

## **2020 Gratitude Report: Parkinson Canada**

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Transforming the lives of  
People Living with Parkinson's.  
NO MATTER WHAT.



# Thank You For Being There in 2020

**Thank you for consistently supporting the Parkinson Canada team with care, friendship and generosity. Your dedication and solidarity during these extraordinary times ensured we could continue providing support for everyone who needed us. We couldn't have done it without you.**

Thank you for your commitment to driving and funding innovation and research. Your support and participation are impacting more people affected by Parkinson's and supporting important programs and initiatives, such as the innovative Canadian Open Parkinson's Network. This incredible network is increasing the rate of research discovery and driving exciting new

breakthroughs that could change everything for people living with Parkinson's.

Today and always, thank you for partnering with us and advocating for the entire Parkinson's community in Canada, as we face the future with hope for a better life today for People with Parkinson's and imagine a world without Parkinson's tomorrow. Thank you for raising funds, raising your voices, and raising hopes for a future free from Parkinson's. Under the strong leadership of our new CEO, Dr. Karen Lee, I'm confident that together, we're going to get there.



A handwritten signature in black ink that reads "Marlin Stangeland".

**Marlin Stangeland**  
Parkinson Canada Board Chair

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## A message from Dr. Karen Lee

**Thank you, thank you, thank you.**

What a year 2020 was. A year of challenge. A year of change. A year of staying apart but coming together in purposeful, life-changing ways. A year of funding groundbreaking research. A year of uncovering more ways to improve the lives of Canadians with Parkinson's. A year of virtual exercise classes, informative webinars, and fundraisers that looked different but managed to be just as successful and meaningful.

**YOU and your determined support made it all possible. Thank you.**

You spoke out for change, advocating for better access to care for Canadians with Parkinson's. You embraced a new virtual format, tied up your running shoes, and got moving with the 30th Annual Parkinson Canada SuperWalk. You donated generously, ensuring the pandemic didn't impede our ability to be there for people. You joined me on my virtual, cross-country

CEO Listening Tour, telling me how Parkinson Canada could better serve and reflect you.

**We listened. We heard you. We acted.**

We pivoted almost all of our services to be digital-first, because that's where you needed us. As part of our commitment to always keep your voice at the centre of everything we do, we created the Parkinson Advisory Council, comprised of members from across Canada, who have diverse perspectives on the impact of Parkinson's.

From improving connection in communities, advancing changes in Parkinson's care, and driving research and innovation to spreading awareness and support by sharing more of your stories, we're here for you and with you. And we'll continue to be here. Walking beside you. Aiming our sights at stopping Parkinson's. No matter what.



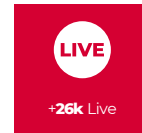
A handwritten signature in black ink that reads "Karen Lee".

**Karen Lee, PhD**  
President & CEO Parkinson Canada

# Impact You Made Incredible Things Happen in 2020

No matter the fact we were immersed in a global pandemic. No matter the hardship and heartache. No matter the challenges you faced personally. **NO MATTER WHAT**, you stepped up to make 2020 a year filled with impact. This past year, you responded with the same resilience that people with Parkinson's exhibit daily in the face of their symptoms. You shared your experience, you leaned on each other, and you joined in to find out more about supports and exciting new research projects. Here are some of the powerful ways your support helped make a difference for Canadians with Parkinson's in 2020.

**5340 calls** received for Information & Referral



**20 research grants** awarded

\$1,015,000 committed to new projects

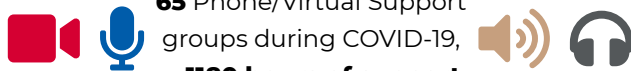


**56 Online exercise classes** with Parkinson Canada's **Lance Letain**



\$1.6 million was raised by SuperWalk with 1000+ walk in a box kits distributed.

