, sponsors and community members in Saskatoon, Saskatchewan, who have come together during the past seven years to be part of the Lows in Motion fundraiser. Including the 2016 event, they have raised a total of \$516,000.

Travis Low founded the event in 2009 in honour of his grandfather who had Parkinson's disease and his father who was newly diagnosed at that time.

The annual event is more than a gala, featuring entertainment and moving videos of Life with Parkinson's.

"There is so much to be hopeful for," says Low. "Hope that we will continue to progress our understanding of the disease. Hope that new treatments will allow those living with the disease to live a better quality of life. And our biggest hope is that we will one day find a cure!"

Inspiration meets science at World Parkinson Congress 2016

A packed schedule of scientific presentations, workshops, plenary sessions, roundtables, discussions and posters, as well as unmatched opportunities to network and socialize with the international Parkinson Community, made the World Parkinson Congress 2016 (WPC 2016) an exciting and inspiring event.

Canada was well represented at the event held in Portland, Oregon from September 20 to 23, 2016. Participants from Canada included speakers, researchers, health professionals and people living with Parkinson's and their care partners. Parkinson Canada proudly sponsored the Stanley Fahn Young Investigator Award, presented for the first time at WPC 2016, to Danish researcher Morten Gersel Stokholm, for his cutting edge research on neuroinflammation in prediagnostic Parkinson's disease.

The World Parkinson Congress is the only global Parkinson's conference that brings together the entire Parkinson's community every three years – people with Parkinson's disease, those who care for them, medical and health professionals, and dedicated researchers working toward a cure and better treatments.



Sharing international knowledge

Dr. Robert Nussbaum delivered the 12th Donald Calne Lecture in conjunction with the 2016 Canadian Association for Neuroscience annual conference. His topic of *Genetics and Parkinson's* was suitable for both the public and the scientific community. Dr. Nussbaum's presentation was given in person to a full house and was also posted on Parkinson Canada's YouTube channel.



Dr Robert Nussbaum

Dr. Nussbaum directed the original research that led to the discovery of mutations in alpha-synuclein in hereditary Parkinson disease in the mid-1990s and has been studying its role in Parkinson disease ever since. He received his training in medicine in the Harvard-MIT Joint Program in Health Technology, his internal medicine training at Barnes Hospital/Washington University, and his genetics training at Baylor College of Medicine.

The Donald Calne Lectureship celebrates a distinguished neuroscientist whose research is helping us learn more about how to understand, diagnose, and treat Parkinson's. The recipient gives a speech, on the state of Parkinson's research, to Canadian scientists, medical professionals, people with Parkinson's and their families.

Education and Support

Help and hope for people living with Parkinson's and their care partners. See infographic on back for statistics.

Your giving, participation, and advocacy are helping provide critical support for everyone affected by Parkinson's disease.

Every bit of **your support** makes a better world possible.

Your gift changes lives.

