Live Wife ontario

Spring 2017



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Spring is here and I am sure you all are as excited about that as I am!

Before I go any further, I want to share some great news. Late

in 2016 we received news that we would receive a three-vear Trillium Grow Grant that would start in January 2017. On this page, you will see the listing of all of the Community Development Coordinators and the areas they serve. You will see that we now have nine Community Development Coordinators in Ontario thanks to this Trillium grant to grow our capacity and serve you where you live. Thank you Ontario Trillium Foundation.

In addition to the great articles in this issue (one of them is in French), please pay close attention to the education opportunities we have planned for 2017. The webinars and podcasts available to anyone in Canada are listed on page 8 and on page 9, you will see the in-person education opportunities available in Ontario. So mark your calendar and listen/watch the webinars and podcasts each month, then check the list for the closest in-person session.

There are lots of events taking place (listed on page 11) but don't forget that the SuperWalk website opens for registration on April 4th.

Thank you, as always, for your continued support. We could not accomplish all that we do without you.

I welcome any questions or suggestions so please feel free to reach out to me at debbie.davis@parkinson.ca



Who Are You Going to Call in Ontario?

www.parkinson.ca

800-565-3000

TORONTO: 416-227-9700 OTTAWA: 613-722-9238

Debbie Davis, VP, Mission, and Managing Director, Ontario 800-565-3000 ext. 3373 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, Coordinator, Client Services and Education

416-227-3375/800-565-3000 ext. 3375 sandie.jones@parkinson.ca

Robert TerSteege, Information and Referral Associate

416-227-3372/800-565-3000 ext. 3372 robert.tersteege@parkinson.ca

Angela Supino, Support Services Counsellor, Ottawa

613-722-9238 angela.supino@parkinson.ca

Shannon Harrison, Information and Referral Associate

613-722-9238 shannon.harrison@parkinson.ca

You would like more information about volunteer opportunities:

Elisabeth Schoep, Volunteer Services Coordinator

800-565-3000 ext. 3304 elisabeth.schoep@parkinson.ca

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

Naseem Jamal, Community Development Coordinator, Toronto

416-227-3377/800-565-3000 ext. 3377 naseem.jamal@parkinson.ca

Diane Newman Reed, Community Development Coordinator, Eastern Ontario 800-565-3000 ext. 3315

diane.newmanreed@parkinson.ca

Karen Dowell, Community Development Coordinator, Western Ontario

416-227-3376/800-565-3000 ext. 3376 karen.dowell@parkinson.ca

Paul Scibetta, Community Development Coordinator, Southwestern Ontario

800-565-3000 ext. 3337 paul.scibetta@parkinson.ca You would like more information about support groups, chapters, or events in your community (continued):

Tamara Gagnon, Community Development Coordinator, Northeastern Ontario 800-565-3000 ext. 3317

tamara.gagnon@parkinson.ca

Marielle Henderson, Community Development Coordinator, Northwestern Ontario 800-565-3000 ext. 3331

marielle.henderson@parkinson.ca

Anne McNamara, Community Development Coordinator, Central Ontario

800-565-3000 ext. 3326 anne.mcnamara@parkinson.ca

Ginette Trottier, Community Development Coordinator, Eastern Ontario / Coordonnatrice au développement communautaire, l'est de l'Ontario

613-722-9238 ext. 201/800-565-3000 ext. 3329 ginette.trottier@parkinson.ca

Margaux Wolfe, Community Development Coordinator, Eastern Ontario / Coordonnatrice au développement communautaire, l'est de l'Ontario

613-722-9238 ext. 206/800-565-3000 ext. 3425 margaux.wolfe@parkinson.ca

You would like more information about Parkinson SuperWalk:

Amanda Stanton, Events and Partnerships

416-227-3371/800-565-3000 ext. 3371 amanda.stanton@parkinson.ca

Shauna Quinn, Events and Partnerships Associate Ottawa

613-722-9238

shauna.guinn@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

Sue Rosenblat, Manager, Major, Planned **Giving and Foundations**

416-227-3386/800-565-3000 ext. 3386 sue.rosenblat@parkinson.ca

Ronen Tal, Manager, Direct Marketing 416-227-3381/800-565-3000 ext. 3381

ronen.tal@parkinson.ca



Parkinson's and the Female Brain

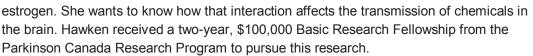
Dr. Emily Hawken, Post-doctoral Fellow Queen's University

Basic Research Fellowship: \$100,000, 2 years

Sex-specific Neurophysiological Traces of L-DOPA-induced Dyskinesia in the Bed Nucleus of the Stria Terminalis of 6-OHDA-lesioned Rats

Although Parkinson's disease affects both men and women, women are less likely to develop the progressive neurological disorder but more likely to experience severe motor symptoms and side effects of treatment.

At Queen's University in Kingston, neuroscientist Emily Hawken investigates those gender differences. She's studying the interaction between Parkinson's disease and hormones that are intrinsic to females, such as



For example, when women with Parkinson's are treated with levodopa, the medication used to reduce the symptoms of the disease, they often develop more severe involuntary movements (dyskinesia) than men with Parkinson's on the same medication.

"What is it about females that make them less likely to develop symptoms of Parkinson's, yet more likely to be severely impaired by the side effects of the treatment?" she asks.

Using animal models, Hawken will transmit electrical currents through brain cells to measure the activity of those neurons in specific regions of the brain. Then she will observe and record the effect of specific neurotransmitters on the neurons she measures.

Recent evidence suggests estrogen may affect other brain chemicals, such as dopamine, and estrogen may itself become a neuromodulator that transmits information to brain cells. Hawken hopes she will observe physiological evidence that animals that develop dyskinesia experience changes in their brain cells that differ depending on the animals' gender.

