

Your 2021 Impact

We are more powerful in what we can achieve together. Thank you for your important support and belief in our mission. You make a difference to the Parkinson's community of researchers, care and service providers and those living with Parkinson's.

A Message From Our CEO

In my second year as President and CEO of Parkinson Canada, and in these unprecedented times, I am amazed at the devotion that every volunteer, participant, and employee showed towards our mission to transform the lives of Canadians living with Parkinson's. From launching the Parkinson Advisory Council, to creating national support groups that unite Canadians from coast to coast, 2021 was a pivotal year of enhancing programs and services to respond to the needs of our community – and we couldn't have done it without your support.

We focused on accessibility and responded to increased demand for our digital resources. As a result, the participant numbers in virtual support groups more than doubled, we diversified our wellness programs, and provide access to eBooks – like our recently released medication booklet – through our Information and Referral services. We are committed to moving forward with a digital-first approach to our programs and resources that help people live well with Parkinson's regardless of where they live.

The recently released National Advocacy Roundtable Report, which you will read about in the pages to come, helped prioritize our advocacy efforts to improve access to care, and highlight issues and barriers in our healthcare system. Thanks to the 150 community members across Canada who shared their experiences, the findings from this report will provide the roadmap for our future advocacy efforts. As a member of the research community, I know firsthand how important it is to continue to support our incredible network of researchers, collaborating and partnering to drive research innovations in finding new treatments. Our strategic direction over the coming years will ensure we invest in research rooted in collaboration, not only with healthcare professionals and expert researchers, but also with those living with Parkinson's to ensure they continue to thrive.

None of this would have been possible without the support of our Parkinson Canada community. You have been instrumental in all of the initiatives we were able to undertake in 2021, and we couldn't do what we do without your unwavering support. As we work to expand our national reach, we will continue to improve the delivery and accessibility of all our programs and services for the benefit of all Canadians living with Parkinson's and their care partners.





Karen Lee, PhD President & CEO Parkinson Canada

Thank You For Your Support in 2021

On behalf of Parkinson Canada's Board of Directors, I am pleased to present the 2021 Impact Report.

In 2021, Parkinson Canada's donors and supporters helped the Parkinson's community in immeasurable ways. While it was another year of Covid-19 related challenges, it was also a year of hope and progress. Filled to the brim with achievements that brought us closer to realizing our vision of a world without Parkinson's tomorrow and our mission to transform the lives of Canadians impacted by Parkinson's today.

Digital-first resources were embraced far beyond what anyone could predict, and the results speak for themselves. With virtual support groups and national monthly webinars reaching record-breaking attendance numbers, we made real headway in breaking down the locational barriers of access to the Parkinson's community across Canada and the resources within it.

To our selfless volunteers, dedicated staff, and our incredible donors, I extend my sincere

gratitude for the guidance in how best to deliver virtual support and remote access to the community that allowed us to be there precisely when we were needed. Our partners who helped us elevate our research program provided all-important counsel while developing a new research strategy in 2021.

Our event participants showed tireless support in fundraising for a cause that impacts more than 100,000 Canadians, even during the second year of Covid-19 related restrictions. We saw Canadians from the Pacific to the Atlantic participate in SuperWalk, Pedaling for Parkinson's, and other events to help make certain that no Canadian living with Parkinson's has to walk (or ride) alone.

Canadians with Parkinson's are at the center of everything we do. It's because of the continued generosity of our supporters like you that Canadians living with Parkinson's remain hopeful for improved care and treatments now, and a future without Parkinson's disease.



Veeral Khatri Parkinson Canada Board Chair

Parkinson Canada 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, as well as people living with Parkinson's. We acknowledge the leadership and contributions of our officers and directors.