**65 Phone/Virtual Support groups** during COVID-19, or **1180 hours of support.**



Listening Tour sessions with **CEO Karen Lee**

**8 sessions** with **80 attendees**, a precursor to the upcoming **Parkinson's Advisory Council**



# Impact A Year of Community Connection

In 2020, you learned that support is all around you despite the need for social distancing. Together, with our Parkinson's Awareness Month campaign and e-book highlighting your stories, we showcased that with Parkinson's, you are not alone.

*"My greatest satisfaction and joy in life has always come from connecting with others, sharing ideas and observations about life, love, kids, dreams, disappointments, hopes for the future, and lessons from the past."*

**Heather**

Contributor to the You Are Not Alone e-book

## 1,180

We helped 65 different support groups transition to phone or online meetings during COVID-19, with more than 1,180 hours of support.

## 82,000+

Thanks to you, we registered 82,000+ views of online webinars.

## 1,387

Thanks to you, we registered 1,387 downloads of our "You Are Not Alone" e-book.

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# Impact Fueling Advances in Parkinson's Research

Because of your generosity, Parkinson Canada awarded 20 research grants in 2020, committing over \$1-million to new projects. It's an exciting time and we're so grateful to YOU for making this kind of groundbreaking research possible.

- New drugs to treat Parkinson's
- Uncovering better speech and language therapies
- Studying ways to stop dyskinesia, involuntary movements
- Looking at how to provide essential deep brain stimulation without surgery
- And a range of other projects focused on increasing access to care; improving treatments; and supporting research into the cure

## 20

research grants awarded by Parkinson Canada in 2020

## \$1M+

committed to new research projects

## \$1.6M

in total research investment; including C-OPN

# Impact SuperWalk and Pedaling for Parkinson's

The COVID-19 pandemic may have changed how you walked or rode in 2020, but it didn't impact your dedication to these events. It didn't affect your determination to raise money, raise awareness, and help change lives. A million thanks for your support.



## Parkinson SuperWalk

In 2020, thousands of participants in 80 communities across the country joined the 30th anniversary of the Parkinson SuperWalk. Due to restrictions for gathering, we changed our format, which you embraced by making your own walk with our Walk in a Box. You raised an astounding \$1.6 million for Parkinson's support, advocacy, and new research working to change lives and find a cure. Since 1990, your SuperWalk participation has garnered more than \$38-million dollars for Parkinson's research, support, and care.



## Team Bacchus

Sadia Bacchus wanted to support her husband, Manzil who has Parkinson's disease, by participating in SuperWalk. Family and friends joined Team Bacchus, with Sadia leading the way as Team Captain since 2010. Last year, they raised an impressive \$14,000 for a cause near and dear to their hearts.



## Boxing4Health

Last year presented challenges for team members of Boxing4Health and the namesake Ottawa gym that hosts the team for exercise classes. Boxing4Health not only pivoted, they flourished, and raised an incredible \$97,098 for SuperWalk - the highest fundraising total for any team in the history of SuperWalk.



## Pedaling for Parkinson's

Last year, you adapted to conditions and rode more than 1KM for every Canadian living with Parkinson's. Riders rode safely in pods for Pedaling for Parkinson's in Prince Edward County, virtually tracking more than 70,000 kms through 'Go the Distance' and we welcomed the support of the Growling Beaver Brevet for the first time. The Rigid Riders, Canada's only cycling team composed of people impacted by Parkinson's, adapted in the face of the pandemic the same way they do in the face of their symptoms.

All together, 447 cyclists raised \$335,788 funding a new Pedaling for Parkinson's grant through the Parkinson Canada Research Program and providing funding for a new app focused on living well with Parkinson's that will be launched in 2021.



## Drumming to His Own Beat How Larry Linton found peace with Parkinson's.

Meet Larry Linton: drummer, marathon-runner, author, husband, dad, lawyer, and chair of the newly formed Parkinson Advisory Council (PAC). The council is an exciting new initiative launched by Parkinson Canada in 2020.

Almost a decade after his Parkinson's diagnosis in 2012, Larry never imagined he'd be so involved in the Canadian Parkinson's community.