If she can pinpoint a gender difference, Hawken hopes her research will inform treatments for Parkinson's disease that are designed differently for women and men.

"Instead of a blanket treatment ... perhaps if we did tailor the treatment for women, it would be equally therapeutic but with fewer side effects," Hawken says.

Historically, most health research has been conducted using men and a male model of disease, Hawken points out.

"We could be completely missing something just by looking at the male model," Hawken says. "Women are suffering as a consequence, because they generally don't present the same symptoms. Their treatments are often subpar because our knowledge base isn't adequate in terms of how the female brain operates."

Visit the research section of www.parkinson.ca to read about other researchers recently funded by the Parkinson Canada Research Program.



Repurposing Existing Medications For Other Conditions

By Robert TerSteege

The term 'repurposing drugs' usually refers to investigating whether drugs that are currently approved for the usage of one condition may actually hold potential for the treatment of another condition. This involves further testing to see if they are safe and effective at new dosage levels or for different periods of time.

An example of a drug that was repurposed for Parkinson's disease is amantadine. Amantadine was first developed as an antiviral medication for influenza in the 1960s. When it was used in long term care facilities, there was a coincidental benefit to some residents who had Parkinson's.

What are the benefits to repurposing?

In general, translational research—the period of time to test a new drug molecule through the clinical trial process—can take upwards of 15 years before it can even be considered for getting to the market. This time is needed to first test the safety of the drug, determine the most effective dosage for treatment, and look at potential side-effects over time.

A repurposed drug already has known qualities about it, so there is the potential to significantly reduce the wait times in getting it approved more quickly, as well as decrease costs involved with clinical trials.

What are the drawbacks?

Medications that are used for one purpose may have a noticeable, but not a significant, improvement in symptoms for people or could have serious side-effects if used for a very long time.

Some medications that may be taken safely for a short period of time, or whose benefits outweigh the side-effects for the original condition, may not be safe for usage in other conditions.

For example, certain chemotherapy drugs could have potential in addressing symptoms of Parkinson's; however, they may suppress the immune system or be toxic to the liver. For someone who is dying from a serious cancer, serious short-term side-effects may be well worth the risk. For someone living with a chronic condition like Parkinson's, there may be a short term benefit, but then further issues caused by the drug.

How does Parkinson Canada help get access to drugs?

Parkinson Canada is committed to:

- ensuring all available treatment options are accessible to Canadians living with Parkinson's disease; and
- supporting the inclusion of drugs deemed safe and

effective by Health Canada in all provincial formularies. Parkinson Canada supports the current process for drug approval, including the use of Health Canada's Special Access Programme, and post-marketing surveillance and evaluation.

Parkinson Canada also plays an active role to ensure Canadians living with Parkinson's disease get equal access to medications and treatments approved by Health Canada for the treatment of Parkinson's disease. This includes providing messaging for Canadians affected by Parkinson's to lobby federal, provincial, and territorial governments, ensuring Parkinson's medications/ treatments are financially covered under provincial and territorial formularies. Parkinson Canada does not actively lobby to get Parkinson's drugs/treatments approved by Health Canada through a Notice of Compliance.

Summary

While an existing medication may hold potential, and could get to market sooner because of certain known factors, all medications have the potential for side-effects, and changes in existing dosages of medications or long-term effects need to be known. The benefits must outweigh the risks.

Certain Parkinson's medications have had serious sideeffects for some individuals, both in the short term and in the long term. It would be irresponsible of us to try to bypass certain safety steps in the approval process.

Advocacy ... 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 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? Want to be part of a movement to move this initiative forward? Go to http://actionfordementia.ca/ to learn more.

Exercise Proven Beneficial for Parkinson's Symptom Management and Quality of Life: Physiotherapists Can Help

By Rebecca Gruber BPT MSc and Jan Goldstein-Elman BSc(PT) MSc

Parkinson's disease (PD) is a common and disabling neurodegenerative disorder with no known cure and for which current medical treatments alone are not optimal. Current research shows that individualized exercise treatment—which physiotherapists are experts at prescribing and monitoring—can promote important therapeutic outcomes for people with PD.

A 2013 Cochrane best evidence review of 39 high methodological-quality Randomized Control Trials (RCTs of 1827 participants) reports evidence in favor of physiotherapy compared to no therapy, with statistically and clinically meaningful improvements in endurance, balance, walking, mobility, and perceived quality of life with physiotherapy intervention.²

Until recently, exercise was not thought to be of benefit for PD, and physiotherapy was only recommended in later stages of disease progression when substantial disability was present. Today research is showing that people with PD benefit from physiotherapy along the continuum of disease progression, and that these benefits do not disappear when the physiotherapy program ends.

As part of a coordinated multidisciplinary approach to treating people with PD, physiotherapists evaluate and improve movement and function, with particular emphasis on physical mobility, movement amplitude, posture, balance, endurance, fatigue, and pain.

Exercise and Neuroplasticity in PD

The process through which the brain utilizes experience to modify existing neural circuitry, called neuroplasticity, can lead to brain repair post-injury or with disease.

Exercise may provide the PD brain with an ideal environment for neuroplasticity to occur through increased blood flow, immune system activity, and release of trophic factors. Exercise that incorporates **intensity**, **repetition**, and motor and cognitive **challenge** promotes neuroplasticity⁴ and improves motor performance.

Research is showing that improvement in both automatic and cognitive motor control in PD is possible with a combination of goal-directed motor skill building and intensive aerobic exercise.³

Why Therapeutic Exercise Prescribed by a Physiotherapist?

