

LiveWire

 Parkinson Canada

ONTARIO

Life Lists Challenge

2016

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Parkinson SuperWalk
Pledge Form Inside!

Summer 2016



Happy Summer everyone!

I am so glad the postal strike held off so we could make sure this great issue got into your hands. This is our first newsletter that is being distributed throughout Ontario and I am now splitting my time between the Toronto and Ottawa offices so I can meet more of you.

As you sit back and enjoy reading LiveWire, don't forget to find a location near you (page 6) to attend our Ontario-wide Education Sessions being live-streamed to 16 locations in October. You will note that we are accepting art submissions for the 2017 Hope on Display annual calendar (page 9) and, of course, we hope to see all of you at a Parkinson SuperWalk in September (pledge form on page 12 and locations listed on pages 13 and 14).

Thank you for your continued support. It is a true privilege for us to work with, and be associated with, all of you.

Debbie

Who Are You Going to Call?

Find Help Near You in Ontario

1-800-565-3000

www.parkinson.ca

Debbie Davis,
VP, Mission & Managing Director, Ontario
416-227-3373/800-565-3000 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, RN, Coordinator, Client Services and Education
416-227-3375/800-565-3000 ext. 3375
sandie.jones@parkinson.ca

Robert TerSteege, Information & Referral Associate
416-227-3372/800-565-3000 ext. 3372
robert.tersteege@parkinson.ca

Angela Supino, Support Services Counsellor, Ottawa
613-722-9238/800-565-3000
angela.supino@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

Diane Newman Reed, Community Development Coordinator East
800-565-3000 ext. 3315
diane.newmanreed@parkinson.ca

Karen Dowell, Community Development Coordinator West
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Tamara Gagnon, Community Development Coordinator North
800-565-3000 ext. 3317
tamara.gagnon@parkinson.ca

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

Ginette Trottier, Community Development Coordinator, Ottawa
Coordonnatrice au développement communautaire
613-722-9238 ext. 201/800-565-3000 ext. 3329
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

Shauna Quinn, Events and Partnerships Associate Ottawa
613-722-9238/800-565-3000
shauna.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

You would like information on joining the Partners for Parkinson's Monthly Giving Program or making a donation to Parkinson Canada.

Alan Muir, Manager Resource Development Ottawa
613-722-9238/800-565-3000
alan.muir@parkinson.ca

Sue Rosenblat, Manager, Major, Planned Giving & Foundations
416-227-3386/800-565-3000 ext. 3386
sue.rosenblat@parkinson.ca



Life Lists Challenge

This May, participants took part in five 'Life Lists Challenge' events in support of Parkinson Canada. Ranging from 24 to 77 years of age, our participants took their philanthropy to the extreme with a new lens on event participation. After raising a minimum fundraising amount, Parkinson Canada's newest supporters jumped, dove, rode, floated, and soared with six creative events: skydiving, closed-track car lapping, hot air ballooning, ziplining, indoor skydiving, and bungee jumping.

Beyond its potential for new fundraising revenue, Life Lists Challenge is an event with heart. Participants were connected with a virtual partner with Parkinson's along the way who helped teach them about life with Parkinson's as part of their fundraising journey. Those partners included AB Rustin and Jamie Fobert, who met participants at the closed-track car-lapping day, with 77-year-old AB leaving with a hug from 30-year-old Matt (who had chosen her to partner with) and Jamie sharing an empowering message with participants: "The fight for us is daily, but the fight for everybody isn't over until the last person is cured of Parkinson's in Canada."

Looking ahead to the fall, there is another round of the same events scheduled in what is already being recognized (including articles in Metro News and fundraising benchmark publisher Peer-to-Peer Professional Forum) as an innovative new approach to making a difference. Jamie, AB, and our other partners will be back for 'Round Two' in October, introducing Parkinson Canada and the realities of Parkinson's disease to a new set of participants. Read the stories of all our partners at www.lifelistschallenge.ca and join them in the fall!



Why Should I See a Speech-Language Pathologist?

By Gillian Barnes M.A., RSLP, S-LP(C)
Speech-Language Pathologist
Movement Disorder Clinic
Deer Lodge Centre, Winnipeg, MB

Speech-language pathologists specialize in optimizing people's communication health, which includes assessing and treating speech, language, and swallowing disorders. Almost 90% of people with Parkinson's disease (PD) experience some type of difficulty with communication. Communication problems in PD may be related to the difficulties in coordination and initiation of the muscles used in producing speech. These challenges range from decreased volume of voice or a soft voice, monotonous sounding speech, breathiness, hoarse vocal quality and imprecise articulation, or slurred speech. Communication problems can impact a person's quality of life and should be addressed as early as possible.

Also, at some point in the progression of the disease, many individuals will experience difficulty with their eating or drinking. Aspiration is a symptom associated with swallowing problems or "dysphagia" and this can lead to complications. Other symptoms of dysphagia include, but are not limited to, weight loss, chest infection, and dehydration. Like communication problems, swallowing issues should be addressed early in the process.

If you or someone you care about is experiencing difficulties with communication or swallowing due to PD, ask your physician to refer you to a speech-language pathologist.

What is a Speech-Language Pathologist?

Speech-language pathologists (S-LPs) are highly educated professionals who have a minimum of a master's degree in their field. As in any healthcare-related profession, S-LPs are required to study anatomy and physiology, but they also study neuroanatomy, genetics, human and language development, linguistics, psychology, acoustics, and more, which is why they are qualified to evaluate, diagnose (restricted in some provinces/territories), and treat a broad range of delays and disorders.

