

# LiveWire

Fall / Winter 2018  
ONTARIO

INSIDE: 2019 PRIORITIES | SUPERWALK RESULTS | IMPROVING ACCESSIBILITY | 2019 EDUCATION EVENTS



**Pat Evans**  
SuperWalk National Hero

 Parkinson Canada



## Message

from **Olivier Bonnet**

So much has transpired since we last connected, and we continue to evolve with your support and feedback. I extend a special welcome to you if you have just connected with Parkinson Canada for the first time. Parkinson Canada's team of staff and volunteers provides that link between you, your health team and community partners. Our role is to ensure that you have all the information to access programs near you to manage and to provide tips and tools so you can and live well with Parkinson's.

In this issue, we are proud to honour our supporters, and one important volunteer in particular – our Parkinson Canada SuperWalk National Hero for 2019, who hails from Eastern Ontario.

You'll read about some of our plans for 2019 to address gaps in resources and community offerings that we hope will make a difference to you and to the Parkinson's community. In 2019, we'll be launching the second edition of the Canadian Guidelines on Parkinson's Disease. And, we will be introducing a new program called Act on Time, which provides resources to people with Parkinson's and health professionals, while in hospital and other health settings.

Last but not least, we are grateful to partner with global partners to enrich learning opportunities. In June 2019, we will attend the World Parkinson Congress in Kyoto, Japan, where we will launch Care partnering: Managing Parkinson's disease together, a new resource targeted to care partners. And we'll be working with the Davis Phinney Foundation to bring another Victory Summit® event to Canada – this time, in Ottawa. Check out the back page for more details and save the date for these special events that you won't want to miss.

I would like to wish you and your family all the best for a safe and healthy holiday season. The holidays are about gratitude and generosity. We are honoured that you choose to make Parkinson Canada one of your charities of choice. Your gifts of time and financial support ensure that we are here to serve and support you, no matter what.

Connect with us in person, online at [parkinson.ca](http://parkinson.ca) or by phone at 1 (800) 565-3000.

We look forward to connecting in the New Year.

**Olivier Bonnet,**  
*Managing Director, Ontario*

***PS, LiveWire will become ParkinsonPost in 2019 – watch for our new look for this Canada-wide publication with special community updates delivered in two print issues.***

## Questions? Contact us.



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## Join our team

Volunteers and ambassadors make our mission possible for events and support groups. Training is provided.

**Email us at [info@parkinson.ca](mailto:info@parkinson.ca) or call 1 (800) 565-3000**



# Looking Ahead at 2019 Activities in Ontario

When we set out to plan our programs and activities for you in 2019, our top 3 goals were designed to address gaps. We will:

- 1 Ensure **services and resources** are available for **health professionals**. Better informed members on your care team; engage with Local Health Integration Networks, local hospitals, community stakeholders and associations in Ontario with a view to ensuring more timely and better access to resources and services in a person's language of choice
- 2 Strengthen **volunteer connections** – enhanced and increased network of volunteers, trained to support Parkinson Canada staff and help reach new and underserved communities; we will open new support groups and expand reach through facilitator training and leveraging technology for those who can't get to groups in person.
- 3 **Advance advocacy initiatives** to address needs of Ontarians affected by Parkinson's disease including wait times, benefits, access and inclusion to community programs.

## Spotlight on New Tools for Individuals and Health Professionals:

### Canadian Guidelines on Parkinson's Disease

The 2<sup>nd</sup> edition of the *Canadian Guidelines on Parkinson's Disease* will be released in collaboration with the Canadian Medical Association, with print and digital distribution to more than 80,000 family physicians coast to coast. Additional copies will be distributed to other members of your care team. It's important to make these experts aware that updated guidelines are available, and that new recommendations address gap areas such as palliative care through all phases of the disease, updates in advanced therapies, and benefits of exercise from the time of diagnosis.

### Care Partnering: Managing Parkinson's Disease Together

Did you know that more than 1 in 4 caregivers have fulltime jobs? This new, comprehensive resource developed for care partners provides tips and tools to successfully guide them through challenges they may face at every step of the disease considering the unique needs of their person with Parkinson's. This resource will be available through

support groups, education events and online as well as our Information and Referral service.

### ACT on Time™

This program includes resources that will help you manage your Parkinson's disease in healthcare settings. All components work individually and as a kit that will foster conversations between you, your care partner and your health team. Resources targeted to stays in hospitals and long-term care homes will education staff in those settings to better understand your needs around medication and other treatments. Pictured below are some examples of the tools that you will be able to take with you to your appointments.



