

# LiveWire

ONTARIO  
Fall & Winter 2016

 Parkinson Canada



| Research Program

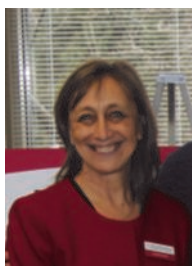
| World Parkinson Congress

| Lessons in Caregiving

| S.O.S.

| Parkinson SuperWalk

| Help Near You



*As we come to the end of our first year as the newly formed and united Parkinson Canada, I want to thank all of you for*

*your continued support. It has been a great year with many high points!*

*If you have received your copy of LiveWire in the mail, you will find the 2017 Hope on Display calendar, featuring the creative expressions of people living with Parkinson's. I hope you enjoy seeing the work of these artists in your home all year long. More than 10,000 copies of this year's calendar are being distributed across Canada.*

*Parkinson SuperWalk is always a great highlight in our year—make sure you visit pages 10 to 14 to see photos and results for 2016.*

*Hopefully many of you were able to attend Dr. Ahlskog's presentation at an Ontario location on October 21. Thank you for being part of this pilot initiative—we had more than 700 people join us at one of our 16 locations. We ran this as a pilot so we could learn how to deliver education to many locations at once; thank you for your patience as we work to serve you better!*

*I look forward to sharing 2017 with you. Please let me know if you have any questions or suggestions.*

*Debbie*

## Who Are You Going to Call? Find Help Near You in Ontario

**800-565-3000**

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

### **TORONTO**

316-4211 Yonge St.  
Toronto, ON M2P 2A9  
Phone: 416-227-9700

**Debbie Davis,**  
VP, Mission, and Managing Director, Ontario  
800-565-3000 ext. 3373  
[debbie.davis@parkinson.ca](mailto:debbie.davis@parkinson.ca)

*You or someone you care for has been recently diagnosed, a diagnosis has changed, or you are looking for information on a particular topic related to Parkinson's disease:*

**Sandie Jones, RN, Coordinator, Client Services and Education**  
416-227-3375/800-565-3000 ext. 3375  
[sandie.jones@parkinson.ca](mailto:sandie.jones@parkinson.ca)

**Robert TerSteege, Information & Referral Associate**  
416-227-3372/800-565-3000 ext. 3372  
[robert.tersteege@parkinson.ca](mailto:robert.tersteege@parkinson.ca)

**Angela Supino, Support Services Counsellor, Ottawa**  
613-722-9238  
[angela.supino@parkinson.ca](mailto:angela.supino@parkinson.ca)

**Shannon Harrison, Information and Referral Associate**  
613-722-9238  
[shannon.harrison@parkinson.ca](mailto:shannon.harrison@parkinson.ca)

*You would like more information about support groups, chapters, volunteer opportunities, or events in your community:*

**Naseem Jamal, Community Development Coordinator, Toronto**  
416-227-3377/800-565-3000 ext. 3377  
[naseem.jamal@parkinson.ca](mailto:naseem.jamal@parkinson.ca)

**Diane Newman Reed, Community Development Coordinator, East**  
800-565-3000 ext. 3315  
[diane.newmanreed@parkinson.ca](mailto:diane.newmanreed@parkinson.ca)

**Karen Dowell, Community Development Coordinator, West**  
416-227-3376/800-565-3000 ext. 3376  
[karen.dowell@parkinson.ca](mailto:karen.dowell@parkinson.ca)

**Tamara Gagnon, Community Development Coordinator, North**  
800-565-3000 ext. 3317  
[tamara.gagnon@parkinson.ca](mailto:tamara.gagnon@parkinson.ca)

### **OTTAWA**

1-200 Colonnade Rd. South  
Ottawa, ON K2E 7M1  
Phone: 613-722-9238

*You would like more information about support groups, chapters, volunteer opportunities, or events in your community (continued):*

**Anne McNamara, Community Development Coordinator, Central**  
800-565-3000 ext. 3326  
[anne.mcnamara@parkinson.ca](mailto:anne.mcnamara@parkinson.ca)

**Ginette Trottier, Community Development Coordinator, Ottawa / Coordonnatrice au développement communautaire**  
613-722-9238 ext. 201/800-565-3000 ext. 3329  
[ginette.trottier@parkinson.ca](mailto:ginette.trottier@parkinson.ca)

*You would like more information about Parkinson SuperWalk:*

**Amanda Stanton, Events and Partnerships Associate**  
416-227-3371/800-565-3000 ext. 3371  
[amanda.stanton@parkinson.ca](mailto:amanda.stanton@parkinson.ca)

**Sauna Quinn, Events and Partnerships Associate Ottawa**  
613-722-9238  
[sauna.quinn@parkinson.ca](mailto:sauna.quinn@parkinson.ca)

*You would like more information about the Hope in Bloom campaign or the Parkinson SuperWalk in Toronto:*

**Samantha Clegg-Yundt, Events and Partnerships Associate**  
416-227-3374/800-565-3000 ext. 3374  
[samantha.cleggyundt@parkinson.ca](mailto:samantha.cleggyundt@parkinson.ca)

*You would like information on joining the Partners for Parkinson's Monthly Giving Program or donating to Parkinson Canada:*

**Alan Muir, Manager, Resource Development Ottawa**  
613-722-9238  
[alan.muir@parkinson.ca](mailto:alan.muir@parkinson.ca)

**Sue Rosenblat, Manager, Major, Planned Giving & Foundations**  
416-227-3386/800-565-3000 ext. 3386  
[sue.rosenblat@parkinson.ca](mailto:sue.rosenblat@parkinson.ca)

**Ronen Tal, Manager, Direct Marketing**  
416-227-3381/800-565-3000 ext. 3381  
[ronen.tal@parkinson.ca](mailto:ronen.tal@parkinson.ca)



# PARKINSON CANADA RESEARCH PROGRAM

## INVESTING IN KNOWLEDGE – GROWING HELP & HOPE

\$269,340 in donations has multiplied almost  
10 times, generating \$2.3 million in new funding!