Directors

Veeral Khatri Chair

Laura Edgar Vice Chair

Mike Zegers Treasurer

Dr. Karen Lee Secretary Marlin Stangeland Director

Joseph Bartlett Director

Dr. Julie Cafley Director

Director

Nancy MacCready-Williams Director Daphne FitzGerald Director

Dr. Wendy Horbay Director

Margaret Hanlon-Bell Director

Sprague Plato Director Judi Richardson Director

Michael Rothe Director

Dr. Antonio P. Strafella Director

A Community of Impact

At Parkinson Canada, people living with Parkinson's are at the core of everything we do. Our quest to improve lives and find a cure for the disease affecting more and more Canadians every day makes Parkinson Canada the hub for all impacted by Parkinson's.

With the generous support of more than 58,000 Canadians in 2021, Parkinson Canada continues to fund critical research, provide information and support, increase awareness and advocate for improved healthcare outcomes for people with Parkinson's across Canada.

See your Impact

Amount raised through community fundraising events



People reached through our webinars

13,000

Calls and emails answered through our Information and Referral Helpline



Community support groups across the country

120

17 grants awarded for a total of





In 2021, Tony Zwig and Thea Caplan, a couple from Ontario, donated a transformational gift of \$750,000 to Parkinson Canada. A sizable portion of which helped to fund the 2021-2023 Parkinson Canada research competition. Their generosity has empowered us to drive research innovation towards personalized treatments for people with Parkinson's and ultimately a cure.

Tony's mother lived with Parkinson's. Thea's father lived with another neurological condition: Guillain-Barré syndrome.

The couple's shared experience of parents with neurological conditions gave them an understanding of how research collection done on a large scale can begin to fill the knowledge gaps the research community still has about Parkinson's.

Tony and Thea have a deep appreciation for the initiative of C-OPN as they understand that the significant discoveries required to improve the lives of people living with Parkinson's are not possible in any single lab or clinic in the world.

Their transformational gift will help to shape future research and accelerate knowledge across the field. We are grateful and thank them for their support.

Parkinson Advisory Council

Launched in 2021 and comprised of 12 members from around the country, the Parkinson Advisory Council (PAC) ensures the perspective of people impacted by Parkinson's is integrated into our strategic initiatives by providing advice to our CEO and our team members in delivering our mission.

The PAC is a diverse and inclusive representation of Canadians diagnosed with Parkinson's, care partners, family members and others with lived experience who represent diverse genders, expertise, socio-economic levels and cultural demographics. Parkinson Canada sought their input and guidance for many – if not all – of our 2021 initiatives and we will continue to absorb their invaluable perspective into our future work. "The Parkinson Advisory Council has assumed an important role at Parkinson Canada. The PAC has allowed us – people living with Parkinson's and their care partners – to move from being passive beneficiaries of the programs and services offered by Parkinson Canada to being active participants in the co-creation, co-production and collaboration of those programs to ensure that they are meeting the evolving needs of the community."

Larry Linton

Chair of the Parkinson Advisory Council

Members

Larry Linton Chair

Sprague Plato Board Liaison

Robert Kuhn Vice-Chair Hugh CrosthwaitStevenLiz LoewenJoe VarManon DayLloyd CRisa RosenfieldDan SteSharanjeet Kaur

Steven Iseman Joe Van Koeverden Lloyd Cowin Dan Steele



Programs and Services Your Partners in Parkinson's

In 2021, we tailored our services to be digital-first, so we can be accessible to everyone, everywhere. Parkinson Canada's programs and services reached over 10,000 Canadians impacted by Parkinson's. You reached us through our Information and Referral Services where our team provides free and confidential non-medical support, connected with others through support groups across the country, and accessed educational monthly webinars and up to date information and resources.

Support Groups

Support groups provide a safe space to be heard and to discover new ways to cope with the journey of living with Parkinson's.

"The Care Partner Support Group has given me the lifeline I so desperately needed. I felt like I was on the verge of a complete mental breakdown as was probably evident in the first care givers support group meeting I attended. I so look forward to each monthly meeting. I so wish that it was more often than once a month as well!"