# A HERO for all Seasons

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**Pat Evans appreciates what it's like to have access to services and programs that help her live well with Parkinson's.**

She was first introduced to the Parkinson's club about 12 years ago; her initiation came at the words of a movement disorders specialist who matter-of-factly announced, "You've got Parkinson's". Up to that point in life, Pat had worn many hats—social worker, mother, wife, activist, constituency assistant, friend and volunteer.

She learned to manage her Parkinson's diagnosis with the same level of energy and commitment she brings to all these roles. Get the facts, don't settle. Make it happen, no matter what. With a skilled medical team, healthy life choices, a supportive husband, and a purposeful exercise routine, Pat Evans is challenging Parkinson's every step of the way. Life has taken the family outside of the big city, to a more bucolic setting on the shores of the Big Rideau Lake, Ontario.

Not long after relocating to eastern Ontario, she realized that resources for people with Parkinson's in certain rural communities were either not readily available or they were not accessible for a variety of reasons. For folks in Lanark and Leeds counties, this was about to change. Pat turned to Parkinson Canada, began a dialogue and put her plan of action in place.

The word "no" simply isn't in Pat's vocabulary. She replaces it with "how". How can we make this possible? How can we make this accessible?

Pat approaches these challenges with the same logical, motivated approach she brings to managing

her Parkinson's symptoms. Yes, it's challenging. But she's ready. To listen to Pat describe her boxing and exercise regime, you get the sense that for that brief period of time, nothing else matters. To her credit, with passion and staff support from Parkinson Canada, she has created a new support group, and with others, raised more than \$70,000, which also supports community exercise programs.

For those who stand with Pat and look on, they are in awe of her energy, her superpowers.

To Gayle Truman and Dan Linton, she is a hero. Gayle Truman who nominated Pat for the SuperWalk National Hero Award wrote, "through Pat's attitude and example, I came to realize that there is life after Parkinson's."

In his nomination, Dan Linton stated, "Pat was instrumental in initiating the SuperWalk in this area in 2017. She spearheaded the local support group, exercise groups, and educational events in the area ... there is no stopping this lady."

The SuperWalk website has closed for the year, the totals are being announced and Pat is already thinking about next year. "Yes, that \$42,000 was great, now what will we aim for in 2019?" Pat considers each of the hundreds of individuals who stepped up to support the cause and is grateful for each and every contribution. She is proud to be able to tell them that through their efforts, they are enabling Parkinson Canada to fulfill its



## **PARKINSON CANADA** **SUPERWALK™**

mandate of keeping people with Parkinson's at the heart of everything they do. And she gets to witness first-hand what that support means in terms of programs, resources, support groups, research, and advocacy.

Winter in Canada brings changes and challenges. Depending on where you call home, and as you read this, your landscape could be painted with snow-covered vistas. What we know with certainty is that Pat Evans won't be waiting for the first sign of spring to don her superhero persona. Every week, she steps back into the community to be an active voice for others. It's who she is.

We think that's pretty amazing. Congratulations to your Parkinson SuperWalk National Hero for 2019—Portland, Ontario's Pat Evans!

**Pat Evans**  
SuperWalk National Hero ►

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Location	Top Walker	Top Team	Walk Total
Alliston	Liana Maltby	Joe's Family	\$1,059.00
Barrie	Susan Catton	Team Anneville	\$27,486.00
Belleville	Robert Ritzer	Team Ken	\$30,749.17
Brampton	Johanna Roy	Shakes Daly	\$23,826.00
Brockville	Olenka Mckee	Parkinson Pals	\$3,643.00
Burlington	Fred Weston	Team Igniski	\$40,236.79
Cochrane	n/a	n/a	\$400.00
Collingwood	Jim Karn	Papa's Proud Posse	\$13,880.00
Cornwall	Elise Wells	Team Wells	\$20,472.45
Durham	William Gardner	Team Ted	\$52,059.25
Guelph	Alan Farmer	Farmer Family	\$17,255.00
Haliburton	Gail Leach-Wunker	Sisson Sisters	\$8,751.00
Hamilton	Carrie Lamont	Shaking Yet Stirred	\$19,403.31
Hawkesbury	Pierrette Laframboise	Les pieds de l'espoir	\$5,573.40
Kingston	Lidia Binnie	The Walking Runnings	\$21,540.15
Kirkland Lake	Dianne Merell	Kirkland Lake Support Group	\$2,843.65
Lanark North Leeds	Pat Evans	Pat's Pacers	\$42,845.50
London	Jenna Boersma	Badgers	\$13,371.00
Manitoulin Island	Clifford Tann	Cheryl's Shakers	\$2,024.00
Markham	Peter Wong	Markham in Motion for Parkinson's	\$30,858.00
<b>Mississauga</b>	<b>Laura and Angelo Zega</b>	<b>Mississauga Wilkinson Warriors</b>	<b>\$70,625.72</b>