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. 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.

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
<b>Total Funding</b>	<b>\$269,340</b>	<b>\$2,312,405</b>

Parkinson Canada invests in new investigators and pilot project grants to explore novel theories that may lead to significant findings. These novel ideas offer new pathways of exploration and contribute to future collaborations. Researchers and their discoveries bring hope to people with Parkinson's.

"Parkinson Canada funding gave me an amazing opportunity to successfully launch my research program, build my research team and develop collaborations, not only here in Canada but also internationally. I am truly grateful to Parkinson Canada donors for making all that possible."

*Julie Nantel, Parkinson Canada funded researcher*

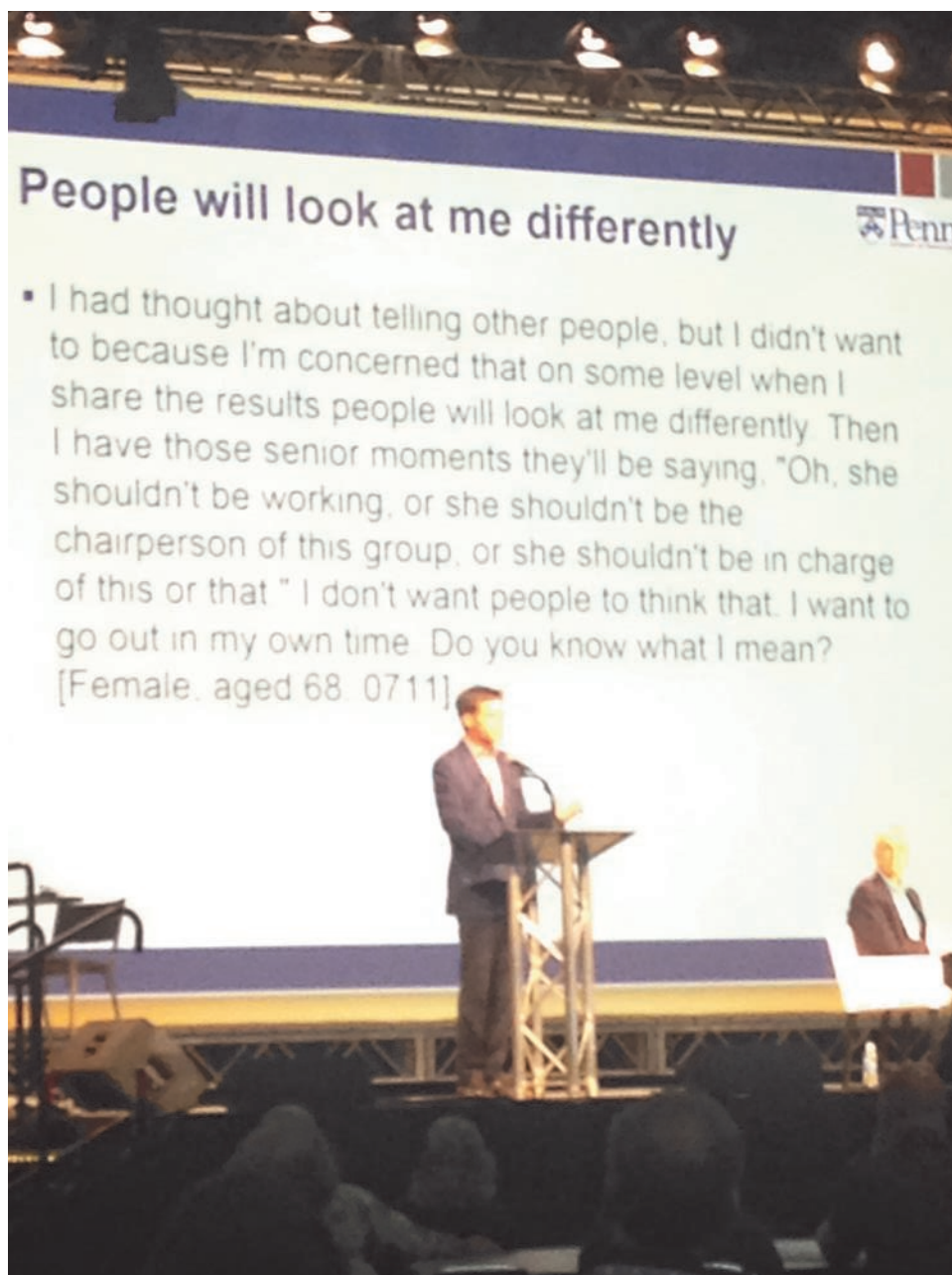


Since 1981, Parkinson Canada has invested more than \$26 million in 503 projects, grants, and awards thanks to generous donors. As of September 2016, Parkinson Canada is proud to support 19 new grants, fellowships, and student awards, totalling \$1,124,018 to support new research projects in Canada during the next two years. Including the nine research awards in their second year, and the 19 new projects, the Parkinson Canada Research Program is currently investing \$1,439,018. Discover more and donate at [www.parkinson.ca](http://www.parkinson.ca)

# World Parkinson Congress (WPC): Portland Oregon, September 2016

## Quick Facts:

- ♦ 4,555 registrants at WPC
- ♦ 20% caregivers
- ♦ 28% People with Parkinson's
- ♦ 8% exhibitors
- ♦ 4% guests/medical staff
- ♦ 40% neuroscientists, clinicians, researchers, nurses, etc.
- ♦ 199 speakers
- ♦ 67 countries
- ♦ 125 hours of scientific sessions
- ♦ 600 posters
- ♦ 28 not-for-profits represented
- ♦ 120 travel grants
- ♦ 260 donations made by delegates so that registration fees could be given to others
- ♦ 125 volunteers





## In His Own Words: World Parkinson Congress

For a person with Parkinson's, participating in the World Parkinson's Congress at the end of September in Portland, Oregon was about as good as it gets! More than 4500 registered participants from around the world, including people with Parkinson's, caregivers, medical professionals, and researchers all gathered in one place to share experiences and support each other.