Speech-language pathologists screen, assess, identify, and treat speech, language, voice, fluency (stuttering), swallowing, and feeding problems for all age groups, in addition to advocating for the prevention of these disorders. They work independently or as part of inter-professional teams in

hospitals, clinics, schools, rehabilitation centres, nursing homes, early intervention programs, universities, colleges, research centres, and private practices. You can find a S-LP near you at www.communicationhealth.ca or contact your provincial association or regulatory college.

What can I do while I wait to see the S-LP?

While you are waiting to see the S-LP, there are things that you can do take care of your voice and avoid complications with swallowing.

- Protect your voice with HYDRATION (keeping the vocal folds moist).
- Drink plenty of water each day.
- Limit caffeine and alcohol use, as they dehydrate the vocal cords and make them more susceptible to damage.
- Increase humidity to help lubricate the vocal cords, and use a humidifier.

Protect your voice by KEEPING YOUR VOCAL FOLDS FREE FROM THE FOLLOWING IRRITANTS:

- Smoking or constant exposure to smoke or other pollutants can irritate your vocal cords. Tar and nicotine can also cause changes in the blood supply of the vocal cords, making them more susceptible to damage.
- Acid reflux can irritate your vocal cords and lead to voice problems. The sensation of a lump in your throat, a sour taste, excessive phlegm, worse voice in the morning, and unproductive throat clearing/coughing are signs that you may be experiencing acid reflux. If you have these symptoms, talk to your physician about the possible presence of acid reflux.
- Chemicals and allergies can affect your voice. Some people may be very sensitive or allergic to specific chemicals or other irritants in the environment that may cause vocal fold swelling and/or increase mucous. If you think you may have allergies, speak to your physician about seeing an allergist.

~continued on page 14~



Vivre sa santé en français.

Par Ginette Trottier



Pas facile! En 1969, la Loi sur les langues officielles fait du français et de l'anglais les deux langues officielles du gouvernement fédéral. Cette disposition est confirmée par la Loi constitutionnelle de 1982 qui déclare : « Le français et l'anglais sont les langues officielles du Canada; ils ont un statut et des droits et privilèges égaux quant à leur usage dans les institutions du Parlement et du gouvernement du Canada. »

Pourquoi c'est important pour ceux qui vivent avec la maladie de Parkinson?

Il est important pour tous de recevoir les soins dans la langue de son choix. Parfois même, il faut insister. Comme la maladie progresse, il est possible que les facultés cognitives soient également affaiblies. Il peut alors devenir plus difficile de comprendre les directives des spécialistes qui communiquent dans notre deuxième ou même troisième langue. Les barrières linguistiques nuisent à une communication efficace qui est fondamentale à une relation de soin de qualité et ultimement à un meilleur état de santé. La langue est souvent le premier outil dans le maintien de la santé. En s'exprimant dans sa langue, un patient a plus de facilité à demander de l'aide, d'expliquer son vécu et sa condition, d'exprimer ses besoins et ses préférences et d'assumer la prise en charge de sa santé.

Plusieurs centres et établissements de santé en Ontario mettent des services à la disposition de la population francophone. Cependant, il existe toujours plusieurs défis, telles la disponibilité des ressources humaines francophones et la responsabilisation du système de santé. Par exemple, la continuité des services en français est-elle assurée d'un établissement à un autre ou d'un secteur à un autre? Est-ce que les francophones disposent de l'information sur les services en français?

Mais mon neurologue est anglophone et je ne veux pas changer de spécialiste.

En effet, il y a très peu de neurologues francophones hors du Québec. Cependant, plusieurs centres neurologiques, hospitaliers et médicaux emploient du personnel infirmier bilingue. C'est votre droit de demander et même d'exiger qu'une de ces personnes vous accompagnent lors de votre consultation pour faciliter la conversation avec votre médecin ou neurologue.

Une personne ne peut pas changer le système.

Faux. Laissez-moi vous raconter l'histoire de Mme Diane Dupelle. Diane habite à Hawkesbury, Ontario. Jeune mère de famille, elle reçoit un diagnostic précoce de la maladie de Parkinson. En 2014, elle communique avec Parkinson Canada exigeant des services dans la région d'Hawkesbury. « Les gens dans les petits secteurs ruraux francophones ont droit à autant de services que dans les grands centres urbains », affirme Madame Dupelle avec raison. Avec l'aide des Services communautaires de Prescott-Russell, elle rassemble les gens de la région pour assister à notre rencontre. Suite à plusieurs réunions dans la région, des services de soutien prendront naissance à Hawkesbury en septembre 2016. Donc oui, une personne peut faire changer les choses.

Vous avez aimé lire un article en français dans ce numéro? N'hésitez pas à nous en faire part. Pour continuer un dialogue en français, faites-moi parvenir vos idées de discussions pour les prochains numéros : au 1-800-565-3000 poste 3329 ou Ginette.Trottier@Parkinson.ca

Join Parkinson Canada on October 21 for Our Speaker Presentation

Dr J. Eric Ahlskog, M.D., Ph.D. The Nuts and Bolts of Parkinson's Disease Management

Cost: \$25.00 per person

**You can join us in any one of the 16 locations:
same speaker, same price, different location!**

Please plan to arrive at your chosen location by 9:30 a.m.

The presentation begins promptly at 10:00 p.m.

**Register at <http://donate.parkinson.ca/ahlskog>
or contact Diane at 800-565-3000 ext. 3315
diane.newmanreed@parkinson.ca**



We're going to finish the session with a question and answer period. If you already know what you'd like to ask Dr. Ahlskog, please send your question to diane.newmanreed@parkinson.ca by October 12, 2016.