# Parkinson SuperWalk Ontario Results

Location	Top Walker	Top Team	Walk Total
Muskoka	Scott Ball	Ballstars	\$27,254.00
Napanee	Fern Joyner	n/a	\$1,679.35
Newmarket	John Gutteridge	Body Design	\$26,545.00
Niagara	Cheryl Smith	Cheryl's Shakers	\$28,537.00
North Bay	Shaun Billingsley	North Bay Recovery Home	\$10,049.80
North Simcoe	John Parkhurst	N/A	\$2,632.35
Northumberland	Don Hackney	Rogie's Rockets	\$45,518.00
Oakville	Earla Fitzjohn	The Dukes of Earl	\$15,929.00
Orillia	Connie Bagley	Team Bagley	\$4,809.00
<b>Ottawa</b>	<b>John Spero</b>	<b>Boxing 4 Health</b>	<b>\$227,565.82</b>
Parry Sound	n/a	n/a	\$605.00
<b>Peterborough</b>	<b>Vivian Heinmiller</b>	<b>Peterborough Movers and Shakers</b>	<b>\$49,961.14</b>
Port Dover	Gary Ball	Gary's Gang	\$12,931.10
Renfrew	Scott Edwards	Team Edwards	\$25,864.85
Sudbury	Bruce McCulloch	Slacker's Backers	\$36,994.00
Thunder Bay	Donald Ian King	Team Morrone	\$5,587.00
Timmins	Janice Martell	Timmins Support Group	\$6,871.50
Toronto	Margot Friedman	Team Friedman	\$232,617.04
Toronto East	Julie Wood	YOPD of Toronto	\$68,747.68
Vaughan	Veeral Khatri	Cookies & Cream	\$56,487.10
Windsor	Wanda Tarnowski	Michael's Misfits	\$2,953.10

**GOLD**



**SILVER**



**BRONZE**

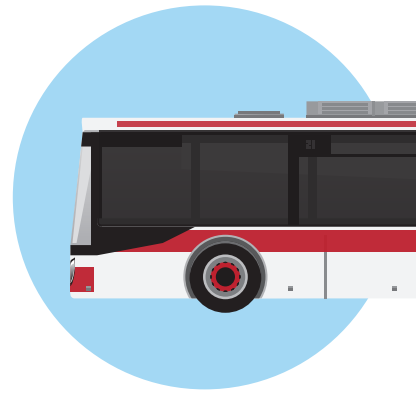


...and Thank You to Subway for providing  
free sandwiches at 27 SuperWalk locations!



# At Ease:

## A guide to improving accessibility in the workplace and on route for people with invisible disabilities



People living with Parkinson's likely have invisible disabilities and face many barriers as they go about their daily lives. Invisible disabilities include sight, hearing, learning, and speech impediments; diabetes; anxiety; chronic pain; sleep disorders and chronic fatigue.

Ontario was the first province in Canada and one of the first jurisdictions in the world, to enact specific legislation establishing goals and time frames for accessibility. These considerations were guided by the *Accessibility for Ontarians with Disabilities Act (AODA)*.

With partial funding from a grant from the **EnAbling Change Program** with support from the Government of Ontario, Parkinson Canada recently produced a booklet entitled “*At Ease: A guide to improving accessibility in the workplace and on route for people with invisible disabilities.*” The resource helps individuals understand what an invisible disability is, and what private and nonprofit organizations need to provide to meet the *AODA Customer Service Standard*. It also sheds some light on how best

to remove barriers for people with invisible disabilities, especially in the workplace and on transit systems.

“People with Parkinson's and other neurological conditions can remain in the workforce for many productive years, and often, they continue to utilize public transit to get to and from work. It's important that they are provided with safe transport on transit and given every opportunity to advocate for their independence and self-sufficiency at their places of employment, especially when their symptoms and disabilities are not well understood. That includes having appropriate accommodations made while in the workplace,” says **Neli Gontier**, Training and Education Specialist at Parkinson Canada, and project lead.

This free booklet introduces readers to *AODA*. It also provides answers to *frequently asked questions* as well as a *glossary of definitions*, and contact information for other organizations that help remove barriers for individuals living with neurological conditions.