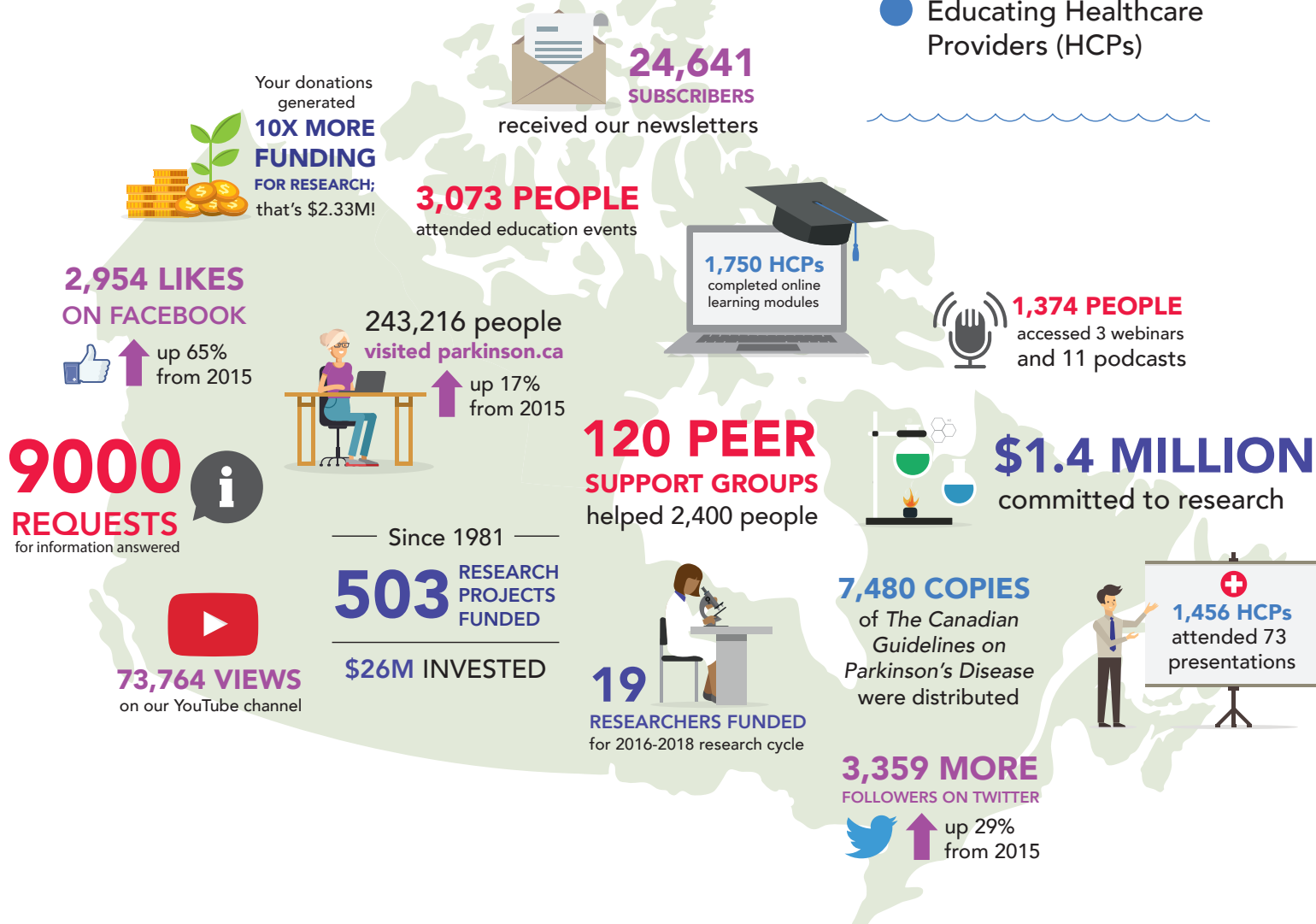


Thank you

Parkinson Canada 2016

Helping You and the Parkinson's Community Coast to Coast by:

- Providing Support
- Providing Information
- Funding Research
- Educating Healthcare Providers (HCPs)



Everyday
HEROES
Extraordinary
HOPE

- **\$2.15 MILLION** raised across Canada
- **68 COMMUNITIES** involved
- **10,000** walkers, participants and volunteers
- **3,792** registered walkers
- **\$501.53** Average raised by a fundraising participant

THANK YOU

for your support. for being part of the Community.
for sharing in hope. for the inspiration.



Everyday Heroes Peter Istvan

Volunteer wins Cash, Sweat and Tears award

Peter Istvan, co-founder and organizer of Pedaling for Parkinson's – an annual bike ride that has raised more than \$700,000 for Parkinson Canada – won the 2016 Cash, Sweat and Tears award, from Peer-to-Peer Fundraising Canada.

Istvan started the ride with friend David Newall in rural Parry Sound, Ontario, six years ago to raise money to fight Parkinson's disease. The ride has grown from 18 riders raising \$18,000 to 250 people taking part and raising \$200,000.

“We work hard to connect riders to the research and research to the riders,” says Istvan. ***“That’s an important connection to use. We want to make it clear to the riders where the money is going and why what they are doing is important.”***



Everyday Heroes Geoffrey Hesketh

The value of basic research: Discovering links to Parkinson's

“Knowing exactly what goes wrong at the cellular level is critical for the design of any future drug to treat Parkinson's,” says, Dr. Geoffrey Hesketh, who is close to completing a two-year, \$100,000 Basic Research Fellowship from the Parkinson Canada Research Program.

At the Lunenfeld Tannenbaum Research Institute in Toronto, cell biologist Geoffrey Hesketh is investigating the function of the Retromer group of proteins, which he has linked to 10 genes that, when damaged, cause Parkinson's disease. Unlocking exactly how these genes work together and what other proteins they communicate with may eventually point the way to a new drug or therapy that can treat Parkinson's.

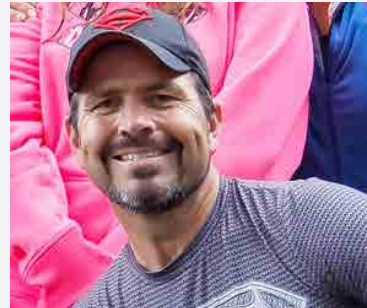


Everyday Heroes Nurse Kelly Williams

Nurse fills a care gap with heart and expertise

Meet Kelly Williams, the only clinical resource nurse working in a movement disorders clinic in Manitoba. She specializes in assisting people living with Parkinson's disease, and thanks to the generosity of our donors, Parkinson Canada funds a portion of her salary. Kelly also educates health care professionals about the complexities of caring for people with Parkinson's disease. In 2015 she delivered 22 presentations to patient groups and health care professionals. In 2016, she gave 50 presentations.

“I fill a care gap for people with Parkinson's; to live their best life possible, to be able to advocate for themselves in medical situations and in the community, and to connect with others living with Parkinson's by joining Parkinson Canada support groups and exercise programs.”



Everyday Heroes Jamie Fobert

Life reclaimed with peer support from Parkinson Canada

Jamie Fobert sobbed during the entire two-hour drive home after learning he had Parkinson's disease at age 40 in 2010. Today, Fobert helps organize local Parkinson Canada events, shares his story with the media and helps support others living with the disease. Fobert credits a chance meeting with Stephanie Bruder, who also has Young-onset Parkinson's, and her introduction to the Parkinson Canada support group in Belleville, with changing his outlook.

“I believe I have a responsibility to live every day to the fullest, and to not take anything for granted,” says Fobert. ***“A cure for Parkinson's isn't just going to happen, we need to go after it.”***



Parkinson Canada received accreditation under Imagine Canada's national Standards Program. The Standards Program is a Canada-wide set of shared standards for charities and non-profits 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. Parkinson Canada is one of just over 200 organizations in Canada to obtain this highest accreditation standard.



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