Thanks to the generous support of:

abbvie

Join us at one of the following locations:

Ancaster: The Meadowlands, 1248 Mohawk Road West

Barrie: Hampton Inn, Opal/Topaz Room, 74 Bryne Drive

Belleville: Fairfield Inn and Suites, 407 N Front Street

Bracebridge: Quality Inn, Maple Meeting Room, 300 Ecclestone Drive

Brampton: Bramalea Retirement Home, 30 Peel Centre Drive

Guelph: St. Joseph's Health Centre, 100 Westmount Road

Manitoulin Island: Mindemoya Library, Ontario 542

Oshawa: Tosca Banquet Hall, 800 Champlain Avenue

Ottawa: Centurion Conference Centre, 170 Colonnade Road South

Peterborough: Peterborough Naval Association Admiralty Hall 24 Whitlaw Street

St. Catharines: Best Western, 2 North Service Road

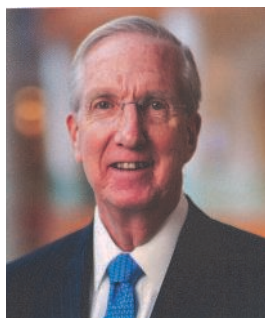
Sudbury: Lexington Hotel, 50 Brady Street

Thunder Bay: Lakehead University, Conference Centre, Bartley Building, 955 Oliver Road

Timmins: Cedar Meadows Resort, 1000 Norman Street

Toronto: Le Parc Banquet & Conference Centre, 8432 Leslie Street

Toronto: Novotel Toronto North York Hotel, 3 Park Home Avenue



Dr. J. Eric Ahlskog, M.D. Ph.D., is widely considered to be a leading authority on Parkinson's disease (PD) with more than 30 years of experience treating people with PD in the clinic. He has recently published a book called *The New Parkinson's Disease Treatment Book: Partnering with your Doctor to Get the Most from Your Medications*. He is a Professor of Neurology at the Mayo Medical School and Chair of the Mayo Section of Movement Disorders, Mayo Clinic, Rochester, Minnesota.

Frequently asked questions

By Dr. J. Eric Ahlskog, M.D. Ph.D.



What drugs should be avoided by someone with Parkinson's?

Medications that block dopamine receptors may cause the symptoms of Parkinson's disease (PD) and also block the effect of the medications used to treat PD. These include certain drugs to reduce nausea, notably metoclopramide (Reglan) and prochlorperazine (Compazine). Nearly all the drugs used to treat psychosis and schizophrenia have those same dopamine-blocking properties, such as haloperidol. Occasionally, drugs from this dopamine-blocking class are used to complement the treatment of depression, such as aripiprazole (Abilify). Note that the anti-psychotic medication, quetiapine (Seroquel), does not block dopamine receptors and can be used by those with PD.

What is “neuroprotective therapy” for Parkinson's? Is there any neuroprotective therapy currently available and if not, is there anything currently being investigated that looks promising for the future?

“Neuroprotective therapy” implies treatment to slow the disease progression. There are no drugs proven to slow the progression of Parkinson's disease. Note, however, that with the advent of levodopa therapy around 1970, the longevity of those with Parkinson's disease substantially increased, time-locked to levodopa availability (i.e., levodopa treatment was associated with living longer). Why? Most likely, the increase in lifespan related to the mobilization of a generation of Parkinson's disease patients. Without levodopa, they tended to progressively become sedentary and immobile, which was reversed.

Not to be overlooked in this discussion is the likelihood that ongoing aerobic exercise appears to slow the progression of Parkinson's disease. Although there are no clinical trials addressing this, there is a wealth of published scientific evidence to support regular exercise as the single strategy that may slow the PD progression. “Aerobic exercise” is any physical activity that tends to increase fitness and which tends to make you hot, sweaty, and tired.

Why do I sometimes feel worse for a while right after I take my medication?

If that medication is carbidopa/levodopa, the most likely explanation relates to a short-duration levodopa response (with wearing-off). Specifically, among those whose carbidopa/levodopa doses produce benefit only lasting a few hours after each dose, too long of an interval between doses will allow the benefit to end around the time of the next dose. If it ends before that next dose has a chance to work, there will be a gap in coverage.

Does speech therapy work and when should it be started?

The most common speech therapy strategy for treating the soft voice of Parkinson's disease involves loudness exercises. If there is associated imprecision of speech (i.e., slurring), then slowing the speech rate and more deliberate pronunciation is also emphasized. These can be helpful, but only as long as these speech strategies are consciously kept in mind.

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Be Ready to Speak Your Mind

By Sandie Jones, RN

Is it me or has technology worsened our ability to communicate? People email colleagues in the office beside theirs. On the street, people are texting with their heads down, oblivious to the world around them. Headphones drown out casual conversation. Because I love to talk, these things make me feel ignored and isolated!

How important is it to you to:

- Speak on the phone?
- Make an appointment?
- Talk to your kids/grandkids?
- Joke with friends?
- Say “I love you?”
- Be able to self-advocate?
- Call for help?
- Participate in discussion on your health and treatment?
- Live independently?

Twenty years ago, I was a community visiting nurse. One patient living with Parkinson’s disease (PD) still stands out in my mind. Although she had dealt with many motor and non-motor challenges, her biggest problem was that she had lost her ability to speak. She lived alone, so at times was completely cut off from life. Part of my job was to make phone calls for her: to her hairdresser, her doctor, Meals on Wheels. She had to move into a long-term care facility before she really needed to be there, simply because she couldn’t communicate. She knew if she had had taken speech therapy lessons she might have stayed in her home for several more years.

Think about the tools we use to communicate: voice, body language, and facial cues. All three of these tools are often compromised with PD. Gestures and facial expressions are less spontaneous, while a host of issues can occur with speech.