"At the start of my Parkinson's journey, I was a mess. I lived my life on the couch, away from my family. In my office, I buried myself in file work and declined team events and client meetings. Convinced that my life was over at 49, I often struggled to make it through the day."

One day, tired of the couch, Larry made some choices that would change his future. He pulled on his running shoes. He picked up his drumsticks. He started writing. And he reached out to Parkinson Canada. In the days since, Larry has run three marathons. He played the drums at the Beaches Jazz Festival in Toronto. He published his first book (Shaken, Not Stirred: Living With Parkinson's Disease came out a year ago). And he's found connection, friendship and support with those travelling a similar Parkinson's path.

"I wish I had reached out to Parkinson Canada sooner than I did. It took me years to attend my first support group meeting. At support groups, I felt that I belonged, hearing from others and finding comfort

in sharing my own experiences. I came to appreciate that living with Parkinson's is a community event. And that there is comfort in numbers."

*"The formation of the Parkinson Advisory Council puts the voice of the community at the table with Parkinson Canada. It gives us the opportunity to be active participants and advisors, ensuring that all actions taken by Parkinson Canada are done with the lens focussed on us and our care partners, all the time."*

**Larry Linton**

Chair of the Parkinson Advisory Council

## From Tears to Laughter to Acceptance

**Coming to terms with Parkinson's.**

Almost a decade after his Parkinson's diagnosis, what advice would Larry share with his younger self?

"With the benefit of hindsight, there are a number of things I would have done differently.

Instead of putting on a brave face, I would have given myself permission to grieve, to be angry, to shout, to question, to cry and to eventually get to that point of acceptance.

I would have given myself permission to laugh and experience some bright moments."

# Facing the Future with Hope and Resilience

Canada has the highest prevalence of Parkinson's, per capita, in the world, increasing at a rate of 43%. In the next ten years, the number of Canadians diagnosed with Parkinson's is predicted to double to more than 50 a day. **With your determined support, Parkinson Canada is working to change this.**

Our 2021-23 Strategic Plan focuses on navigating through this time of uncertainty while expanding our reach to impact more Canadians affected by Parkinson's. Central to our vision is

ensuring that anyone, anywhere affected by Parkinson's can live well today, while we drive support and efforts towards finding a cure.

For the 100,000 loved ones with Parkinson's in Canada today; for the 25 people who will be diagnosed tomorrow; for the countless numbers who will be diagnosed next year and the year after that: we're working relentlessly to turn the tide.



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## Facing the Future: Research Innovation

Research holds the key to unravelling every Parkinson's mystery. Last year, Parkinson Canada partnered with Brain Canada and the leading Parkinson's disease researchers in the country to found the Canadian Open Parkinson Network (C-OPN). This network aims to accelerate breakthroughs, improve patient outcomes, increase clinical trial involvement, and transform the lives of people living with Parkinson's.



### **YOU Can Change the Future** **Join the Canadian Open Network with Canadians like Linda Bérard.**

In the summer of 2013, just 44 years old, Linda Berard received the diagnosis that would change her life: Parkinson's disease.

"...this diagnosis was tragic for me," says Linda. "However, I have come a long way and am far more knowledgeable today about Parkinson's. I now focus on helping others understand this disease."

One way she's doing that is with the Canadian Open Parkinson Network (C-OPN).

"I registered without hesitation," Linda says. "As parents, and now proud grandparents, our greatest wish is to win the fight against this chronic and degenerative disease, so that generations following us will speak about Parkinson's as a curable disease."

**Be part of making Parkinson's a curable disease too. Find out more about C-OPN at [www.copn-rpco.com](http://www.copn-rpco.com)**

# Facing the Future: Expanding Our Reach



Parkinson Canada's 2021-2023 strategic plan puts people with Parkinson's at the centre of everything we do—always. With your generous support and solidarity, we're working hard to diversify our programs, expand our reach and serve the unique needs of Canadians with Parkinson's wherever they live.

