

parkinson SOCIETY
SOUTHWESTERN
ONTARIO

THE PARKINSON'S UPDATE

SUMMER/FALL 2022
ISSUE 76



Research

Page 8

Pet Therapy

Page 14

**Energy
Conservation**

Page 18

MISSION STATEMENT

Parkinson Society Southwestern Ontario enhances the quality of life and care for people living with Parkinson's in Southwestern Ontario.

BOARD

Brad Richards (Chair)
Alysia Christiaen (Vice-Chair)
Joseph Salamon (Treasurer)
Anthony Bender
Cam Crosbie
Chris Curry
Dr. Jeff Holmes
Matthew Mitchell
Janis Shkilnyk
Dr. Mandar Jog (Honorary)

STAFF

Shelley Rivard
CEO

Joanne Bernard
Manager of Administration

Kassie Harker
Education Coordinator

Mandy McDonagh
Programs and Services Coordinator

Dylan Murphy
Special Events Coordinator

Justine Travnicsek
Data Operations Specialist

Meagan Warwick
Community Engagement & Volunteer Coordinator

Mark Womack
Community Development Coordinator

Front Cover Photo:

John Geminari and his family at the 2021 Sarnia-Lambton Walk for Parkinson's. (back row left to right): Claudette Geminari, Louise Cooke, Paul Cooke and Tiana Cooke (Front row, left to right): John Geminari and Olivia Cooke.

FROM THE CEO's DESK

Where has the time gone! It is hard to believe that we are already into summer. We kicked off April awareness with our "I love someone with Parkinson's" campaign. It was our hope to share a positive message, letting those living with Parkinson's know how much we care.

Through a partnership with Mitacs, Parkinson Society Southwestern Ontario (PSSO) has been able to fund seven graduate students through the Graduate Student Scholarship Program. These students will each receive funding of \$25,000 to continue their research programs. *(Go to pages 8-11 for further information)*

We are also extremely grateful to announce that the Ontario Trillium Foundation (OTF) awarded PSSO \$97,500 through the Resilient Communities Fund to support our efforts to rebuild our resilience and capacity, building a healthy, vibrant Parkinson's community in Southwestern Ontario.

This year our focus is on building relationships. Mark Womack and I will be on the road once a month visiting our local communities. Our goal is to make sure that PSSO has a presence in each of these communities with funding agencies, sponsors, donors and clients. So far, we have visited Chatham-Kent, Sarnia-Lambton, Brant-Norfolk and Grey-Bruce. We hope to meet as many of you as possible, as we continue to make our way through Southwestern Ontario.

Over the last several years, PSSO has been working on a multidisciplinary approach to our support services. From support and exercise groups, Louder, Clearer with Speech Language Pathologists, Occupational Therapy through our Occupational Therapy Students, in partnership with The School of Occupational Therapy, as well as our Counselling Program, in partnership with King's College Western University, we are here to ensure the well-being in those living with Parkinson's.

Summertime for us means walk preparations are underway. Coming September 10th and 11th, we will be hosting 14 in-person walks throughout Southwestern Ontario. **Walk for Parkinson's** brings the community together across the region to support and raise awareness for those living with Parkinson's. Come for the walk, but stay for the fun, entertainment, refreshments, and of course those social interactions we have undoubtedly missed. If you are unable to walk, please come out and meet some new friends! Whether you walk, volunteer or just join us for the fun, we hope to see you this September!

Thanks to you, funds raised through **Walk for Parkinson's** help enhance our existing programs and allow us to create new ones that have an immediate impact on the lives of those living with Parkinson's. All funds raised stay local to support the work of Parkinson Society Southwestern Ontario.

Enjoy your summer and get ready to walk on September 10th and 11th, as we walk in support of those living with Parkinson's in Southwestern Ontario!

Who Will You Walk For?