They all shared one goal—to make it better. To make it better by

- empowering and supporting those with Parkinson's and their caregivers;
- providing opportunities for people with Parkinson's to tell their stories;
- learning about and sharing the most up-to-date diagnostic and symptom relief treatments;
- sharing cutting-edge research to find a cure.

Simply walking into the huge Portland Convention Centre was an intense emotional experience: Sadness at seeing so many struggling so hard to participate in the Congress, many in wheelchairs, or lurching forward with the help of a walker or cane, sometimes bent over and glancing at their watch to see if it was time for more medication. Immense pride and exhilaration at the courage and determination exhibited by so many to continue moving, moving, ever moving forward. And finally, tears of appreciation at the extraordinary efforts of caregivers, volunteers (identified by their bright red T-shirts), and staff to ensure that people with Parkinson's had the best experience possible.

This all came together at the opening exercises on Tuesday evening, which was the first time that the massive conference Hall 3 was filled with all 4500 registrants. My wife and I had participated in an online choir practice with 80 or so others to be ready to sing a song especially written for the Congress, about our determination to keep moving no matter what. Earlier that afternoon was our first rehearsal in person, and we had a wonderful time getting to know each other. That evening as we climbed up on the stage or lined up our wheelchairs and walkers in front, it's fair to say we were a little bit nervous. However, we sang our hearts out, and they loved us! 4500 people cheering, clapping, and whistling was a very exhilarating experience! As I chatted afterwards with my new choir mate and friend Yeoh from Malaysia—his mother has Parkinson's—I realized the choir performance embodied from the first moment the spirit of courage, determination, and empowerment the WPC represents. After we sang, there were some speeches of welcome and inspiring testimonials including one by Brian Grant, all 6'9" of him (he is a retired NBA All-Star with Parkinson's), and another by Mohammed Ali's daughter, Marayum "May May" Ali. Then it was off to conference Hall 1 where there was a reception for all 4500 of us; that was a lot of hors d'oeuvres!

And so, the Congress was underway. It is impossible to give many details in a short article; often there were two or three workshops and presentations of interest to me on at the same time. For me, however, there were a number of overarching themes. Briefly stated, some of them were as follows:

- the mis-folding of the protein alpha-synuclein in the brain is the key to defeating Parkinson's, along with a growing awareness of similarities in the disease process between Parkinson's and Alzheimer's
- the role of the auto-immune system and inflammation in the development of the disease
- growing evidence that exercise, especially the right kind of exercise, is the best non-drug treatment available
- integrated care—being supported by a team that talks with you and each other to provide the best care possible
- patient empowerment—become informed, ask questions, expect answers
- optimism—the sweet smell of success in the air. Although it could easily take 20 years before breakthrough treatments are readily available, clinical trials aimed at stopping the progress of the disease are now getting underway!

Meaning and community are fundamental aspects of a good life. The World Parkinson's Congress provided both. Learning about and powering through the obstacles presented by Parkinson's adds meaning to life. As well, the WPC reflects a world-wide community of individuals dedicated to supporting those with Parkinson's and eventually to eliminating the disease altogether. I would like to conclude by saying that I was proud that Parkinson Canada had a popular booth in the display area (another massive hall), well covered by Canadian staff and volunteers. It was a centre of continuous learning and networking for and about Parkinson's for people from all over the world. **By Sprague Plato**



## Lessons in Caregiving: Essentials and Choices

If you are reading this article, you are likely in a caring role or a player on a team of folks who are supporting a person with Parkinson's; you are a member of a "tribe" ... a word used at the recent World Parkinson Congress to describe the breadth of people involved in this job. Just as Parkinson disease (PD) is particular to the individual, so is the impact and experience of being a carer (the word I will use). This is a unique journey for all and the diagnosis and responsibilities associated with it "changes everything."

If you are reading this article as a person with PD, you can be instrumental in supporting your carer to make the appropriate self-care choices as you collaboratively manage this journey. Some of the lessons and choice in this article are applicable to you as well, and especially so if you find yourself in the role of having to be the carer when an illness or the health requirements of your spouse, family member, or other demands it of you.

**How to define caregiving?** In PD, it often starts as a partnership in health and life management; you are a care partner first and evolve over time to becoming a care provider. Early on it can be fairly hands-off; over time it becomes an increasingly hands-on relationship with the person in your life with PD. Being a carer has been described as a fluid experience, one with successes and fulfillment, hurdles, and increasing demands. And while the "tribe" comprises family, friends, neighbors, medical, and community resources, most often the spouse or partner assumes the key role; however, a child or friend can also be in a primary or supporting role. You may be a carer sandwiched between children and parents, balancing work and life demands; or you may be adjusting expectations of retirement, aging, and those golden years we all aspire to. The diagnosis of PD forces a certain foresight of the road ahead. Those of you already fully immersed in this role know its expectations: to be knowledgeable about the disease, a skilled multi-tasker, effective communicator and negotiator, emotionally and physically strong, positive and motivating, the ultimate decision maker—and yes, the list of demands and competencies does go on! You may not have anticipated also becoming social convener, financial administrator, household manager, driver, personal assistant, and nurse. Carers have described their place in the tribe as both appointed leader and doer. If at times one feels like a juggler ... the description would be apt.