Research shows that 90% of people living with Parkinson’s disease (PlwPD) experience some speech problem. Just



like with everything else and Parkinson’s, everyone is different when it comes to speech problems. Some folks have a very soft voice which is often monotone and lacking expression. Other people have a hoarse voice. Speech festination can occur: this is when people stutter uncontrollably, or can’t pronounce their words clearly, sounding like their mouths are full of marbles.

Though there have been great improvements in treating PD in the 18 years I have been with Parkinson Canada, we still regularly get clients calling to say the following:

- “My voice is so soft, I have to repeat myself all the time.”
- “I feel left out of conversations.”
- “People don’t think I have anything worthwhile to say.”
- “I have to shout to be able to be heard.”
- “People have stopped listening to me.”
- “I don’t get invited out because no one can hear me.”

There are clients who call and are barely audible at all and we have to ask if there is a time of day when their speech is better. Worse are urgent sounding voicemails so garbled that we cannot understand the name or number to call back!

The problems which lead to bradykinesia (slow movement) and hypokinesia (small movements) in the limbs can also trigger speech disorders caused by reduced movements of the muscles in the respiratory system (breathing), and larynx (voice box), which reduces vocal loudness and clarity. A tremulous voice is just like the tremor in other parts of your body.

~continued on next page~

Another issue is that clinical observations suggest that people living with Parkinson's disease are unaware that their speech is getting softer and difficult to understand. Because of the amount of effort and energy required to project their voice, PlwPD think they are shouting when their voice is actually in the normal conversation range.

Frustrated people living with PD think "I don't have a problem. My spouse needs a hearing aid!" But because they can often speak normally if asked to speak up, their loved ones may also get frustrated!

So what can be done about these problems? There are numerous forms of speech therapy in the community, but not all conventional speech treatments are tailored to the specific needs of those with PD.

The Lee Silverman Voice Treatment (LSVT – Think LOUD) is the one that is best known, proven to be effective, and is a globally standardized treatment. Visit www.lsvtglobal.com to find a trained practitioner in your area.

There is an excellent webinar available that outlines many aspects of speech issues and goes into detail about LSVT and how you can access it. Visit Webinars under Resources in the Living with Parkinson's section of www.parkinson.ca.

The last point I want to share with you today is that if you don't use it, you will lose it. Medication can only help so much. Just like starting physical therapy and exercise for your motor symptoms, being proactive is important. PREHABILITATION versus REHABILITATION is the key. Speech therapy is intensive, expensive, and time consuming, and requires a great deal of commitment to practice on your part, but is an investment in your future.

Research shows that speech therapy is most effective for those in early or mid-stage PD. The earlier you obtain a baseline speech evaluation and speech therapy, the more likely you will be able to maintain your communication skills.

Communication is a key element in quality of life and can help you maintain confidence and a positive self-concept while dealing with all the other challenges PD can pose.

For more information, the following resources are available in printed or pdf format. Please contact Parkinson Canada at 800-565-3000 or go to <http://bit.ly/L0bX5o>

- *Enhancing Communication*
- *Parkinson's, Dementia, and Communication Challenges*
- *Voice and Parkinson's*

Showcase Your Creativity

The **Hope on Display 2017 Calendar** provides an opportunity for those with Parkinson's disease to showcase their creativity through artistic expression.

Each year, Parkinson Canada invites individuals to feature their art in our **Hope on Display Calendar**, inspiring hope for others.

If you are a person with Parkinson's, an artist of any kind (painter, photographer, jewelry maker, quilter, wood-worker, sculptor, etc.), and you would like to be considered for the 2017 calendar, please send us an email telling us a little bit about yourself and include an image of your art.

Deadline for Submissions: Friday September 2

File format: high resolution picture format (.jpg, .tif, .png, .ai, .psd; image file should be approximately 2 to 6 mb in size). **Send the files** (electronic image, where you live, plus a little background about your work and yourself) to Diane at diane.newmanreed@parkinson.ca





SuperHero Colouring Contest

1. Colour and personalize by drawing your own head.
2. Submit by Sept. 1 by mail or through our Parkinson SuperWalk Facebook Page.
3. Children's contest prize will be a SuperHero themed prize pack!