Research shows that at the time of diagnosis, people with PD are already more sedentary than their agematched peers.⁵ Physical activity is important for long-term health and preventing secondary conditions such as heart disease, obesity, and diabetes. For people with PD we know that physical activity has benefits beyond preventing secondary conditions, and likely has neuro-protective benefits as well.³

People with PD receive similar fitness and psychological effects from exercise as the general population: Studies show that gait, balance, strength, flexibility, and cardiovascular fitness all improve when people who have PD participate in exercise. 6 However, prescribed exercise is different, and is crucial to improving and maintaining mobility and limiting disability in people living with PD. Everyone with PD presents with unique manifestations of the condition that vary over time. Physiotherapists experienced in PD treatment can assess symptoms and prescribe and monitor the type, duration, and intensity of exercise for best results.

Physiotherapists are also uniquely qualified to assess and treat the movement impairments that lead to disability in PD. The ability to get up from a low seat, in and out of a car, into and out of bed, put on and take off a jacket with ease, walk, run, use a computer, and cut food are all affected by PD. General exercise, dance, yoga, tai chi, and boxing, though potentially beneficial for posture, balance, and

perceived quality of life, do not retrain the person with PD to move and do everyday activities in a normal way. Physiotherapists with specialized training and experience do.

Exercise Matters

When: Early and often. Best results are achieved when the person with PD is assessed by an expert physiotherapist when first diagnosed and at regular intervals thereafter.

What: Highly-intensive exercise that focuses on motor-skill building and engages cognition.³

How: Exercise needs to address the specific PD-related movement impairments and functional disabilities of the individual.⁷

Appropriate medication combined with individualized, neuroplasticity-promoting exercise prescribed by a physiotherapist with expertise in PD rehabilitation can minimize the movement impairments and functional disability in PD.

¹Rosenthal and Dorsey, 2013. The benefits of exercise in Parkinson disease. *JA-MA Neurol* 70(2) 156-7.

²Tomlinson et al, 2013. <u>Physiotherapy for treatment of Parkinson's disease</u>. Cochrane Review Movement Disorders Group, published 10 September 2013. <u>www.cochrane.org/CD002817/Movement retrieved April 6</u>, 2016.

³Petzinger et al, 2013. Exercise – enhanced neuroplasticity targeting motor and cognitive circuitry in Parkinson's disease. *Lancet Neurol* 12(7) 716-26.

⁴Kleim and Jones, 2008. Principles of experience-dependent neural plasticity: Implications for rehabilitation after brain damage. *Journal of Speeech, Language, and Hearing Research* 51 S225-39.

⁵Van Nimwegen M et al, 2011. Physical inactivity in Parkinson's disease. *J Neurol* 258 2214-21

⁶Ellis et al, 2013 Barriers to exercise in people with Parkinson disease. *Phys Ther* 93 (5) 628-36.

⁷Keus et al on behalf of the Guideline Development Group, 2014. <u>European</u> <u>Physiotherapy Guidelines for Parkinson</u> <u>Disease.</u> <u>www.parkinsonnet.nl</u> retrieved March 29, 2016.

PARLONS SANTÉ

S'agit-il de la dépression ou de la mauvaise humeur ?

Par Sandie Jones

Les changements temporaires d'humeur font partie de l'expérience humaine. Quand une humeur dépressive ou de tristesse persiste pendant des semaines, elle aggrave la maladie et nuit éventuellement aux activités quotidiennes, les conseils d'un professionnel sont alors requis.

En 1817, le Dr James Parkinson décrivait la « paralysie agitante », il parlait du masque, du tremblement de repos, du ralentissement des mouvements volontaires et de la posture inclinée qui sont les caractéristiques communes de la maladie de Parkinson. Mais il a également décrit ses patients comme des êtres malheureux, abattus ou mélancoliques de sorte que le lien qui existe entre la dépression et la maladie de Parkinson n'est pas une nouveauté.

Longtemps après leur diagnostic, les personnes atteintes de la maladie de Parkinson et les médecins se souviennent que la dépression était l'un des symptômes initiaux, mais personne ne l'avait reconnu comme tel. Pourquoi? Le tableau des critères de similitudes entre la maladie de Parkinson et la dépression peut vous éclairer ce sujet (voir page suivante).

Il en existe deux grandes catégories : réactionnelle et clinique.

La dépression réactionnelle :

La dépression est provoquée par un événement marquant comme la mort d'un être cher, les problèmes familiaux ou conjugaux, les difficultés en affaires et recevoir un diagnostic lié à une maladie chronique comme la maladie de Parkinson. L'annonce d'un tel diagnostic est difficile à accepter et c'est normal d'éprouver de la consternation et du chagrin quand notre état de santé décline. Les gens se préoccupent tellement de leur santé qu'ils n'ont plus aucun intérêt pour un certain temps. Parfois, les gens ont de la difficulté à imaginer que ces sentiments de perte et de tristesse diminueront avec le temps; ils finissent par accepter la maladie et peu à peu, ces sentiments disparaissent.

La dépression clinique :

Ce type de dépression sévère et persistante est très différent de celui décrit ci-dessus, et provoque une impression de tristesse, des sentiments de désespoir insoutenables, d'écrasement, de peur, d'angoisse, d'incapacité décisionnelle ainsi que des troubles du sommeil et de l'appétit.

Certains s'accrochent aux vieilles idées autour de la maladie mentale et ils sont convaincus qui la vaincront avec leur simple volonté. D'autres parlent ouvertement de diabète, d'arthrite et d'autres maladies chroniques mais sont gênés d'annoncer qu'ils souffrent de dépression.