**What to make of this experience?** You are not alone in this journey, and if you are not a primary carer now, one day each of us will be, with or without PD in our lives. Importantly as well, and difficult at times to remember, is that you will always be you as will the person you care for. Carer feedback cites this as a key lesson—to hold onto one's

identity, to reclaim yourself when lost in the midst of demands. As one carer stated: "I am more than solely a caregiver and

should not be defined by this role alone." Maintaining one's individual voice, acknowledging needs and wants, and pursuing aspirations are health sustaining choices. Enabling the person with PD to be invested in their life and to let him or her and other tribe members "do" supports personal resiliency and identity.

Sounding like cliché statements and too much advice giving so far? While the clichés on managing such a complex dance abound and can be tough to implement, they are often spot on. Think of them as the choices you make and need to make as you navigate the various phases of the journey to negotiate a quality of life with PD. They are proposed with respect for the challenges each carer faces in their unique situation and the understanding that it takes determination to implement them.

### Physical and Emotional Health

While many carers share that they cope well, for others the anticipatory worry of what caregiving responsibilities may develop, the progressive reliance of the person with PD, and the demands of emerging symptoms become challenging over time. Studies of caregivers have shown that the overall unpredictability of the journey or what any given day may present is a particular stressor. These studies report that half of caregivers experience physical health problems. Mental wellness can also be affected resulting in depression, mood, and behavioral changes.

#### To Remain Physically Robust:

- exercise
- maintain good nutrition
- rest and relax
- see your doctor regularly and attend to your own health and well-being
- assemble your own personal health team and take their self care advice

#### To Remain Emotionally Robust:

- sustain a life separate from PD, safeguard interests, keep your identity, create "you" moments
- let go of the unimportant



- remain social
- communicate
- express emotions (anger, grief, fear, success, and humor)
- seek individual or relationship counseling as may be needed

To be human is to experience stress. There has been much written about stress and distress. The former touted as necessary to move forward and to getting things done; the latter type as tense, disabling, and feeling unrelenting. Think of it as an inability to see relief in sight or to muster coping strategies. The challenge of PD varies and each of us has a different capacity to harness stress and to prevent distress.

#### To Remain On The Right Side Of Stress:

- watch for signs of depression (changes in sleep, appetite, attitude, focus and thinking, mood and emotions) and get help
- be mindful of health changes, continued illnesses, bouts of panic
- be aware of personal neglect and neglect of responsibilities
- ask for and accept support and interventions by others
- seek respite—daily, short term, and longer
- prepare a plan of action for tough times and crises to

better cope in those situations, and for peace of mind

- incorporate all of the tips discussed into your survival toolbox

#### Last Words

One can never say enough about the individual uniqueness of the journey, both in how the disease presents itself and progresses, and how people face and manage it. Its complexities, access to resources, personal resiliency, and attitude impact how one travels the journey. Similarities in the journey with PD abound as well. The lessons and tips shared come from folks who have walked the carer road, and the professionals who have supported them. Consider options and choices that ensure your well-being, adapt them to meet your needs, and above all, acknowledge and reward yourself for all you do. And, keep exploring who you are as both a person and a caregiver.

I encourage you to delve into caregiver resources and the services of Parkinson Canada and to consider a caregiver support group whenever you are ready. Support groups lessen feelings of isolation and strengthen confidence through shared information and strategies, through emotional support and friendship. Discover a new and supportive community in an environment that understands.

One last cliché: If you don't take care of yourself, how can you care for the loved ones in your life?

**By Angela Supino, BA Psych., MA Individual Counseling Support Services Counselor and Group Facilitator**

## Caregivers: In Their Own Words

*"My lesson learned was that I had to remember that I was more than a caregiver, that I was a wife, married for 46 years. We had to find ways to still enjoy time together even though the demands of caregiving were almost overwhelming. I also realised how important it was for me to take care of myself which I did with counselling, exercise, yoga, and time spent with friends.*

*As caregiving becomes more difficult, more time consuming, more tiring (both physically and mentally), it is important to get all the help available to share some of the load."* Pat, primary carer for 13 years of husband Denny

*"There are two things I found helpful when coping with my father's decline in health. One was to find moments where I could be in the present with him—not wrapped up in grief and regret of how things used to be or worried about what was to come. If I remained in the present moment, I could enjoy driving him to an appointment, holding his arm as we walked along slowly together, or playing yet another card game. I so miss those moments now that he is gone."*

*Another helpful focus for me as the adult child in the scenario was to remember to support my mom, who was the main caregiver, no matter what. I knew by being there for her I was helping her continue her role—which was a complex and difficult journey—but which was also the key to my dad's quality of life remaining positive."* Joanne, daughter in family living with PD

*Continued on next page*





Demander de l'aide n'est pas facile. Au moment où on y pense, on est épuisé, fatigué, sous pression. Il faudrait que l'aide arrive immédiatement mais nous n'avons encore approché personne. Que faire?

Nous l'avons tous entendu, même répété nous-mêmes : « Mes enfants sont trop occupés, ils ont leur propre famille, je ne veux pas les déranger ». Comment demander sans imposer? En premier lieu, on doit se donner la permission d'accepter l'aide. Reconnaissons-nous toujours le soutien qui nous est offert? Suis-je rendu au bout du fil? Accepter de l'aide n'est pas un signe de faiblesse mais plutôt un signe de respect envers ceux qui nous sont chers. Notre famille, nos amis ne savent pas toujours comment nous aider.