## Reaching Out, No Matter What

Expanding our reach also includes offering webinars and online workshops that inspire, provide comfort or spark hope. Perhaps they'll connect you with each other. Maybe they'll fill you in on new research breakthroughs or therapies. Possibly they'll make you laugh. From lived experience to medical expertise, we hope they remind you that you're part of a community. And you're never alone.

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# Facing the Future: Raising Your Voice



We're committed to giving you space to tell your stories and share your needs so that, together, we can improve access to care and create systemic change across the country. To that end, we're shaping an advocacy framework focused on access to health services and mobilizing the community to raise its collective voice.

## Parkinson Advisory Council

The Parkinson Advisory Council (PAC), created in 2020 and populated by people across the Parkinson's community, provides guidance and insight to the CEO - and Parkinson Canada as a whole - to ensure programs, service delivery and policy are improved through their firsthand knowledge and experience. PAC's mission is: to ensure the voice of people affected by Parkinson's disease - including caregivers - is integrated.

## Demanding Better Access to Care

You've told us that diagnosis wait times and accessing multidisciplinary care are your highest priorities. We're listening, we're taking action and we're advocating for change. From ongoing roundtables with key stakeholders (including, most importantly, people like you), we're creating real solutions that we'll take to policy-makers to demand change. We'll keep speaking out until everyone can access the care they need when they need it.



## 2020 Numbers and Financial Reports

# Thank You For Being There

**As Parkinson Canada Vice Chair and Treasurer, I'll admit I was deeply worried when COVID-19 hit. How could Parkinson Canada possibly continue to provide the same level of care, support, and advocacy amid the onslaught of challenges we were suddenly facing? How would we meet the financial goals that would help us continue to be there for Canadians with Parkinson's?**

Very quickly, you proved there was no need to fear. You stepped up. You donated. You participated. You spoke out. You shared your time and your expertise, committing to making life better for Canadians affected by Parkinson's. You signed up

for research trials. You were there whenever we asked you to be, so we could continue to be there for everyone who needed us, no matter what.

For eight years, I saw my own grandfather struggle with Parkinson's. I know how important community is when you're living the daily reality of Parkinson's. Thank you for being a community who's in it for and with each other, in good times and bad, no matter what.

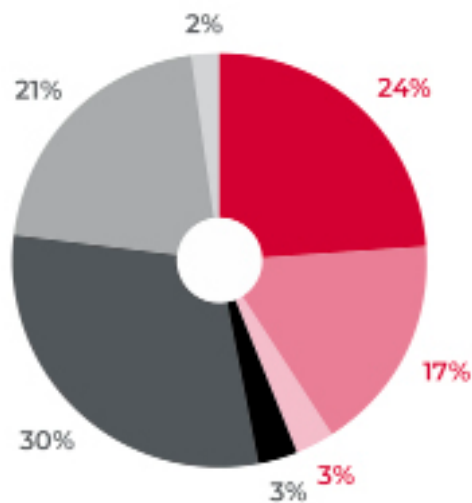
With sincere gratitude,



**Veeral Khatri**

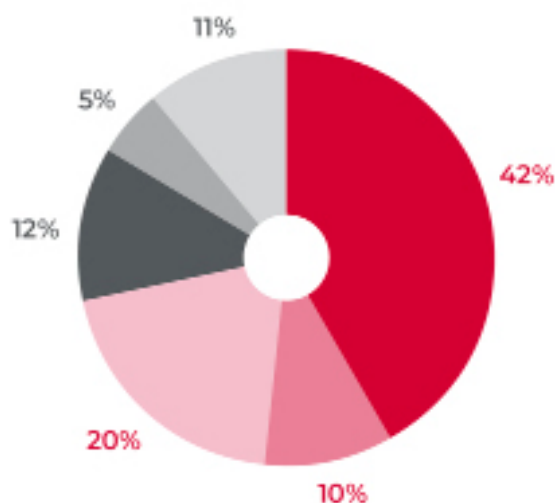
Parkinson Canada Vice Chair and Treasurer