D'après certains renseignements, entre 40 et 70 p. cent des patients expérimentent les symptômes liés à la dépression. De nombreux patients ressentent fortement leurs émotions qui sont à fleur de peau, un simple détail les rend heureuses ou tristes ou bien, les font pleurer. Cette situation peut devenir très embarrassante. Cette instabilité émotionnelle n'est pas rare, et est le résultat de changements qui se produisent dans le cerveau, ce ne sont pas les mêmes causes que celles liées à la dépression.

Il faut bien comprendre que la dépression causée par la maladie de Parkinson est largement due aux changements neurochimiques du cerveau. La recherche a prouvé que les systèmes du cerveau qui se détériorent incluent non seu-lement ceux responsables des mouvements, mais également ceux qui gèrent les émotions. Nous savons que la destruction des neurones dopaminergiques entraîne des problèmes de mouvement. Dans un même temps, les concentrations d'autres produits chimiques tels que la sérotonine et la norépinéphrine sont également touchées et aident à contrôler nos réponses émotionnelles. Donc, la dépression peut être un effet de la maladie. Certaines personnes se sentent dépressives suite à la difficulté à s'ajuster à leur diagnostic, mais pour d'autres, elle est le résultat de la combinaison des deux.

6 Parlons santé



CRITÈRES RELATIFS À LA MALADIE DE PARKINSON ET À LA DÉPRESSION

Maladie de Parkinson	Dépression
Absence d'expression faciale spontanée	Absence d'expression faciale spontanée
Lenteur des mouvements	Lenteur des mouvements
Position courbée	Position voûtée
Agitation / Anxiété	Agitation / Anxiété
Discours lent, monotone	Discours lent, monotone
Constipation	Constipation
Troubles du sommeil	Troubles du sommeil
Fatigue	Fatigue
Apathie	Apathie
Manque d'intérêt et de plaisir attribuable aux symptômes physiques	Manque d'intérêt et de plaisir attri- buable au sentiment d'apathie
Faiblesse	Faiblesse
Diminution de l'activité sexuelle causée par l'immobilité et la perte de libido.	Diminution de l'activité sexuelle causée par la perte de libido et le traitement médicamenteux.,
Ralentissement des activités physiques et mentales dû à la bradykinésie et la bradyphrénie.	Ralentissement des activités physiques et mentales causé par un retard psychomoteur.

Chez certaines personnes, les symptômes de la dépression sont liés au bienfait de la lévodopa. Dès que l'effet de la première prise diminue, vous vous sentez triste et éprouvez de la difficulté à vous concentrer à l'approche de la deuxième prise. Aussitôt, votre humeur et votre motivation s'améliorent. Voilà un facteur déterminant tel le dosage optimal des médicaments contre la maladie de Parkinson qui devient encore plus important.

VOUS N'AVEZ PLUS À SOUFFRIR!

La dépression peut être traitée efficacement grâce à un large éventail de médicaments antidépresseurs. Avant tout, assurez-vous d'aviser votre médecin de la manière dont vous vous sentez. Il est difficile d'obtenir l'aide adéquate pour guérir de la dépression si vous cachez votre état de santé et êtes embarrassé d'en parler.

Choisir un antidépresseur n'est pas chose aisée.

Trouver le bon médicament exige de la patience, car il faut de quatre à six semaines afin que le médicament puisse atteindre son effet optimal. Si un médicament ne s'avère pas efficace, essayez-en un autre. Même si un médicament ne vous convient pas, il en existe d'autres pour traiter les symptômes de la dépression. Par contre, les patients qui commencent un traitement veulent obtenir de bons résultats rapidement.

Pour les personnes atteintes de Parkinson

- Faire de l'activité physique. Rien de mieux pour remonter le moral. N'oubliez pas de programmer votre séance d'exercice au moment de la journée où vous vous sentez bien.
- Développer et entretenir des rapports sociaux. Les personnes ayant des liens solides avec leur famille, leurs amis et la collectivité sont moins susceptibles de souffrir de dépression.
- Établir une liste d'activités quotidiennes simples à accomplir. Rien de mieux pour recouvrer l'estime de soi quand on réussit un tel défi.
- Demander de l'aide et en discuter avec un thérapeute, une infirmière ou un travailleur social.

Pour les aidants naturels

- Quand vous croyez avoir des doutes quant à la dépression d'un conjoint ou d'un membre de la famille, discutez-en avec eux et, avec leur permission, parlez-en avec leur médecin ou tout autre professionnel de la santé.
- Dans les cas où la personne soignée est dépressive, maintenez son attention sur ce qui est positif.
- Tentez de l'amadouer en lui faisant accomplir de simples tâches sans la plaindre ni la surprotéger.
- Assurez-vous d'obtenir tout le soutien nécessaire; s'il y a lieu, adhérez à un groupe de soutien. Tout seul, vous n'y arriverez pas.
- N'oubliez pas, vous pourriez également souffrir de dépression et de troubles du sommeil.

Publié initialement dans LiveWire, édition automne 2013 (révision : printemps 2015)

Cet article ne se substitue pas à un avis médical spécifique à un individu, mais est à des fins d'information générale. Veuillez consulter votre médecin pour toute information diagnostique et thérapeutique.

Parlons santé 7

WEBINARS AND PODCASTS

EXPERT WEBINAR SERIES

Please pre-register for the webinars to reserve your spot: parkinson.ca/knowledge. All webinars begin at 12PM EST. Registration opens a month prior to each webinar.