Pour faciliter la demande et l'acceptation, je vous propose donc un petit truc. Asseyez-vous confortablement, en toute tranquillité, une tasse de thé, un papier et stylo devant vous. Vous allez rédiger une liste des tâches à faire durant une période d'une semaine ou d'un mois, des tâches qui vous soulageraient. Voici des exemples : couper le gazon, ramasser les feuilles, peindre la clôture, accrocher un cadre, changer le filtre de la fournaise, laver les planchers, passer l'aspirateur, ou encore plus personnel, venir passer du temps avec mon conjoint pour que je puisse aller chez le coiffeur ou à l'épicerie, venir cuisiner quelques portions supplémentaires pour nous, venir chercher mon bien-aimé pour aller prendre un café ou aller au cinéma, venir jouer aux cartes avec lui ou le conduire à son groupe de soutien. Indiquez tout ce à quoi vous pensez à la première ébauche. Revoyez la liste au cours des prochains jours jusqu'à ce que vous soyez satisfaits de celle-ci.

Maintenant, vous êtes prêts. Vous avez un plan concret. Lorsque quelqu'un vous demande si vous avez besoin d'un coup de main ou que pourrait-il faire pour aider, à ce moment vous pouvez leur présenter la liste. Non seulement pourront-ils choisir comment vous aider, mais peut-être envisageront-ils d'autres personnes pour contribuer aux autres tâches de votre liste. Si votre famille vous visite souvent, vous pouvez également laisser cette liste bien à la vue sur une table.

Vous serez surpris des résultats! Pour vous aider, visitez la page « Pour les aidants » sous l'onglet Vivre avec le Parkinson de notre site web [www.parkinson.ca](http://www.parkinson.ca).

Partagez vos trucs et conseils avec nous pour en faire bénéficier le plus grand nombre et faciliter la vie de ceux qui font face à des défis similaires dans la communauté Parkinson. [Ginette.Trottier@parkinson.ca](mailto:Ginette.Trottier@parkinson.ca) ou 613-722-9238 poste 201.

---

### Caregivers: In Their Own Words continued from page 7

*"A very wise neurologist once told my husband that when it comes to Parkinson's disease, it is all about Carpe Diem, "seize the day," and do together what you can until you no longer can. Then, try to keep up some of your own interests and make plans for yourself.*

*Keep your family in your caregiving loop. When we started having more appointments with specialists, I made a point of summarizing the outcome of the appointment and sending that to our children. They need to know what is going on! It is not a kindness to them to keep them in the dark. After all, who will need to make the decisions for care if you are not around for whatever reason. When hard decisions have to be made, involve your adult children in the discussion.*

*Don't isolate yourself! It is very easy to withdraw as things get more difficult. Getting out of the house, staying involved with your faith community, keeping in touch with friends and family and letting them know how you are both doing is so important. Communicating with other people helps to keep you grounded. Take advantage of what CCAC can offer and push for respite as well as supportive care hours so that you can have some blocks of time during which you don't have to focus on your spouse. Handing over responsibility for care, even for a few hours, helps you to be able to clear your mind.*

*Join a support group. You will learn so much including how many strong and wonderful people there are who are trying to do what you are trying to do. Go and shed some tears (and laugh too). Not only will you learn a lot but you may be able to help others too.*

*Make important decisions well before you are in crisis. Think about the changes in your spouse that have occurred in the previous five years and assume that changes will continue to occur in the next five years. Are you prepared for that? If not, start to think about what you need to put into place and make plans." Susan, primary carer for 30 years of husband Ken*



# Cognitive Impairment in Parkinson's Disease – Webinar Summary

*Cognitive impairment is a common symptom in the late stages of Parkinson's disease (PD). Even early on, patients with PD may have problems with decision making, organizing, planning, and multitasking. Healthy living and medications can help people manage some of their symptoms. This September, Parkinson Canada delivered a webinar, presented by Dr. Sean Udow, that reviewed the symptoms of cognitive impairment, the changes in the brain that cause cognitive problems, and the diagnosis and management of these troubling problems in patients with Parkinson's disease. If you missed the opportunity to attend, here is a summary of the webinar or you can visit our website at [www.parkinson.ca](http://www.parkinson.ca) to access the archived video.*

Parkinson's disease is best known as a movement disorder characterized by slowness, stiffness, shakiness, and problems with walking. As medical management of these movement symptoms has improved, an array of non-movement symptoms has become more apparent in PD. Among these symptoms, **cognitive impairment** is one of the more troubling for people living with PD, their families, and their health care providers.

In order to better understand why the symptoms of PD arise, the webinar reviews some of the changes in the brain caused by PD, including the death of brain cells caused by the accumulation of toxic proteins. Some of the brain cells damaged in PD are responsible for producing the brain chemical **dopamine**. Dopamine helps the brain move the body smoothly and quickly. Without dopamine, the brain does not run as efficiently and thus the body moves slower. Other regions of the brain are affected by PD, including the **cerebral cortex** and areas that produce other brain chemicals. Both a functioning cerebral cortex and a healthy balance of brain chemicals are required for normal cognition.

**Cognition** is a set of mental processes that allows us to acquire new knowledge and understanding through experience and thoughts. Normal cognitive processes include **memory**, **language**, **visuospatial ability**, and **executive function**. Cognitive impairment occurs when there are symptoms of thinking problems due to dysfunction of one or more of these processes.

In PD, cognitive impairment exists on a spectrum from normal cognition, normal aging, mild cognitive impairment, and dementia. As people age, some mental processes may become slightly dulled, but do not cause major symptoms. **Mild cognitive impairment** is when someone has symptoms of a thinking problem, but is still able to function in their day-to-day lives. **Dementia** is when symptoms of a thinking problem cause a person to be unable to carry out their day-to-day activities.

While mild cognitive impairment can occur in the earlier years of PD, dementia takes many years to set in; many people with Parkinson's may never develop dementia. The main symptoms of mild cognitive impairment and dementia in PD involve executive dysfunction; even early on, patients with PD may have problems with decision making, organizing, planning, and multitasking. The ability to pay attention and level of alertness may fluctuate from day to day and hour to hour. Memory may be affected, but PD patients typically have problems with retrieving rather than making new memories. Later in the course of PD, the brain is less able to accurately interpret visual scenes and visual hallucinations may occur.