One person with Parkinson's who rides on public transit frequently is **Alice-Betty (AB) Rustin**. AB has learned to live well with Parkinson's and is not slowing down, as she continues to volunteer with Parkinson Canada on the Ontario Advocacy Committee while helping others use various transit systems, including the province's largest, the Toronto Transit Commission (TTC). AB knows that beyond the visible tremors, some of the lesser-known non-motor symptoms can be the most challenging to manage day-to-day.

Some challenges she faces while riding the TTC subway is the lack of elevators at some stations. Unable to go up and down stairs any longer, this poses a huge problem and forced AB to map out and avoid those stations, often lengthening her trip.

The subway has blue priority seats assigned near the car doors, to allow people with special needs to be seated quickly and easily. But not all riders are aware of their purpose or understand the needs of people with invisible disabilities.

"I cannot stand for long periods and am not shy to outright ask someone to give me their seat ... happens about 30% of the time," AB shares. "Maybe the transit commissions can work on more advertising and signage explaining what the blue seats are for."

Another hardship is the lack of public washrooms, as bladder control is a common problem for people with Parkinson's. AB will travel out of her way to a farther station to use the restroom and then double back on her trip.

Another system she uses to get around is *Wheel-Trans*, also run by the TTC and offering pick up

and drop off from door to door, prearranged with flexible options for booking and changing plans as needed. Special rates apply for people with disabilities and the handy *Presto* card can be automatically loaded and used for payments on any TTC route, including *Wheel-Trans*.

"It's a safe and reliable service; helps avoid the mad rush that occurs at peak times, which can be frightening for me as I am not agile on my feet anymore," says AB. "One time there were hundreds of people stranded due to a fire on the subway and I was a few stops from my home. People were very helpful and I got home OK, but was really shaken by the whole experience."

Overcrowding has become a serious issue for many transit agencies in urban areas such as the Toronto and Vancouver. This may result in greater risks for people with visible and invisible disabilities.

AB suffered a stroke recently and still manages to help a friend who has MS and is in a wheelchair, get to her appointments.

"The key to living well with disabilities is to **be informed**—know the services available to help you and also know the shortcomings, to better prepare yourself." It's also important to know what you are entitled to under the accessibility legislation, notes Neli Gontier.

To get your complimentary copy of "*At Ease: A guide to improving accessibility in the workplace and on route for people with invisible disabilities*" write to [education@parkinson.ca](mailto:education@parkinson.ca) or call 1-800-565-3000 ext. 3320.



## Advocating for Parkinson's on National Seniors Day

**L to R:** Olivier Bonnet, Parkinson Canada, Susan Hagar, Founder, Nurse on Board, Dr. Mirza, Deb Schulte, MP, King-Vaughan, Honourable Minister of Seniors Filomena Tassi, Gigi van den Hoef, VP, CARP Ottawa



# Join Us!



Parkinson Canada

## EXPERT WEBINAR SERIES 2019

**JAN**  
**31**

**Parkinson's Disease &  
Dance\***  
David Leventhal and Rachel Bar

**MAY**  
**28**

**Non-Motor Fluctuations of  
Parkinson's Disease**  
Dr. Galit Kleiner

**FEB**  
**26**

**At Ease:  
Accessibility for Daily Living**  
Neli Gontier

**OCT**  
**08**

**Advocating for  
Patient-Centered Care**  
Dr. Andrea Moser

**APR**  
**16**

**Act on Time: A Parkinson's  
Resource Toolkit**  
Neli Gontier

**NOV**  
**19**

**Medical Cannabis:  
Where Are We Now**  
TBD

Registration opens one month prior to each webinar. All events start at 12PM EST (except where indicated with an \*, in which case the event starts at 1PM EST). To replay archives, visit the Parkinson Canada Knowledge Network at [parkinson.ca/knowledge](http://parkinson.ca/knowledge).

1 800-565-3000

[parkinson.ca](http://parkinson.ca)

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SAVE THE DATE

# Join us in 2019



## Join Parkinson Canada at the 5<sup>th</sup> World Parkinson Congress in Kyoto, Japan

We'll be joining global partners to share and learn what's new in the Parkinson community. Register online today at [wpc2019.org](http://wpc2019.org)

## The Victory Summit<sup>®</sup> is coming to Ottawa, Canada

**When:** Saturday, October 5, 2019 full day

**Where:** Ottawa Conference & Event Centre,  
200 Coventry Rd, Ottawa, ON K1K 4S3

Join Parkinson Canada and other community partners for a unique one-day experience that helps you live your best. This event is open to people with Parkinson's, care partners, family members and health professionals. You can attend AT NO COST thanks to a generous donor to the Davis Phinney Foundation. Registration opens in Spring 2019. Visit our website at [www.parkinson.ca](http://www.parkinson.ca) for more details.



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