Shelley Rivard

Shelley Rivard
CEO



Shelley Rivard



PARKINSON'S SUPPORT GROUPS

Brantford Second Tuesday of each month 2:00 pm – 4:00 pm	Kincardine Third Wednesday of each month 1:30 pm – 3:00 pm	South Grey-Bruce Carepartner Fourth Wednesday of each month 1:00 pm - 2:30 pm
Cambridge Second Thursday of each month 1:00 pm – 2:30 pm	Kitchener Fourth Friday of each month 1:30 pm – 3:00 pm	South Grey-Bruce Second Tuesday of each month 1:30 pm – 3:00 pm
Chatham First Wednesday of each month 3:15 pm – 4:45 pm	Leamington First Tuesday of each month 11:30 am – 12:30 pm	St. Thomas Second Tuesday of each month 2:00 pm – 4:00 pm
Coffee Klatch Every Monday at 10:00 am Virtual via Zoom	London Third Saturday of each month 2:00 pm – 4:00 pm	Stratford Second Wednesday of each month 1:30 pm – 3:30 pm
Dunnville Last Saturday of each month 1:30 pm – 3:00 pm	London Carepartner Last Tuesday of each month 1:30 pm – 3:30 pm	Strathroy Third Tuesday of each month 1:30 pm – 3:00 pm
Goderich-Huron First Thursday of each month 1:30 pm – 3:00 pm	Meaford Third Tuesday of each month 1:30 pm – 3:00 pm	Tillsonburg Third Thursday of each month 1:00 pm – 2:30 pm
Grand Bend Last Monday of each month 2:00 pm – 3:30 pm	Orangeville Fourth Wednesday of each month 1:00 pm – 2:30 pm	Waterloo Fourth Wednesday of each month 10:30 am – 12:00 noon
Guelph Second Thursday of each month 2:00 pm – 3:30 pm	Owen Sound Second Tuesday of each month 1:30 pm – 3:00 pm	Windsor Fourth Tuesday of each month 1:30 pm – 3:00 pm
Guelph Carepartner Fourth Wednesday of each month 2:00 pm – 3:30 pm	Sarnia-Lambton Fourth Wednesday of each month 2:00 pm – 4:00 pm	Woodstock Fourth Monday of each month 2:00 pm – 4:00 pm

**To connect with a support group, please contact us at
info@psso.ca or 1.888.851.7376**

Regional Office:
123-4096 Meadowbrook Dr, London, ON N6L 1G4
Phone 519.652.9437
Toll Free..... 1.888.851.7376
Fax 519.652.9267

✉ info@psso.ca
🌐 www.psso.ca
📱 ParkinsonSocietySWO
📷 parkinsonswo
🐦 ParkinsonSWO

Although we make every effort to ensure that the information in The Parkinson's Update is accurate, we cannot take responsibility for any errors or omissions. Information is sometimes taken from letters to the editor, submissions from the Internet or other print material. We make an effort to acknowledge all of our sources.

The information is not intended to take the place of professional medical advice. If you are a patient currently being treated and have questions, or if you think you have Parkinson's but have not been diagnosed, please seek the advice of a medical professional. This information does not replace consultation with your physician.

I Have Parkinson's But It Doesn't Have Me: Suzanne Hatchard

February 28, 2022 is a day we reminisce — a day in which we say goodbye to a wife, a mother. We look up to the sky and say “thank you” to one of the most influential volunteers and early contributors of Parkinson Society, a martyr of Parkinson’s disease (PD) in her own right, Suzanne Hatchard.

As a Seneca College graduate in 1971, Suzanne went on to become a registered nurse (RN) in her twenties. She practised in many different establishments until her last role in the Movement Disorders Clinic. It must have been fate, as she started to experience hand tremors, stiffness and even general fatigue during work in her early thirties.

Over the years she would undergo many evaluations and appointments with specialists. It is important to understand that during the 80's, it was particularly difficult for clinicians to recognize PD in the younger adult. At first, her symptoms were thought to be multiple sclerosis, until her official diagnosis in 1988 for Parkinson’s disease was determined.

Unable to work 12-hour shifts because of fatigue and progressive tremors, Suzanne had to resign from her hospital job. Though she had some limitations, they were not enough to break her down mentally. Quite the contrary. She resumed being a nurse while she was able and, amazingly enough, she became quite active in the community.