Medical Marijuana, Jonathan Zaid, Founder and Executive Director, CFAMM, March 14, live session at Hilton Garden Inn, 746 Old Hespler Road, Cambridge



Parkinson's Disease and Nutrition, Nicole Shuckett, Registered Dietician, ALS clinic and Jeff and Diane Ross Movement Disorders Clinic, Sunnybrook Hospital, May 11



Physiotherapy and Parkinson's, Jan Goldstein and Rebecca Gruber, Physiotherapists and Founders, One Step Ahead Mobility, **July 11**



PD and Driving, Beth Robertson, Occupational Therapist, McGill University Health Centre, September 12



PD Stress Management, Elaine Book, Social Worker, M.S.W, Pacific Parkinson's Research Centre, November 14

PODCASTS



Join Parkinson Canada expert, **Sandie Jones**, in a series of podcasts where she talks about various topics related to Parkinson's disease. These one-hour talks offer information, practical tips, and advice on how to live better with Parkinson's.

To submit questions in advance, send an email to education@parkinson.ca

Here's how to join and listen live:

CONNECTING VIA YOUR COMPUTER:

- Log into the call via the following link: http://parkinson.adobeconnect.com/sandie/
- Choose to enter as a quest.
- Turn on your speakers so you can hear—there will be no visual presentation.

CONNECTING VIA PHONE:

Dial Toronto: 416-915-8692 or Toll Free: 1-866-850-3418

Participant code: 9415905

Visit the Parkinson Canada Knowledge Network at parkinson.ca/knowledge to replay any of the webinars or podcasts.

8 Webinars and Podcasts

EDUCATION IN THE COMMUNITY 2017

March 14, Cambridge, Medical Marijuana, live session in Cambridge plus a national webinar, Jonathan Zaid, Hilton Garden Inn, 746 Old Hespler Road (live session). Karen Dowell, 416-227-3376/800-565-3000 ext. 3376 / karen.dowell@parkinson.ca or Paul Scibetta, 800-565-3000 ext. 3337 / paul.scibetta@parkinson.ca

April 26, 6:00 p.m. to 8:00 p.m., Toronto, Parkinson's Disease & Depression with special guest Andy Barrie, Toronto Botanical Gardens, 777 Lawrence Ave. East. Key Note Address: Dr. Mateusz Zurowski, Assistant Professor, Consultation/Liaison Psychiatry, Toronto Western Hospital. Naseem Jamal, 416-227-3377/800-565-3000 ext. 3377 / naseem.jamal@parkinson.ca

May 5, 3:00 p.m. to 5:00 p.m., Ottawa, Research Symposium (open to the public), Pearson Room, Lord Elgin Hotel, 100 Elgin Street. Margaux Wolfe, 613-722-9238 ext. 206/800-565-3000 ext. 3425 / margaux.wolfe@parkinson.ca

May 31, 1:00 p.m. to 3:30 p.m., Whitby, Managing Your Own Wellbeing: Information and Strategies for people living with Parkinson's and their carepartners. Abilities Centre, 55 Gordon Street. Check in and refreshments at 1:00 p.m.; the session begins at 1:30 p.m. Free but registration is required. Diane Newman Reed, 800-565-3000 ext. 3315 / diane.newmanreed@parkinson.ca

June, Orillia, Movement and Living Well with Parkinson's, Anne McNamara, 416-227-9700/800-565-3000 ext. 3326 / anne.mcnamara@parkinson.ca

June 6, 6:30 p.m. to 8:30 p.m., Toronto, Overview of Parkinson Research and Where We Are Today with Dr. Soania Mathur, Parkinson Canada Conference Centre, 4211 Yonge Street, Suite 305. Naseem Jamal, 416-227-3377/800-565-3000 ext. 3377 / naseem.jamal@parkinson.ca

June 13, Collingwood, Exercise and Parkinson's Disease; Dr. Quincy Almeida, The Sun Life Movement Disorders Research & Rehabilitation Centre, will share research findings and exercise recommendations, Fung Loy Kok Taoist Tai Chi Centre, 58 George Street. Anne McNamara, 416-227-9700/800-565-3000 ext. 3326 / anne.mcnamara@parkinson.ca

June 16, 10:00 a.m. to 3:00 p.m., Kitchener, Developing Your Health Team, multidisciplinary panel of experts, Holiday Inn, 30 Fairway Rd. South; lunch is included. Fee TBD. Karen Dowell, 416-227-3376/800-565-3000 ext. 3376 / karen.dowell@parkinson.ca or Paul Scibetta, 800-565-3000 ext. 3337 / paul.scibetta@parkinson.ca

July, 6:30 p.m. to 8:30p.m., Toronto, Speech and Voice with Bonnie Bereskin, Speech Language Pathologist. Parkinson Conference Centre, 4211 Yonge Street, Suite 305. Naseem Jamal, 416-227-3377/800-565-3000 ext. 3377 / naseem.jamal@parkinson.ca

September 27, Thunder Bay, Conference with Sandie Jones. Marielle Henderson, 800-565-3000 ext. 3331 / marielle.henderson@parkinson.ca



October 4, Sudbury, Conference with Sandie Jones. Steelworker's Hall. Tamara Gagnon, 800-565-3000 ext. 3317 / tamara.gagnon@parkinson.ca

October 14, Toronto, Davis Phinney Victory Summit, Congress Centre. Debbie Davis, 800-565-3000 ext. 3373/debbie.davis@parkinson.ca and Naseem Jamal, 416-227-3377/800-565-3000 ext. 3377 / naseem.jamal@parkinson.ca

October 20, Ottawa, Francophone Conference, Pine View Golf Course, 1471 Blair Road. Ginette Trottier, 613-722-9238 ext. 201/800-565-3000 ext. 3329 / ginette.trottier@parkinson.ca

Contact the Community Development
Coordinator listed with the event for more
information or to register, or visit our event
calendar at parkinson.ca

Making an Impact in Your Community

Fundraising Your Way is an event program developed in recognition of the many different ways people who are passionate about a world without Parkinson's are choosing to make their mark in support of Parkinson Canada.