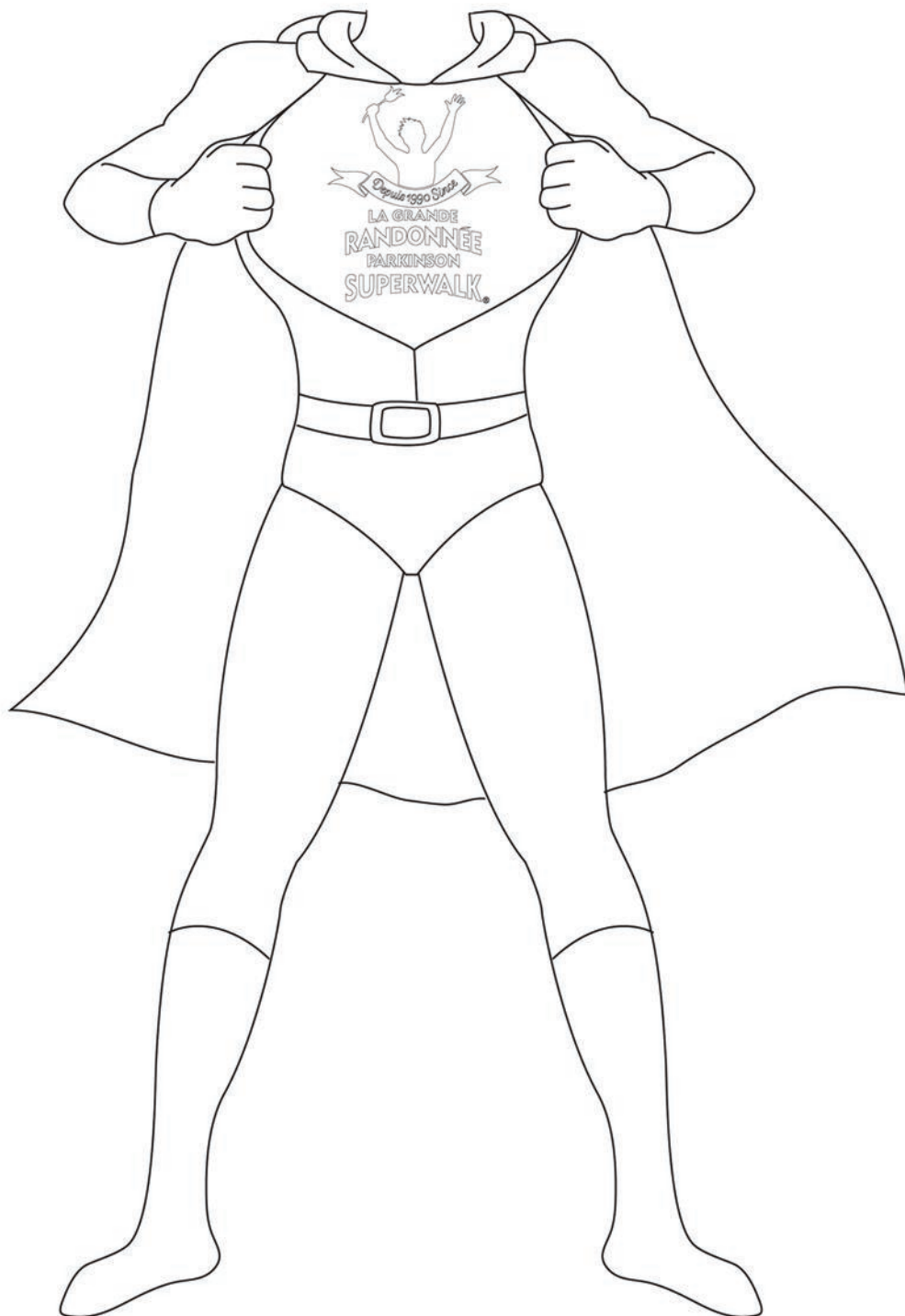
Note: there are 3 different age categories: 3-5 years , 6-9 years and 10+

DID YOU KNOW?

Colouring can help adults de-stress, relax, reduce anxiety and help with coordination and fine motor skills. If you don't meet the contest criteria, consider completing the page for some SuperWalk colouring therapy!

Mail to:
316-4211 Yonge St.
Toronto, ON M2P 2A9

EVERYDAY HEROES. EXTRAORDINARY HOPE.



FUNDRAISING FORM & WALK DAY INSTRUCTIONS

Register and fundraise using this form or online at www.parkinsonsuperwalk.ca

1. Complete the registration form and sign the waiver.
2. Print clearly and include full mailing addresses for your supporters.
3. Bring the completed form(s) and money to registration on walk day.
4. Cheques are payable to: Parkinson Canada or Parkinson SuperWalk.



PARKINSON SUPERWALK 2016 REGISTRATION FORM

WALKER INFO

Last Name _____ First Name _____ Walk Location _____

Address _____ E-Mail _____

City _____ Province _____ Postal Code _____ Telephone _____

Teams – Save time by registering online! ☐ I am part of a team Team Name _____

WAIVER

I agree that I am participating in Parkinson SuperWalk (PSW) voluntarily and do so at my own risk. I hereby fully release Parkinson Canada, the corporate sponsors of PSW, and any other parties connected in any way with PSW, as well as their respective officers, directors, agents, employees, staff and volunteers, from all claims or lawsuits for any injuries, death, property damage or theft, losses, or any other liability of any kind, arising directly or indirectly out of my participation in PSW or any of the activities associated therewith. I consent to being provided with emergency treatment in the event of my illness or injury during my participation in PSW, and agree to not hold Parkinson Canada responsible for any costs associated with such treatment. I consent to the publication and/or other use of my name, voice, photograph or other likeness without further notice or compensation in any publicity or advertisement carried out by Parkinson Canada in any manner whatsoever, including print, broadcast, or the internet. By signing below, I confirm that I have carefully read this Release and Consent and fully understand and agree to its contents.

Signature of Participant _____ Signature of guardian if under 18 years of age _____

INCENTIVE PRIZES Please indicate your preference below.

If neither box is checked, your fundraising incentive will not be sent and the money saved will be invested to help Canadians living with Parkinson's. You will be included in the National Draws for which prizes have been generously donated.

☐ NO, please do not send me fundraising incentives so that more money can be directed to services provided by Parkinson Canada. I will be included in the National Draws.

☐ YES, please send me incentives.

Incentives may vary by province. Roots gift cards not offered in all locations. Please contact us for more information.



DID YOU KNOW?

- Each day in Canada, more than 10 people are diagnosed with Parkinson's disease.
- By 2031, the Parkinson's population in Canada will double by 2031.
- Parkinson's is a chronic, degenerative brain disease that affects every aspect of daily living for those with Parkinson's and their families.
- The average age of onset of Parkinson's is 60, but it can affect people in their 20s, 30s or 40s.
- There is no known cause or cure for Parkinson's.



Need Help? Visit www.parkinsonsuperwalk.ca or call us at 1-800-565-3000.