**Dementia with Lewy Bodies** is another syndrome that shares the same cognitive problems as PD but begins with cognitive impairment. Problems with movement develop later in the course. Similar changes in the brain occur in both PD and Dementia with Lewy Bodies, and these two conditions are therefore managed similarly.

In diagnosing cognitive impairments in PD, one of the most important things is ruling out reversible causes that can cause thinking problems. These include other medical illnesses like infection and medications that can interfere with thinking. Brain imaging tests and pen-and-paper cognitive testing are both used to help diagnose cognitive impairment in PD.

There is no cure for Parkinson's disease but people with PD can do some things to slow down the progression of symptoms. Healthy living, including a well-rounded diet, regular exercise, and social interactions, is very important in helping prevent the development of these cognitive impairment. Some medications can help to manage these symptoms but treatment is always different for every person. Research is going on worldwide to find ways to predict which people with PD will develop cognitive impairment and how to prevent this from happening, and neurologists are optimistically anticipating new discoveries.

**By Sean J. Udow, MD, FRCP(C)**

# PARKINSON SUPERWALK RESULTS FOR ONTARIO

	TOP WALKER	TOP TEAM	WALK TOTAL <i>As of October 1, 2016</i>
Alliston	Bob Nichols	Joe's Family	\$1,917.21
Barrie	Alva LaPlante	Life is Good	\$26,416.58
Belleville	Robert Ritzer	Parky's Pacers	\$35,009.95
Bracebridge	Don Ruud	Marn's Mob	\$13,250.00
Brampton	Lorne Collis	Shakes Daly	\$23,161.90
Brockville	Isabelle Brennan	Team Ralph	\$1,940.00
Burlington	Fred Weston	Team BFF	\$57,930.81
Collingwood - Blue Mountain	Jim Karn	Right at Home	\$8,385.00
Cornwall	Police Chief Dan Parkinson	Durwin Steppers	\$5,131.40
Durham	Leslee Wills	Team Murphy	\$39,825.00
Embrun	Brenda Tobin	Team Alex	\$4,621.00
Guelph-Wellington	Alan Farmer	Team Q	\$32,364.00
Haliburton	Gail Leach-Wunker	Sisson Sisters	\$5,804.00
Hamilton	Carrie Lamont	Shaking yet Stirred	\$23,470.13
Huntsville*	Jennifer Laidlaw	The Tartan Army	\$4,620.00
Kemptville*	Bev Nye	n/a	\$500.00
Kingston	Ian Binnie	Extraordinary Team English	\$24,461.55
Kirkland Lake*	Diane Merrell	n/a	\$2,445.00
Manitoulin Island*	Lloyd Neganegijig	n/a	\$1,569.15



# PARKINSON SUPERWALK RESULTS FOR ONTARIO

	TOP WALKER	TOP TEAM	WALK TOTAL <i>As of October 1, 2016</i>
Markham-Unionville	Michael Zegers	Sonny Side Up	\$22,255.00
Mississauga	Laura & Angelo Zega	Mississauga Wilkinson Warriors	\$51,013.05
Newmarket	John Gutteridge	Team Irish	\$35,616.00
Niagara Region	Maureen Thun	Walker Industries	\$56,740.10
North Bay	Shaun Billingsley	Royal LePage & Friends	\$6,689.35
North Simcoe*	Penny McDowell	n/a	\$4,557.30
Northumberland	Don Hackney	The Northumberlands	\$43,013.84
Oakville	Megan Boyle	Dukes of Earl	\$19,899.35
Orillia	Connie Bagley	Team Bagley	\$3,723.00
Ottawa	Brenda Lavergne	Walkie Talkies	\$153,128.73
Parry Sound*	Residents of Belvedere Heights	Dean's Team	\$861.00
Peterborough	Vivian Heimiller	Peterborough Movers & Shakers	\$48,928.00
Renfrew	Scott Edwards	Team Edwards	\$26,924.00
Sault Ste. Marie*	Anne Laidlaw	n/a	\$460.00
Sudbury	Bruce McCulloch	La Belle Louise	\$23,263.05
Thunder Bay	Patty Bates	Team Ruberto	\$6,292.00
Timmins	Alice Palangio	Timmins Support Team	\$9,850.50
Toronto - East	Shirley Harris	Walking for Bert & YOPD	\$44,363.00
Toronto - North	Margot Friedman	Team Bearg	\$240,707.30
Vaughan	Angela Rossi	Cookies & Cream	\$48,190.00

\* support group walk

**GRAND TOTAL**

**\$1,159,297.25**





## Thank You Toronto SuperWalk



**BRONZE**



## Thank You Eastern Ontario Media



Thank you to Subway for providing free sandwiches at 13 SuperWalk locations!



# Parkinson SuperWalk Raises More Than \$1,159,297 in Ontario

We are proud to be celebrating another successful Parkinson SuperWalk campaign in Ontario!

Rain or shine, more than 3000 participants at 40 walk sites gathered in their communities to show their commitment to funding support services, education, advocacy, and research for the Parkinson community. As of October 1 2016, Parkinson SuperWalk in Ontario raised \$1,159,297; an amazing achievement that will directly impact those affected by Parkinson's disease. More than \$2 million was raised across the country.

Laura and Dillon Long had an important reason for not attending Parkinson SuperWalk—their wedding! Participating in memory of Laura's grandfather, the couple brought the spirit of SuperWalk into their special day with a superhero theme and Parkinson SuperWalk wedding attire. It was an amazing way to recognize the family's experience with Parkinson's disease and continue the important tradition of participating in SuperWalk. Congratulations Laura and Dillon!