She started the London Parkinson Resource Centre at St. Joseph’s Hospital in London in 1988. She helped people navigate the challenges associated with Parkinson’s and founded the Young Onset Parkinson Connection Support Group. She created awareness of Parkinson’s and promoted the first Cut-A-Thon for Parkinson’s on a live TV news show.

Suzanne’s husband, Gary, still remembers when she introduced the powerful quote on a badge “I Have Parkinson’s But It Doesn’t Have Me!” By doing this, she empowered the Parkinson’s community and led by example.

Continuing her brigade for her fight against Parkinson’s, she was recruited by Dr. Stoessl to work at the UH Movement Disorders Clinic. New diagnoses were referred to Suzanne pertaining to Parkinson’s-related disorders. She did what she did best for these people — armed and empowered them with the knowledge to handle their disease; the notion that they were not alone in this journey.

On a national level Suzanne would spread this message even further. She was a regular contributor during the national annual neuroscience convention conference.

She would even speak in long-term care homes about the importance of administering medications at a specific time. Unfortunately, it was becoming more and more difficult for Suzanne to navigate her way to these facilities. The illness was progressing.

She hung up the scrubs in 1996. While she did retire from her career, she wasn’t done giving just yet. Suzanne would assume roles in the Young Onset Parkinson Support Group, as well as plan potlucks and charitable events.

Her community work took a momentary back seat when she received DBS (Deep Brain Stimulation) surgery in 2002.



For those who don't know, this surgery is quite invasive and requires the patient to be awake.

Dr. Andrew Parrent often consulted Suzanne to attend surgeries for patients who needed support during their procedures. She would also help educate and assist individuals with their indecisiveness about DBS surgery.

Her flower of contribution blossomed over whom she helped until she attended her last support group meeting in 2018.

Suzanne's volunteer diploma of distinction reads, "I would like to thank you on behalf of the citizens of our community for your dedication and selfless service to others."

Suzanne Hatchard embodies the notion that Parkinson's never had her. Quite the contrary. She continued to live her life despite the trials and tribulations involved. Parkinson's was present, but it was only along for the ride while Suzanne continued to cement her legacy — by endowed giving.

Forever strong in the community and on behalf of Parkinson Society Southwestern Ontario, R.I.P. Suzanne Hatchard. Your influence and contribution will never be forgotten.

.....
Written by
Steven Vrecic
Volunteer,
Tecumseh



2022 FALL REGIONAL PARKINSON'S CONFERENCE

October 22, 2022 | 9:00 am to 3:00 pm

SPEAKERS:



PARKINSON'S AND PROBLEMATIC ANXIETY - WHY, WHEN AND WHAT TO DO
Dr. Nicole Didyk,
MD FRCP(C)



NEUROLOGIC MUSIC THERAPY: REWIRING THE BRAIN THROUGH MUSIC
Sophia Christopher,
MTA, RP, NMT-F



IS GUT BACTERIA IMPORTANT FOR OUR BRAIN?: UNVEILING THE ROLE OF GUT MICROBIOME IN PARKINSON'S DISEASE
Dr. Olga L. Rojas,
MD, PhD



THE AFTERMATH OF COVID-19: HOW PARKINSON'S RESEARCH, REHABILITATION & CLINICAL PRACTICE HAVE EVOLVED!
Dr. Quincy Almeida PhD

LOCATION:

DoubleTree by Hilton
30 Fairway Rd S
Kitchener

COST:

\$50 per person for in-person or virtual.
Register early to reserve your spot.

.....
For more information, visit www.pssso.ca/events

A GIFT TODAY IS HOPE FOR TOMORROW...

To leave a legacy is to sow seeds for the future. To leave a legacy is to ensure that access to support services and educational opportunities remain available. To leave a legacy is to ensure that others that come after you have the opportunity to fight well.

We all want a world without Parkinson's, but until that day comes, we remain ready, able and willing to support the needs of today. A legacy gift makes that work possible.

Call 1.888.851.7376 for more information on leaving your legacy.