Care Partner Support Group member

Webinars

"I would like to say this by far was the best webinar on Parkinson's Disease I have attended. It took me a few years to get my head around having been diagnosed with Parkinson's. You hit the nail on the head with many points that I felt I was the only one experiencing. Apathy being the latest in my life. It was encouraging to hear a speaker (in the Parkinson's Awareness Month webinar) say about staying on the couch for a day. Your panel spoke clearly and in plain not technical terms, you were extremely knowledgeable on Parkinson's and Entertaining as well."

Anonymous webinar attendee

Information and Referral Services

In 2021, our Information and Referral service team heard the very real concerns of Canadians living with Parkinson's and their care partners that continued to be exasperated in the second year of the Covid-19 pandemic.

We heard an increase in the experiences of anxiety, apathy and depression from people living with Parkinson's. We heard an urgency from care partners trying to find resources and support for their loved ones from afar. And we heard an increase in the overall compounding effects of physical isolation due to Covid-19.

Knowing the many benefits to providing digital resources, we are still very aware of the need for human connection and hold the deeply personal stories we hear very close to our hearts. We feel privileged to provide real-time support to Canadians living with and impacted by Parkinson's. During our conversations in 2021, we shared programming links, resources like our Introductory guide to Parkinson's, and virtual options to meet the exercise requirements to keep moving safely and productively, like the "Be Active" exercise options on our website. We shared educational resources when access to care specialists was limited at best – a problem that certainly existed pre-Covid. And we organized virtual community events to help engage our Parkinson's community.



Wellness Partnerships

Recognizing the benefit of exercise on the overall health and well-being of people living with Parkinson's, we are focused on developing partnerships for different wellness programs across the country to help people living with Parkinson's to live well now.

Researchers have shown that exercise generally and dance specifically can have a positive impact on living with Parkinson's, and this includes research that was made possible thanks to donor support of Parkinson Canada. We are proud to partner with Dance for Parkinson's Network Canada (DFPNC). We share the belief that high quality dance programs for people with Parkinson's should be easily accessible anywhere in the country, and our wellness partnership seeks to do just that.





In 2021, Parkinson Canada invested in 17 researchers and clinicians totaling \$790,000. With support from donors like you, we continue to fund research dedicated to finding a cure and improving the quality of life for people affected by Parkinson's.



Parkinson Canada in partnership with Brain Canada, founded the Canadian Open Parkinson Network (C-OPN) – an initiative to accelerate Parkinson's research by bridging clinicians, researchers, data and resources, with the goal of improving the lives of those living with Parkinson's.

2021 involved building the network and database by engaging more participants and researchers. C-OPN has opened clinical sites across the country to collect biological and survey data, and continues to expand and reach additional communities and researchers across Canada.

The database containing anonymous participant data can now be accessed (as of March 2022), and researchers across the country have begun to utilize this data to make exciting new discoveries.

Research and Clinical Advisory Committee

In 2021, we established the Research and Clinical Advisory Committee (RCAC). The committee oversees Parkinson Canada's Research Competition and advises Parkinson Canada's Board of Directors on the state of Parkinson's research, clinical care and emerging trends relevant to the Parkinson's community. The makeup of the committee mirrors the professionals who come together to provide a multidisciplinary care approach for Canadians with Parkinson's. It includes members of the scientific community, the clinical community, health professionals engaged in patient care, patient advocates and a director of the Parkinson Canada board.

Members

Dr. Martin McKeown Chair	Dr. Jennifer G. Goldman	John Parkhurst	Dr. Vesna Sossi
		Dr. Ronald Postuma	Dr. Antonio P.
Dr. Wendy Horbay Vice-Chair	Dr. Heidi McBride	Dr. Heather Rigby	Strafella
Dr. Richard Camicioli	Dr. Tiago A. Mestre	Dr. Angela Roberts	Dr. Stephen Workman
Dr. Susan Fox	Dr. Julie Nantel		Yu Yan Poon, RN

Advocacy

The National Advocacy Roundtable Report

The final product of more than 150 conversations with Canadians impacted by Parkinson's and the healthcare professionals who work with them, this national report summarizes the unique realities faced by members of the Parkinson's community across the country. Following the in-depth discussions from eight regional roundtables covering every province and territory and one National Roundtable, the report illuminates the key themes expressed by the Parkinson's community around improving the quality of life for people living with Parkinson's. These priorities will help provide a roadmap in developing our future advocacy work to support Canadians affected by Parkinson's.