Although the traditional way to support SuperWalk is to attend a local event, there were some who got creative and brought SuperWalk to them! Peter and Carol Thompson are dedicated SuperWalkers, but found themselves away from home on walk weekend. That didn't stop them from donning their Parkinson SuperWalk shirts in Gaspé, Quebec as virtual walkers, while their son Michael and girlfriend Britt represented Team Thompson at their home walk in Ontario.

We're thankful for the support of all of our participants across Ontario. You'll find the Top Walkers, Top Teams, and Walk Totals listed on pages 10 and 11. Congratulations on your fundraising success!

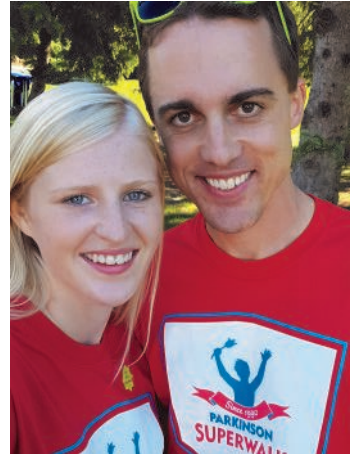
Thank you again for your passion and dedication to this cause. We look forward to seeing you at next year's Parkinson SuperWalk on September 9 and 10, 2017. *Do you want to show us where YOU SuperWalk? Contact our office to set up the details for your own virtual walk experience at 800-565-3000 or visit [parkinson.ca](http://parkinson.ca)*



Laura and Dillon Long



Peter and Carol Thompson



Michael and Britt

## Lunchtime Chats with Sandie

Join Sandie Jones on the second Tuesday of each month at noon EST for our monthly education presentation. Sandie will talk briefly about the theme of the month and then answer questions sent in by you. Please send in your questions ahead of time to [debbie.davis@parkinson.ca](mailto:debbie.davis@parkinson.ca).



You can connect to the call in one of the following two ways (*you only need to access the call one way; if you do both you will have double audio playing*):

- On your computer, log into the call via the following link: <http://parkinson.adobeconnect.com/sandie/>. Once you have opened the link, choose to enter as a guest and then turn on your speaker.
- To connect by phone, call our toll-free number 866-850-3418 (Toronto callers may dial 416-915-8692), and the participant code is 9415905.

Can't make it? No problem ... catch up on previous lunchtime chats by logging on to <http://bit.ly/29geVDT>



## The Drum Beat to Make Parkinson's Retreat

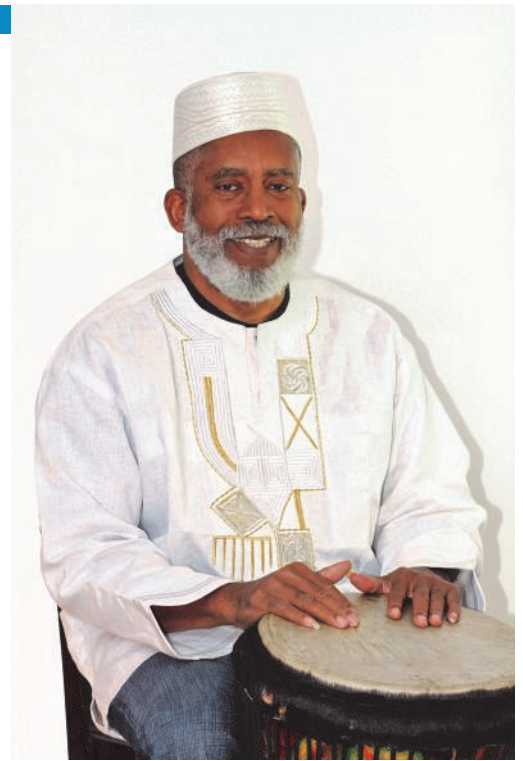
Muhtadi Thomas immigrated to Canada from Trinidad and Tobago in 1974. As one of Canada's premier percussionists, Muhtadi plays djembe, bongos, congas, timbales, steel pan, and a wide assortment of other percussion instruments. He has performed extensively, both nationally and internationally. However, much of his career has been devoted to teaching the art of drumming in community arts programs, schools, and community centres.

Muhtadi has received numerous awards and commendations from communities in and around the GTA for his contributions to the artistic community and for work with at-risk youth.

Most significantly, he is well-known as the founder and artistic director of the highly successful two-day annual Muhtadi International Drumming Festival, which celebrates the drum, its universality as an art form, and its presence in all cultures. The festival features drumming groups of all ages and skills that display the diverse cultural traditions and drumming styles from all over the world.

This year, the drumming festival and associated events will take on extra meaning for Muhtadi and the participants who have a great respect for him. Parkinson's disease has had an impact on his family, and recently, Muhtadi was also diagnosed with the disease. For those close to him, Muhtadi has faced his diagnosis with "a grace and a tenacity bordering heroism" and he wants to help others living with the condition as well.

With a focus on diet, exercise, and creative expression, Muhtadi credits drumming as an outlet to help manage his Parkinson's. Now, he wants to share the positive impact of Drum Therapy to others in the Parkinson Community. This November, Parkinson Canada and the Muhtadi International Drumming Festival will collaborate on a 24-Hour Drum-A-Thon fundraiser, and look forward to extending that partnership to the flagship event in June.



The June festival is entering its 18th year and brings together members from diverse communities in Ontario and beyond. With an unofficial goal of using drum beats to connect heart beats, a tight-knit community has formed among the drummers centred around the event's founder. In 2017, Parkinson awareness and stories of living well will be at the forefront.

Learn more at [donate.parkinson.ca/muhtadi\\_drumathon](https://donate.parkinson.ca/muhtadi_drumathon)

## Advocacy Updates ... What You Might Like to Know

Parkinson Canada continues to advocate in support of a Pan-Canadian Action Plan for the Brain. So far we've shared this message across the country over 100 times with government officials through the incredible effort and dedication of our Parkinson Ambassador Network.