Parkinson Canada values the support of event organizers and community fundraisers across the country who dedicate their time and energy to supporting our mission, and we've developed an event program to allow you to have your impact in whatever way works for you.

Just like the experience of no two people living with Parkinson's is the same, your way of making a difference is unique too. **Fundraising Your Way** is a do-it-yourself toolbox to help support you in making an impact *in the exact way you want to.*

Choose an event type, develop a plan, and register with Parkinson Canada to commit to making a difference. You'll receive your very own 'Event in a Box' toolkit to help make sure we're both successful in our vision of a better life and a brighter future for Canadians living with Parkinson's today; a world without Parkinson's tomorrow.

In recent years, people have chosen many unique ways to make a difference in the lives of Canadians living with Parkinson's. We've benefitted from a range of events, from golf tournaments, breakfast events, and barbeques to cross -Canada bike rides, climbing Mt. Kilimanjaro, and even jumping out of a plane! This new program is designed to provide fundraisers with the opportunity to showcase unique ways of giving back.

How it works:

Participants will choose to enter one of six event hubs related to the type of fundraising initiative they are planning.



Within each hub, there are a number of different participation types (e.g., runner, cyclist, endurance event, etc. for active) and participants are presented with a custom online experience and are delivered custom planning and fundraising tools to help support their event. These may include physical tools, promotional signage, etc., and event-day giveaways are available to order or on a sliding scale based on fundraising amounts and goals.

Visit http://donate.parkinson.ca/yourway to learn more.



Community Events

From July 14–16, **Pedaling for Parkinson's** returns for a sixth year, after funding two Parkinson Canada Research Program grants in 2016 and raising over \$200,000! The ride, which takes place in picturesque Parry Sound, is designed to attract participants of all backgrounds and skill levels with the option to ride one, two, or three days (or volunteer!) and a range of distances from 40–120 km. For more information, call 800-565-3000 or visit the event online at www.pedalingforparkinsons.ca.

Hey Runners—introducing a whole new way to support Parkinson Canada! This May, when you lace up to go the distance in the Tamarack Ottawa Race Weekend (Canada's largest running weekend), you can now choose to support Parkinson Canada as part of the **2017 Scotiabank Charity Challenge.** Last year, almost 47,000 people participated in six different race events over the weekend, including the Scotiabank Ottawa Marathon. With something for everyone, race events include a full marathon, half marathon, 10K, 5K, 2K, and 1K race—ideal for the entire family! This year, every step you take can earn funds to help support Parkinson's research, advocacy, and support services.

Here's how to join:

- 1. Sign up for *any* of the races at the 2017 Tamarack Ottawa Race Weekend.
- 2. Choose to support Parkinson Canada, one of the 2017 participating charities.
- 3. As you train for your race, collect pledges from family, friends, and coworkers. You can also share updates about your fundraising on social media using the hashtag #RunScotia.
- 4. Run your race on May 27-28, 2017.

For more information or to register for the Scotiabank Charity Challenge, check out the Run Ottawa website, www.runottawa.ca, or contact Shauna Quinn by phone at 613-722-9238 or email shauna.quinn@parkinson.ca

COMMUNITY EVENT CALENDAR

Parkinson Canada offices and third-party organizers host a variety of events throughout the year.

April 4 (Website)

Parkinson SuperWalk Web Launch

More than 40 locations in Ontario, including one near you

Walk Weekend: September 9 and 10. The only nationwide fundraising event to benefit Canadians living with Parkinson's. www.parkinsonsuperwalk.ca. Parkinson Canada hosted event.

April 8

Comedy Night, Ottawa

A good laugh for a good cause. Corporate clean content—buyer beware. Tickets \$40 Read more about our featured event below. www.centrepointetheatres.com
Community Fundraising Event

May TBD

Wine and Cheese Evening, Port Dover

Call 800-565-3000 to learn more about this third-party event. Community Fundraising Event

May 7

Innisbrook Golf Tournament, Innisfil

Held at Innisbrook Golf Club. Details to be confirmed. Community Fundraising Event

May 27-28

Scotiabank Ottawa Marathon, Ottawa

NEW* Go the extra mile for Parkinson Canada in the Scotiabank Charity Challenge, part of Ottawa Marathon weekend. www.runottawa.ca Community Fundraising Event

July 14-16

Pedaling for Parkinson's, Parry Sound

Ride one, two, or three days with distances ranging from 40 to 120 km. More information at www.pedalingforparkinsons.ca
Community Fundraising Event

November 12

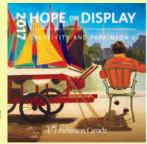
Porridge for Parkinson's, Toronto

A breakfast tasting featuring some of Toronto's most recognized chefs. \$125 per ticket. www.porridgeforparkinsons.ca
Community Fundraising Event



Showcase Your Creativity

The Hope on Display Calendar provides an opportunity to showcase your creativity through artistic expression. Parkinson Canada invites individuals living with Parkinson's in Canada to feature their art in our 2018 Hope on Display



Calendar, inspiring hope for others. If you are an artist of any kind (painter, photographer, jewelry maker, quilter, woodworker, sculptor, etc.), and you would like to be considered for the 2018 Hope on Display Calendar, please send an email to Diane at diane.newmanreed@parkinson.ca before August 8, 2017. Tell us about yourself and include a high-resolution image of your creation.

HELP NEAR YOU

For more information about support groups in or near your local community, visit www.parkinson.ca, call toll-free 800-565-3000, or email info@parkinson.ca.