PARKINSON SUPERWALK 2016 PLEDGE FORM

WALKER INFO

Last Name _____ First Name _____

Walk Location _____ Team Name _____

Twitter handle/user name (e.g. @superwalk) _____

Which age category do you belong to? ☐ Under 18 ☐ 18-25 ☐ 26-40 ☐ 41-55 ☐ 56-64 ☐ 65+

Gender: ☐ Female ☐ Male Do you have Parkinson's disease? ☐ Yes ☐ No ☐ Prefer not to answer

How did you hear? ☐ Family/friend ☐ Website ☐ Radio ☐ TV ☐ Newspaper ☐ Parkinson Canada ☐ Other

Including this year, how many years have you registered for Parkinson SuperWalk (either online or offline)? _____

Are you walking in honour or in memory of someone? Name: _____

PLEDGES Print clearly including full mailing address and postal code. If the information is incomplete, no tax receipt will be issued. Tax receipts will be mailed by February 28, 2017. Tax receipts will automatically be issued for all pledges \$20+.

NAME	ADDRESS REQUIRED TELEPHONE	CITY EMAIL OPTIONAL	PROV.	POSTAL CODE	PLEDGE
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ONLINE TOTAL					\$
Charitable Registration # 10809 1786 RR0001 Parkinson Canada 4211 Yonge Street, Suite 316, Toronto, ON M2P 2A9					TOTAL OF ALL PAGES \$

PRIVACY STATEMENT Parkinson Canada collects personal information to communicate with supporters about initiatives/ fundraising. By providing your information, you give consent to be contacted. For a copy of our privacy policy, please contact us.

THANK YOU FOR YOUR SUPPORT

Need Help? Visit www.parkinsonsuperwalk.ca or call us at 1-800-565-3000.

FIND A PARKINSON SUPERWALK NEAR YOU!



Saturday September 10, 2016

Alliston: Riverdale Park, Lion's Pavilion

Barrie: Heritage Park, Gazebo

Belleville: West Zwick's Park, Tom Gavey Pavilion

Bracebridge: Bracebridge Public School

Collingwood: Harbourview Park

Cornwall: Cornwall Civic Complex - Lamoureux Park

Guelph: First Christian Reformed Church

Kingston: Kingston Memorial Centre

Mississauga: Living Arts Centre

North Bay: Rotary Waterfront Pavilion

Oakville: RioCan Oakville Place

Ottawa: Ron Kolbus Lakeside Centre - Britannia Beach

Orillia: Emmanuel Baptist Church

Peterborough: Thomas A. Stewart School

Sudbury: Delki Dozzi Park

Toronto East: Asbridges Bay Park

Sunday September 11, 2016

Brampton: South Fletcher's Sportsplex

Brockville: Royal Canadian Legion Branch 96

Burlington: Burlington Senior's Centre

Durham: Ajax Rotary Park

Embrun: Parc Yahoo Park

Markham: Crosby Memorial Community Centre

Newmarket/Aurora: Fairy Lake Park

Niagara Region: Grantham Lion's Club

Northumberland: C.R. Gummow Public School

Renfrew: Ma-Te-Way Activity Centre

Timmins: Timmins Regional Athletic & Soccer Complex

Toronto North: Earl Bales Park

Vaughan: Vaughan City Hall

For more information on how you can get involved or host a Parkinson SuperWalk in your community, please contact Amanda Stanton at 800-565-3000 ext. 3371 or via email: amanda.stanton@parkinson.ca

FIND A PARKINSON SUPERWALK NEAR YOU!

OTHER DATES

Haliburton	Head Lake Park - Band Shell	Sunday September 18
Hamilton	St. Peter's Church	Sunday September 18
Huntsville	Robinson's Independent Grocer	Monday August 15
Kirkland Lake	Kinross Pond Walking Trail	Wednesday September 7
Manitoulin Island/ Mindemoya	Mindemoya Public Library	Thursday September 15
North Simcoe	Real Canadian Superstore	Thursday September 22
Parry Sound	Belvedere Heights LTC	Wednesday September 21
Sault Ste. Marie	Seniors' Centre	Thursday September 8
Thunder Bay	Intercity Shopping Centre	Saturday September 24

Check out www.parkinsonsuperwalk.ca for all locations across Canada.

Why Should I see a Speech-Language Pathologist?

~continued from page 4~

Protect your voice by KEEPING YOUR VOCAL FOLDS FREE FROM THE FOLLOWING IRRITANTS:

- Overuse of your voice during respiratory infections can damage your voice. Rest your voice when you are experiencing an upper respiratory infection (a cold) or if you experience hoarseness after excessive talking. Don't wait until you have "lost your voice" to stop talking/singing.
- Clearing your throat or coughing frequently causes the vocal cords to come together forcefully and may damage the tissue.

In general, to protect your voice, don't ignore symptoms of vocal strain, hoarseness, or pain.

Consult your doctor if you experience throat pain or hoarseness that lasts for more than 10 days. While the voice is usually able to withstand occasional trauma, continuous and recurring trauma/irritants may lead to changes in the laryngeal tissues, and result in the formation of nodules or polyps. Once tissue changes occur, persistent and sometimes worsening voice problems may result.

Here are a few general safe swallowing guidelines that can be implemented during meals and snacks:

- Take small sips of liquid and small bites of food.
- Avoid foods that can act like a cork and block the passage of air (such as grapes, olives, and cherries).
- Focus on the act of swallowing and limit distractions during meals.
- Make sure your mouth is empty before taking the next mouthful.
- Always eat in an upright position and remain upright for 20 to 30 minutes after meals and snacks.
- Good oral hygiene is important: clean your teeth and mouth after every meal and snack.
- If you experience a sudden increase in chest congestion or temperature, seek medical attention immediately.

Early intervention for both communication and swallowing difficulties is key; however, it is never too late to seek help.