**Parkinson Canada  
Use of Resources**



Education & Services	\$ 2,285,748
Research	\$ 1,603,320
Community Services	\$ 323,973
Advocacy	\$ 245,027
Fundraising	\$ 2,858,005
Operation & Administration	\$ 1,947,370
Governance	\$ 233,198

**Parkinson Canada  
Source of Revenue**



Individual Giving	\$ 4,100,023
Planned Giving	\$ 989,058
Events	\$ 1,927,535
Corporate & Foundation Donations	\$ 1,173,694
Investment Income	\$ 513,778
Other Revenue	\$ 1,107,958

## Statement of Financial Position as at December 31

	2020	2019
<b>Assets</b>		
<b>Current</b>		
Cash	\$ 418,046	\$ 502,831
Short-term investments	3,133,416	3,613,396
Accounts receivable	709,134	765,682
Prepaid expenses and other assets	253,884	265,508
	4,514,480	5,147,417
Investments	7,477,892	6,972,294
Property and equipment	672,715	756,333
<b>Total assets</b>	<b>\$ 12,665,087</b>	<b>\$ 12,876,044</b>
<b>Liabilities</b>		
<b>Current</b>		
Accounts payable and accrued liabilities	\$ 394,021	\$ 856,400
Deferred revenue	233,914	261,522
	627,935	1,117,922
<b>Long-term</b>		
Deferred revenue	400,115	436,490
	\$ 1,028,050	\$ 1,554,412
<b>Net assets</b>		
Unrestricted	4,493,004	3,783,981
Operating Reserve	5,056,318	5,056,318
Canadian Open Parkinson Network Reserve	498,000	830,000
Research Reserve	687,000	665,000
Invested in property and equipment	672,715	756,333
Endowment funds	230,000	230,000
	\$ 11,637,037	\$ 11,321,632
<b>Total liabilities and net assets</b>	<b>\$ 12,665,087</b>	<b>\$ 12,876,044</b>

## Income Statement

For the Twelve Months Ending December 31

	2020	2019
<b>Revenue</b>		
Individual giving	\$ 4,100,023	\$ 4,617,226
Planned giving	989,058	2,874,920
Events	1,927,535	2,682,346
Corporate and foundation donations	1,173,694	265,508
Investment income	513,778	5,147,417
Other	1,107,958	260,966
<b>Expenses</b>		
Research, advocacy, education & support services	4,458,068	5,615,549
Fundraising	2,858,005	3,150,782
Operating and administration	2,180,568	2,190,224
	<b>9,496,641</b>	<b>10,956,555</b>
<b>Excess of revenue over expenses</b>	<b>\$ 315,405</b>	<b>\$ 1,739,325</b>

## Meet the Board of Directors

Parkinson Canada is governed by a volunteer Board of Directors. Board members represent a cross-section of industries, geographies, experiences and skills. We acknowledge the leadership and contributions of our Officers and Directors.

### Officers

**Marlin Stangeland**  
Chair

**Veeral Khatri**  
Vice Chair and  
Treasurer

**Dr. Karen Lee**  
Secretary

### Directors

**Joseph Bartlett**  
Director

**Julie Cafley**  
Director

**Laura Edgar**  
Director

**Daphne FitzGerald**  
Director

**Margaret Hanlon-  
Bell**  
Director

**Dr. Wendy Horbay**  
Director

**Nancy MacCready-  
Williams**  
Director

**Sprague Plato**  
Director

**Judi Richardson**  
Director

**Michael Rothe**  
Director

**Dr. Antonio P.  
Strafella**  
Director

**Mike Zegers**  
Director

# Thank YOU as Always

Thank you for investing in making life better for every Canadian living with Parkinson's. Thank you for choosing to make a stand with us as we work to change the future. Thank you for helping us search for a cure. Thank you for envisioning a world without Parkinson's...no matter what.

*"You don't know how much your generosity means. You help us hold each other up. And you give us hope by supporting research. I think we're close to a breakthrough and the funds you provide will help us get there."*

**Greg McGinnis**

*Living with Parkinson's*

**NO MATTER  
WHAT**