Almonte Kenora Pembroke
Arnprior Kingston Perth

Barrie Kirkland Lake Peterborough
Beeton Manitoulin Island Renfrew

Belleville-Quinte Markham Stouffville Richmond Hill (Mandarin language)

Belleville-Quinte Early Onset Milton Sault Ste. Marie
Blackburn Hamlet Mississauga Scarborough
Bolton Napanee South Muskoka
Bracebridge Newmarket South Simcoe
Brampton Niagara St. Catharine's

Brighton North Bay Sudbury
Brockville North Muskoka Thunder Bay
Burlington North Simcoe Timmins

Collingwood North Toronto Toronto Adult Children Carepartner

Cornwall Northumberland Toronto Carepartners

Durham Region Oakville Toronto Central/Leaside

East District Early Onset Orillia Toronto Downtown

Embrun groupe de soutien Orleans English Toronto Newly Diagnosed

Etobicoke Orleans French Toronto North York

Guelph Orleans Carepartner Toronto PSP/MSA/CBD Carepartner

HaliburtonOttawa CarepartnerToronto Second DecadeHaltonOttawa Inner WestToronto Young Onset

Hamilton Ottawa Centre Vaughan

Hawkesbury Ottawa Newly Diagnosed Virtual Young & Early Onset

Huntsville Ottawa South Wellington

Kanata Ottawa Young & Active Winchester/Chesterville

Kemptville Parry Sound

Caring Community Helpers

Bolton / Burlington / Huntsville / Bracebridge / Toronto / Renfrew / Chesterville Hawkesbury / Etobicoke / Sault St. Marie

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



Parkinson Canada: Information and Referral Services

By Robert TerSteege

Parkinson Canada provides different forms of client services through local offices, but even people who aren't able to connect with a local office or support group have access to staff through our Information and Referral services. Trained professionals, from a variety of backgrounds in the medical and social service sectors, are there to respond to your questions via our central toll-free number, 800-565-3000, or by email info@parkinson.ca.

What is Information and Referral?

Information and Referral is all about bringing people in need together with the services in their community. You may not know where to start in order to get the help you need, and end up calling many places before connecting with the services you need. AIRS, the Alliance of Information and Referral Systems, says, "Information and Referral (I&R) is the art, science, and practice of bringing people and services together. When individuals and families don't know where to turn, I&R is there for them."

Professionals working in this field need to be able to provide mediated I&R: they need to create rapport with the caller, conduct an assessment of the person's needs and situation, provide an informed choice of referrals so people understand their options, engage in follow-up, and be capable of providing advocacy on a case by case basis. Though we are not a formal crisis service or distress line, staff are also trained in providing crisis intervention.

Why do people call Parkinson Canada for I&R?

You may think that calling for information is simply calling and saying I need information on XYZ, and getting XYZ. There is more to it than that!

Many people first dealing with a diagnosis of Parkinson's may have not heard most of what their doctor said. Some people have additional questions about the condition, symptoms, and medication. Sometimes what a person is experiencing may be embarrassing to talk about, and it is the professional's role to try and help the client clarify what the issue is. For example, many people are not comfortable telling a stranger they are constipated but ask for information on nutrition. A few questions later the staff person usually will identify what the issue is and be able to provide the information that is actually needed.

While we cannot provide individual medical advice, we do provide credible, up-to-date information on Parkinson's and care management. Our purpose is to meet the needs of Canadians living with Parkinson's by enhancing their knowledge in order to make informed decisions. We often follow up calls about Parkinson's disease with individualized information packages, filled with materials reviewed by our Medical Advisory Committee. We provide these packages at no cost to the individual.



What do people ask about?

People may have many more questions than "What is Parkinson's?" Many people are dealing with issues of employment, caregiving, insurance, taxes, or assistive devices. They may not know what sources of support are out there, as well as what programs they may be entitled to access. By getting a clear picture of what a person needs, we can often direct a person towards the services they are entitled to.

With the amount of information sharing available through the Internet, many people also contact us about claims on complementary therapies, breakthroughs reported in the news, and other things they have discovered online. Parkinson Canada will not endorse any specific product, service, or enterprise. We take pride in being able to share credible information. If we do not have an answer, we will do our best to source reputable information, so that people can make informed decisions for themselves.

Do you provide counseling?

The term "counseling" to the average person is used to describe a particular form of therapeutic relationship between an expert in a particular field like social work, psychology, or psychotherapy. This type of counseling is often an ongoing process that takes time to get to the end result. Unfortunately, we simply do not have the capacity to provide everyone in need with a counselor of this kind, but we may be able to make some suggestions if this is what a person is looking for.

We may be able to provide some supportive listening and feedback to people about their immediate situation, but would make a referral for that person to follow up on. For example, a person living with Parkinson's may not realize that they are dealing with depression and call us because they are overwhelmed. We would try to help that person realize that they are dealing with a symptom which is common and treatable ... provided that their doctor knows about it. We would try to let that person know that there are both medical and non-medical options. We may follow that up with the information in writing. We try to empower the person to take charge of their situation.

If you have a question about Parkinson's disease in general, or about your personal situation and aren't sure where to start, feel free to call or email us in confidence, and one of our I&R professionals will get back to you as soon as possible.

In His Own Words: Nathan Langille

By Anne McNamara

Tell us about your diagnosis; what was it like to hear the words "you have Parkinson's disease (PD)?" I was in shock. I went into the appointment because I was feeling really stiff and I was shaking a lot. I knew I had Parkinson's well before I was diagnosed but I was still in shock. I was 38 when my family doctor told me I had PD; I was 39 by the time I saw the neurologist.

You were diagnosed at 38; what different challenges do you face as a young onset individual? To start, it has changed my son—it has made him angry. My five-year-old son feels like he needs to be the 'man' of the house. It has been really hard for my kids to understand. It has also been stressful for my family; my wife worries about my career and how long I will be able to work. I also worry about losing my driver's licence and losing my independence.