If you believe it is important to share your experience and advocate for better public policies and programs, then consider joining our Parkinson Ambassador Network. People like you can help ensure that the voice of Canadians affected by Parkinson's disease is heard loud and clear by our elected officials.

If you would like to know more about the Ambassador program, or would like more information on Parkinson Canada's advocacy work, please contact the advocacy team at [advocacy@parkinson.ca](mailto:advocacy@parkinson.ca) or 800-565-3000 ext. 3478.

Did you know that the Ontario Government is developing a Dementia Strategy? Concerned about issues related to cognitive changes and Parkinson's? Have your voice heard in the development of the Ontario Dementia Strategy. Visit: <https://www.ontario.ca/page/dementia-strategy-consultation> to download the discussion paper and provide your feedback.





## Call for Caring Community Helpers

**Bolton/Burlington/Huntsville/  
Bracebridge/Toronto/Renfrew/  
Chesterville/Cornwall/Hawkesbury/  
Etobicoke**

We are looking for caring individuals to volunteer to facilitate monthly support groups, providing education and support to persons with Parkinson's, members of their families, and/or their caregivers in dealing with the challenges of living with the condition.

Parkinson's support groups encourage members to share experiences, ideas, and feelings; address challenges; develop supportive friendships; and receive current information about Parkinson's disease, all in a safe and confidential setting. These groups are held once a month at various times.

Training will be provided. Once training is completed, the commitment is three to five hours per month.

Experience in facilitation of groups or meetings is an asset. Active seniors are welcome!

**Please contact Elisabeth Schoep,  
Volunteer Services Coordinator,  
800-565-3000 ext. 3304 or  
elisabeth.schoep@parkinson.ca**

### **Young and Early Onset Virtual Support Group**

Are you feeling isolated by your geography? Not able to join a support group with other people your age living with Parkinson's disease? Not anymore!

Parkinson Canada has a virtual support group for those who are 60-ish and under. Now you can attend a support group from the comfort of your own home!

The meetings take place on the *fourth Monday of each month at 7 p.m. EST*. All you need to join is a computer, a laptop, a tablet, or a smart phone with a webcam and a microphone ... and a good internet connection.

If you would like to register for a meeting, or if you have any questions, please email Diane at [diane.newmanreed@parkinson.ca](mailto:diane.newmanreed@parkinson.ca)

## HELP NEAR YOU

For more information about support in or near your local community, visit [www.parkinson.ca](http://www.parkinson.ca), call toll-free 800-565-3000, or email [info@parkinson.ca](mailto:info@parkinson.ca).

Almonte	Newmarket
Arnprior	Northumberland
Barrie	Niagara
Belleville-Quinte	North Bay
Belleville-Quinte Early Onset	North Muskoka
Beeton	North Simcoe
Blackburn Hamlet	Oakville
Bolton	Orillia
Bracebridge	Orleans English
Brampton	Orleans French
Brighton	Orleans Carepartner
Brockville	Ottawa Carepartner
Burlington	Ottawa Inner West
Collingwood	Ottawa Centre
Cornwall	Ottawa Newly Diagnosed
Durham Region	Ottawa South
Durham Region Early Onset	Ottawa Young & Active
Embrun groupe de soutien	Parry Sound
Etobicoke	Pembroke
Guelph	Perth
Haliburton	Peterborough
Halton	Renfrew
Hawkesbury	Richmond Hill (Mandarin language)
Hamilton	Sault Ste. Marie
Huntsville	Scarborough
Kanata	South Muskoka
Kemptville	South Simcoe
Kenora	St. Catharine's
Kingston	Sudbury
Kirkland Lake	Thunder Bay
Manitoulin Island	Timmins
Markham Stouffville	Toronto
Milton	Vaughan
Mississauga	Wellington
Napanee	Winchester/Chesterville

# Our Mission

*Parkinson Canada is the voice of Canadians living with Parkinson's. Since 1965, we have provided education, advocacy, and support services in communities coast to coast to individuals and the health care professionals who treat them. The Parkinson Canada Research Program funds innovative research to search for better treatments and a cure.*



The Standards Program Trustmark is a mark of Imagine Canada used under licence by Parkinson Canada.

La marque de confiance du Programme de normes est une marque d'Imagine Canada, utilisée sous licence par Parkinson Canada.

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

**800-565-3000**

**Charitable No: 10809 1786 RR0001**



LiveWire is published three times a year—our spring edition in March, our summer edition in August, and our fall and winter edition in November—to provide helpful information to people affected by Parkinson's. It is not meant to provide medical advice; readers should contact their doctors in all matters relating to health concerns and/or medication. LiveWire is offered in print and pdf form, and past issues may be accessed at [parkinson.ca](http://parkinson.ca). If you would like to be added to our mailing list, either by regular mail or email (please specify), contact Diane Newman Reed at 800-565-3000 ext. 3315 or email [diane.newmanreed@parkinson.ca](mailto:diane.newmanreed@parkinson.ca).

## What We Do in Ontario

### Support Services

We provide consistent and excellent support to people living with Parkinson's disease and their families to make their lives better. We also provide support to the facilitators and participants of our many support groups and chapters.

### Education

Our goal is to provide excellent seminars and conferences in different locations; we also offer a number of webinars during the year. There are smaller sessions held monthly during support group and chapter meetings.

### Advocacy

Our Ontario Advocacy Committee works to influence the behaviour of key government officials and agencies in support of people living with Parkinson's disease, and build strong relationships with the Local Health Integration Networks across Ontario.

### Research

The Parkinson Canada Research Program has invested more than \$25 million in 483 grants and awards since 1981.

---

#### LiveWire

Parkinson Canada  
316 – 4211 Yonge St.  
Toronto, ON M2P 2A9

Canada Post  
Canadian Publications Mail  
Sale Product Agreement  
No. 40624078

---