There were participants at the National Roundtable who live in more under-serviced, rural parts of the country where no Parkinson's care coordinator nurses, neurologists nor Movement Disorder Specialists (MDSs) live or work. Their input shed light on the varying degrees of access to care for Canadians living with Parkinson's, which was echoed from coast to coast to coast by many others – making it a central takeaway from the conversations and one of three priorities in our advocacy roadmap.

One of the care partners who participated in the National Roundtable is based in the Northwest Territories and has had many challenges over the past eight years with accessing care for her father.



The roundtable series brought together **more than 150 voices** from the Canadian Parkinson's community

The increase in virtual medical care since the COVID-19 pandemic began was an unexpected benefit for the care partner and her family. Through telehealth, she managed to secure an appointment for her father with a neurologist in Calgary, Alberta and during that meeting they learned about Movement Disorder Specialists. They were able to get an appointment with a MDS and recently returned from Calgary where her father had the Duodopa® surgery.

The care partner shared that about a week after the surgery, a nurse called to check in on her father. The nurse gave them useful information on medications, diet, physiotherapy and speech therapy - and as importantly, she gave them the comfort of knowing there was someone there to offer them support.

"The lack of facilitated care in our region to support us through this process has been very frustrating. It is so difficult to navigate the care. How do you get proper care when you don't have people advocating for you?"

Jessica Brace, care partner, Yellowknife, Northwest Territories

Events

Our second event season impacted by the COVID-19 pandemic showed us your dedication in making a difference. Whether it was attending the inaugural Pedaling for Parkinson's Maritimes ride, Growling Beaver Brevet, or hosting a "Walk Your Way," you continued to show resilience to help raise money and awareness to help transform lives.

We are grateful to every event organizer's dedication to event execution, every volunteer who helped make these events happen, every participant who attended.

Our Volunteers

Volunteers are the lifeblood of Parkinson Canada. Their contributions can be felt in every facet of our organization, and in the lives of people impacted by Parkinson's across Canada.

Hundreds of volunteers lent their time and skills in 2021. Reflecting on the results we achieved in last year, it's easy to see that this is a community of impact. Because of our volunteers, people impacted by Parkinson's have access to more resources, more events, more support groups, and more community members to share their experiences with.



Volunteer Spotlight: Charline LeBlanc

From her home in Bouctouche, New Brunswick, Charline LeBlanc spent 2021 becoming a top-notch support group facilitator, SuperWalk fundraiser, and Parkinson Canada Champion.

When asked why she ended up becoming so involved as a volunteer, she offered this:

"So many times, someone has asked me, "are you sure you have Parkinson's?" So, I want to raise awareness that Parkinson's can look very different from person to person. It feels like researchers are so close to finding a cure and better treatments. With all the money being raised and all they're learning about the disease, I'm hoping in the long term it's going to help me out as I get older."

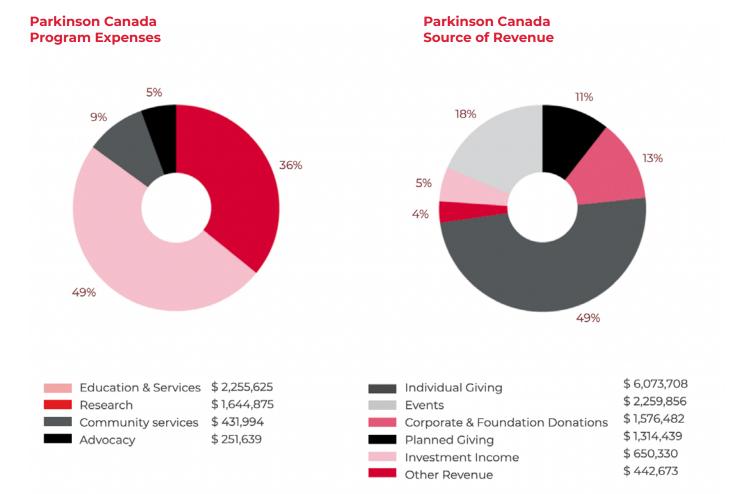
Charline shared what Parkinson Canada means to her, too:

"When you have Parkinson's, it's hard to imagine that someone will be there to help you out; so, when you discover Parkinson Canada, and discover that even though it sounds like a big name, it feels like a small team of folks all on a first name-basis with you, it makes a huge difference. If I have any questions, I know who to call and trust I'll have my answer soon, too. Not every organization has that."

We are so very grateful for Charline's unwavering support, and for the opportunity to share her story and let you know just how important volunteers like Charline are to Parkinson Canada.

2021 Numbers and Financial Reports

A national registered charity, Parkinson Canada fulfils its mission through the generosity of donors and is an accredited organization under the Imagine Canada Standards Program





Parkinson Canada is proud to be accredited with the Imagine Canada Standards Program, which holds us to the highest standards of ethical and financial accountability.

If you have any questions about how we fundraise, please contact us at 1-800-565-3000. Complete audited financial statements for the year ended December 31, 2021 are available upon request and on our website.

Statement of Financial Position as at December 31, 2021

	2021	2020*
Assets		
Current		
Cash	\$ 549,375	\$ 418,046
Short-term investments	5,185,661	3,133,416
Accounts receivable	1,004,978	963,758
Prepaid expenses and other assets	253,833	253,884
	6,993,847	4,769,104
Investments	8,128,037	7,477,892
Long-term accounts receivable	107,500	50,000
Property and equipment	638,624	672,715
Total assets	\$15,868,008	\$ 12,969,711
Liabilities		
Current		
Accounts payable and accrued liabilities	\$ 602,463	\$ 394,021
Current portion of research grants payable	812,576	1,177,624
Deferred revenue	106,188	233,914
	1,521,227	1,805,559
Research grants payable	290,000	312,576
Deferred revenue	363,740	400,115
	2,174,967	2,518,250
Net assets		
Unrestricted	6,805,599	3,307,428
Operating Reserve	5,056,318	5,056,318
Canadian Open Parkinson Network Reserve	250,000	498,000
Research Reserve	712,500	687,000
Invested in property and equipment	638,624	672,715
Endowment funds	230,000	230,000
	13,693,041	10,451,461
Total liabilities and net assets	\$15,868,008	\$ 12,969,711

Income Statement

For the Twelve Months Ending December 31, 2021

	2021	2020*
Revenue		
Individual giving	\$ 1,314,439	\$ 989,058
Planned giving	6,073,708	4,100,023
Events	2,259,856	1,927,535
Corporate and foundation donations	1,576,482	1,182,726
Investment income	650,330	513,778
Other	442,673	1,107,958
	\$ 12,317,488	\$ 9,821,078
Expenses		
Research, advocacy, education & support services	4,584,133	4,543,760
Philanthropy	2,734,093	2,858,005
Operating and administration	1,757,682	2,180,568
	9,075,908	9,582,333
Excess of revenue over expenses	\$ 3,241,580	\$ 238,745

* The Organization has determined that the research grant commitments are an obligation of the Organization at the time that the research grant agreement is signed and the liability and expense should be recorded at that time. Historically, research grants have been recorded and expensed based on the timing of scheduled payments. Similarly, it was determined that the research contracts to fund specific grants are an asset. Historically, research contracts to fund specific grants are an asset. Historically, research contracts to fund specific grants are an asset. Historically, research contracts to fund specific grants are an asset. Historically, research contracts to fund specific grants for the year ended December 31, 2020 have been restated.

Thank you for helping Canadians living with Parkinson's live well now.

There is strength in numbers, there is hope in research, and there is support all around for people impacted by Parkinson's - thanks to supporters like you.



1-800-565-3000 | parkinson.ca



Charitable Registration Number: 10809 1786 RR0001