How has living with PD changed your life? I am not sure if it has changed my life per se, but I do know that I don't want to go back to where I was when I was first diagnosed. I felt awful; I don't want my three-year-old son to have to pull me through doorways because I can't move.

What makes you happy? Seeing my kids smile. And showing my kids that I am healthy. Being at my work (Nathan works at an elementary school) with the kids makes me happy; supporting them in their school journey is really important to me.

Do you feel exercise helps with your motor and non-motor symptoms?

My wife says I don't complain as much about being stiff and my tremors don't seem as bad as they used to be. My mom has also noticed a difference in my tremors, especially in situations like today, being interviewed—I am calm.

How has boxing helped you manage your Parkinson's? Going to Rock Steady Boxing has really helped me; I like being with other people around my age and hearing their stories is really helpful. I've gained a lot of new friends and we support each other and that's important. They know I was a lot worse than what they see now; I've come a long way.

It's great to talk with others and feel part of a team and push ourselves. My boxing nickname is 'The Beast.' I often have a lot of anger and the heavy bag is a great way for me to get out my anger.

I understand you also walk a lot—why do you walk? I was given poles from a physiotherapist at Baycrest Centre; it all started from there. I started to walk short distances but found it too easy, so now I walk all over the place. I walk to work and back every day which is 11 km.

Did you walk before you had PD?

No, when I was first diagnosed the doctors told me I needed to exercise so I started walking. I don't ever want to go back to how I was feeling before, so I will walk a million miles if I have to.

How did you become involved with Parkinson's Canada? When I was first diagnosed my family and I visited Sandie Jones in the Toronto office to learn about how Parkinson Canada can support me and my family. It was good for my wife and kids to be able to talk to someone about their feelings. I went to my first Parkinson SuperWalk in Barrie in 2015 and have been involved ever since.

Tell us about this event you are planning called *Moving Together for Parkinson's*. I am going to walk 7,500 kilometres over a five-month period with some help from friends, family, co-workers, and hopefully some



Nathan Langille

people who are living with PD will join too. I hope to have some fun, get some exercise, and feel good about what we're doing.

What do you hope to accomplish on this journey? I want to contribute to a good cause and help 'us' feel better overall. I hope this journey will encourage others living with PD to talk about our disease and share how we are feeling.

Do you have any words of wisdom to share with others who have been recently diagnosed? Be patient. Wait until you get all of the information from your neurologist. When I was first diagnosed I thought I would never get better; I had so many horrible symptoms. I didn't realize that with the pills I would feel much better. You need to keep fighting.

The day I went down to Toronto to get my formal diagnosis I was shaking so violently in the car that the seat was shaking with me. The doctor had to strap me onto the table because I was shaking so much. I am not shaking like that anymore.

Moving Together for Parkinson's begins April 2, 2017, at Ferndale Park in Barrie. Proceeds will go toward programs and services offered by Parkinson Canada and the Parkinson Resource Centre.

14 In His Own Words

Jim Long and Hope in Bloom

In 1984, a group of dedicated volunteers began the Hope in Bloom campaign selling fresh cut tulips across the Greater Toronto Area (GTA) during the month of April to bring awareness to Parkinson's disease (PD). More than 30 years later, the Hope in Bloom campaign now raises \$150,000 a year while continuing to increase awareness about Parkinson's disease during April which is Parkinson's Awareness Month.

Hundreds of enthusiastic volunteers make this possible as they set out across Ontario and beyond to sell tulip bouquets and pots. All proceeds fund research, advocacy, and support for those affected by PD.

Jim Long is one of those dedicated volunteers. He has been volunteering with



the Hope in Bloom campaign, selling tulips for 30 years. He first got involved with Parkinson Canada after his sister was diagnosed with early onset PD. In helping his sister, he began attending meetings where he met the group of volunteers who started the campaign.

For the past 30 years he worked as a tulip captain, leading venue sales around the GTA. This year he's taking a step back as a captain but is involved in a different role—sharing his knowledge and experience with others who are new to the campaign. His knowledge and experience is invaluable and he has been a great resource to the Parkinson Canada team. Jim will also continue to volunteer at tulip sale venues in April.

Hope in Bloom is important to Jim for many reasons. On the forefront is creating awareness for the cause and raising funds to support research. In order to help improve the lives of Canadians living with Parkinson's, research is the first step. The Hope in Bloom campaign drives awareness and helps move us towards our goal of a world without Parkinson's disease. Getting out into the community allows us to speak to people who may not otherwise know where to get the information.

Speaking about his volunteer experience, Jim feels that not only do you end up with a good feeling, but you are also creating a sense of community with a group and a common goal. You are getting out into the community and spreading awareness to help people. He has used his knowledge and experience with Parkinson Canada to spread awareness not only through Hope in Bloom, but also with friends and members of his curling group. Parkinson Canada relies on the support of Jim Long and others throughout the year, and with the Hope in Bloom campaign specifically. If you would like to get involved, please contact Elisabeth Schoep, 800-565-3000 or elisabeth.schoep@parkinson.ca

Thank You

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



Your gift changes lives.

Together, we are creating hope.



donate.parkinson.ca/donate

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.



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LiveWire Wire 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. 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.

What We Do in Ontario

Research

The Parkinson Canada Research Program has invested more than \$26 million in 503 grants and awards since 1981 and funds innovative and novel research projects each year.

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.

Support

We provide consistent and excellent education to people living with Parkinson's disease and their families to help them live well through seminars and conferences held in different locations across the province. We also offer a number of webinars during the year and smaller sessions held monthly at our more than 50 support group and chapter meetings.

LiveWire

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