PARKINSON AMBASSADORS

Parkinson Canada has launched an advocacy campaign in support of a Pan-Canadian Action Plan for the Brain. The goal of this plan is to ensure equitable access to affordable treatment options, support for caregivers, enhanced income security, increased investment research, the elimination of genetic fairness, access to integrated care, and increased access to specialists for accurate and timely diagnosis and management of Parkinson's disease.

If you believe this is important and could see yourself advocating for issues such as these, then you should consider joining our Parkinson Ambassador Network. People like you can help ensure that the voice of Canadians affected by Parkinson's 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.



Parkinson SuperWalk

Fundraising with a Twist for Parkinson SuperWalk

Mother and Daughter Giving Back

By Louise Rachlis

At last year's Parkinson SuperWalk in Ottawa, Suzy Wong made balloon creations for walkers as a way of giving back to Parkinson Canada, an organization helping Suzy and her mother Lai, who is living with Parkinson's disease, by providing information, support groups, and exercise classes.



Suzy Wong never thought she'd be twisting balloons at a charity fundraiser, but then again, she never thought she'd become a member of the Sandwich Generation before the age of 40 either.

A mother of two (Kendra, 4, and Kirin, 6), she and her husband Brent are also caregivers to Suzy's mother, Lai, 67, who was diagnosed with Parkinson's disease eight years ago and now lives with them. Suzy knows that as her children grow older and require less of her time her mother will need her more.

"My mom is quite a bit younger than most parents who can no longer live independently," said Suzy, 40. "My children were just six months and two years old when my mom moved in. It was a really tough time.

But Parkinson Canada helped us a lot in the beginning and we continue to benefit from their weekly exercise classes and monthly support groups," she said. "And they're a great source of information."

On top of working full-time and her family commitments, she and her family still volunteer at Parkinson SuperWalk each year, as well as fundraise for the cause. Last year, Suzy took up balloon twisting, making fun balloon creations for the young and young at heart at the Parkinson SuperWalk in Ottawa.

"Suzy has always been very supportive of our organization," said Shauna Quinn, Events and Partnerships Associate in Parkinson Canada's Ottawa office. "She's been fundraising, walking, and even volunteering at our Parkinson SuperWalk in Ottawa for years."

Parkinson SuperWalk is the largest national fundraising event for Parkinson Canada. Approximately 14,000 people from coast to coast organize and take part in Parkinson SuperWalk, this year on the weekend of September 10 and 11.

Parkinson SuperWalk in Ottawa takes place on Saturday, September 10 with registration beginning at 9:00 a.m. at the Ron Kolbus Lakeside Gardens, 102 Greenview Avenue. Other nearby walks include Cornwall, Renfrew, Brockville and Embrun.

For more information or to register for a walk near you please visit www.parkinsonsuperwalk.ca.

Does speech therapy work and when should it be started?

The most common speech therapy strategy for treating the soft voice of Parkinson's disease involves loudness exercises. If there is associated imprecision of speech (i.e., slurring), then slowing the speech rate and more deliberate pronunciation is also emphasized. These can be helpful, but only as long as these speech strategies are consciously kept in mind.

I am a caregiver for my spouse who doesn't seem to want to do anything unless I nag. Should I force him to exercise and socialize?

For some with Parkinson's disease, apathy and reduced motivation are part of the condition. Doing first things first, optimize carbidopa/levodopa and treat depression if present. Exercise is very important and should be encouraged but spouse-caregivers should avoid creating an adversarial atmosphere. Caregiving is usually hard enough without having battles.

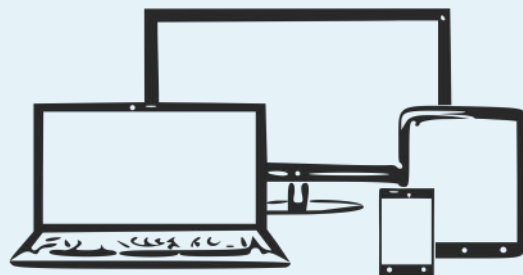
Are there any new medications currently in clinical trials that show real promise and what symptoms will they treat?

We need a medication that targets the cause of Parkinson's disease. We do not know the cause and that is the primary impediment to developing such a drug. The current research directed at alpha-synuclein seems promising and may ultimately generate such a medication.

Join Parkinson Canada at one of 16 locations on Friday October 21 to hear Dr. Ahlskog speak about 'The Nuts and Bolts of Parkinson's Disease Management' and don't forget to send in your questions in advance to diane.newmanreed@parkinson.ca.

New Young and Early Onset Virtual Support Group Starts in September!

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 is starting 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 will take place on the *fourth Monday of each month*, with the first meeting on Monday September 26 at 7 p.m. and pre-registration is required. 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 our first meeting, or if you have any questions, please email Diane at diane.newmanreed@parkinson.ca. *The group size is limited so be sure to sign up soon!*

Pietro Montemarano: A Love Song

When were you diagnosed with Parkinson's disease?

It was the year 2000 and I had a tailoring store with my business partner. One morning I went to work, sat down at the machine to do my job and my fingers started to shake; I was very worried. My business partner said, "you must go to the doctor." I went to the specialist and sure enough, he confirmed I had Parkinson's disease.

What was it like to hear "you have Parkinson's"?

At first, I was sad and very worried and the doctor had to change my medication many times. At that time, I told him I want to live another 10 years. He said, "Pietro, don't worry, you're going to live a long life." Getting diagnosed with something like Parkinson's is really hard on the family as well; you need to have a good support system.

How has living with Parkinson's disease changed your life?

When you have Parkinson's your life is going to be changed, forever. You must stick to taking your pills on time, every time, and then I can do almost anything. There are times when your body slows down and that's hard—you may feel at times like Parkinson's stops you. You need to take care of yourself; I do a lot of walking to stay healthy. Often, you can't project how the day will unfold, every day is very different. One thing I know is that you have to be positive, 100 per cent, and don't think about the disease.

What makes you forget that you have Parkinson's?

I started to write poems and that makes me forget I have Parkinson's, it takes away the worry and the pain. I turn poems into songs and that makes me happy, it makes me forget. When I have trouble sleeping, I start to write down the words and then I feel relaxed. My hobby is writing; I never thought as a tailor I would write but it is my gift of life.

What makes you happy?

Writing, creating, and being with my family and friends makes me very happy.

How did you get involved with Parkinson Canada?

I used to receive envelopes in the mail and I donated every year. One day, I walked into the Yonge Street office and asked for some information. I knew at that time, I had to get involved—it was very important to me. I had to find a way to do something different. I started to write down some words and came up with a beautiful song called *Amore Amore*; a friend of mine had a guitar and we wrote a beautiful song together. We turned the song into a video on YouTube and played it for our friends and family, they all loved it. *Amore Amore* gives us hope that everything will be okay. Funds raised from *Amore Amore* go to Parkinson Canada to help find a cure for this terrible disease. I have raised more than \$5,000 thus far (for more information and to listen to Pietro's song, go to donate.parkinson.ca/goto/pietro).

What has living with Parkinson's taught you?

When you have Parkinson's, your life is different and sometimes it feels like a bad dream. It's like changing religions; it's completely different. You need to accept it and get along with it—be consistent with medications and fight the disease. I fight it every day, I tell my body to listen, and I take the time to fight it. You have to stay busy; it's the best way to fight.

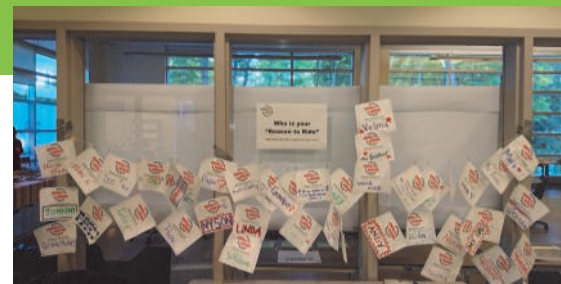
Do you have any words of wisdom for others who are fighting Parkinson's?

You can't quit life; you need to fight it early. If you have any concerns, go to your doctor right away. Live your life as you would normally; stay with your friends, have fun, love your family—do anything you need to do to fight. Sit down, spend 30 minutes alone. Think about which way to go; do I go positive or go negative? Imagine if you were given three months to live; with Parkinson's that is not the case. You may not always be happy, you will have some sad days but that's okay. I will do anything to combat this disease. The best thing I've done to fight is write a song and donate the funds raised from that song to Parkinson Canada.



Pedaling for Parkinson's

It has become a tradition at this annual fundraiser—now celebrating it's sixth year— for locals, cottagers, and city dwellers alike to take to the streets of scenic Parry Sound and area to Pedal for Parkinson's from July 15 to 17.



More than 250 riders, tackling a variety of distances and difficulties, ranging from 40 km to 120 km over one, two, or all three days, raised an impressive \$180,000 in support of the Parkinson Canada Research Program.

Event organizers, Peter Istvan and David Newall, continue to share stories of direct impact with their riders through the Pedaling for Parkinson Canada Parkinson's Research Grant. Last year's recipients, Drs. Frederic Bretzner and Austen Milnerwood, are already hard at work on projects focusing on the optimization of Deep Brain Stimulation and the pathophysiology of LRRK2, while this year's fundraising will support a minimum of two researchers in the next funding cycle.

The direct impact on research, and a growing sense of community, is what keeps riders coming back. Many of this year's participants have been there from year one, spending time on their bikes and at the BBQ on the patio at Canadore College, catching up with a group who are becoming old friends as much as recovering from the rigours of the day's ride. We, and they, know that it takes a community to make a difference in the lives of Canadians living with Parkinson's and our riders are forming one of their own... reminding one another, one pedal stroke at a time, that they and their family members are not alone on their Parkinson journey.



PUBLIC EDUCATION FORUM

New Parkinson's Treatment Options: Deep Brain Stimulation & Duodopa®

Key note speakers: Dr. Alfonso Fasano and nurse specialists from the Movement Disorders Centre of Toronto Western Hospital

Dr. Alfonso Fasano will be covering treatment options for later stages of Parkinson's disease.

Deep Brain Stimulation is an established surgical option used to treat Parkinson's disease. It may help reduce the amount of medication and improve symptom management. New selection criteria, including earlier placement, may open this option to more people.

Duodopa® is a new gel formulation of levodopa/carbidopa for people with more advanced Parkinson's disease which ensures a continuous delivery of medication throughout the day, demonstrated to increase daily on-time, and decreasing side-effects from traditional oral tablets.

Wednesday, September 28, 2016, 7:00 – 9:00 p.m.

This is a free event but advanced registration is required.

Hilton Garden Inn Ajax, 500 Beck Crescent, Ajax

Light refreshments 6:30 – 7:00 p.m. and the presentation begins at 7 p.m.

Register at: www.parkinson.ca/duodopaDBS

OR call Diane Newman Reed 800-565-3000 ext. 3315 or email diane.newmanreed@parkinson.ca

This Education Forum is made possible through an unrestricted grant provided by:

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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.



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>

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.

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www.parkinson.ca

800-565-3000

Charitable No: 10809 1786 RR0001

Did you know?

Each day in Canada, more than 25 people are diagnosed with Parkinson's disease.

Chaque jour, plus de 25 personnes reçoivent un diagnostic de maladie de Parkinson.

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

Support Services

We provide consistent and excellent support to people living with Parkinson's 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, 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

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