ASK THE EXPERT

Dr. Mandar Jog trained in Neurology and Movement Disorders at the University of Toronto and completed a post-doctoral fellowship in Computational Neuroscience at the Massachusetts Institute of Technology in Boston. Currently, Dr. Jog is a Professor of Clinical Neurological Sciences at Western University. He is the Director of the Movement Disorders Program at London Health Sciences Centre. The Clinic has received the prestigious designation of 'Centre of Excellence' awarded by the National Parkinson Foundation, Inc.



How do I best prepare for an appointment with a neurologist? Is there anything specific I need to prepare to share with you to discuss? How long should a normal appointment last?

A good history is the critical part of any consultation. Therefore, either the patient themselves or carepartner, should have as much as possible documented history on what has happened in the patient's life in general. This includes all relevant medical and non-medical events that have occurred. In addition, a medication history is critical. Many times medications have been discontinued and it is critical that the neurologist know all those medications, which could include psychiatric medications and not just neurological treatment. Other than that, there is not anything specific needed for the appointment. If there are language barriers, it is a good idea to have a family member who knows the patient and speaks English accompany them to the appointment.

New consultations last between 1½ hours to 2 hours. Community neurologists who don't have a teaching responsibility, in addition to the consultation that we do, might take less time. Of course, that depends on the complexity of the patient's condition and differential diagnoses we come up with. Most of the time, we don't do any advance testing in the clinic appointment such as MRI scans or CT scans. However, blood work might be required in some cases and we can send the patient to the hospital lab when they are seen at our centre, and this might take a little longer. In the community, outpatient requisitions have to be given since the laboratory for drawing blood is not part of an outpatient clinic.

I'm hearing a lot of Parkinson's patients talking about getting botox injections into areas other than their face (e.g., feet, arms). What are the advantages of a therapy like this, and how do I find out if it would help me with my symptoms (e.g., dystonia, drooling)?

Indeed, Botulinum toxins which have numerous vendors making them (Botox, Xeomin and Dysport) are approved for different indications. Most of the time, Botulinum toxin are not approved for Parkinson's disease treatment, for example tremor of feet and arms. It is approved for indications such as dystonia of the face and neck. Botulinum toxins are approved for spasticity which can involve arms and legs, but Parkinson's disease patients have rigidity, not spasticity. Therefore, injection of Botulinum toxins in those body parts is currently not approved.

However, it is important to know that physicians can and do regularly inject these body parts even though it is "not approved". The important thing is that the OHIP medical plan does not cover these off-label indications. Insurance companies do, depending on the plan, cover these in the arms and feet. Approved indications such as neck dystonia, facial dystonia are covered by OHIP for those over 65 and by all insurance third-party plans. Drooling has been approved for treatment with Botulinum toxins but specifically Xeomin. At the moment, coverage is somewhat sketchy in terms of the third-party insurance plans, but the OHIP coverage at the moment does not exist. However, the approval for injection has been granted by Health Canada.

I've heard a lot about Deep Brain Stimulation (DBS) from other Parkinson's patients. When do I become a candidate for this process, and what symptoms do I need to be exhibiting to be considered?

This is a difficult question to easily answer. To simplify, DBS is an advanced therapy procedure done in patients with Parkinson's disease who have two major symptoms, such as unpredictable fluctuations and dyskinesia that are not managed by oral medical therapy. The candidates for this procedure need to be cognitively intact, meaning no evidence of dementia. Formal testing is done by our team to determine this. In addition, the patient can't have any other reason why symptoms such as bad mobility is occurring, which would include conditions

such as bad back disease, or hip disease, chronic pain syndromes, none of which would improve with DBS. The main requirement to be a candidate is that the patient is very responsive to Levodopa and that the symptoms that are being considered for treatment must be responsive to Levodopa. In order to test this, patients are put through an “off/on” evaluation. During this evaluation, the patient is taken off Levodopa for usually 12-16 hours the day before, brought into our clinic for an “off” assessment and then a higher than normal dose of Levodopa is administered while we examine the patient over several hours. If this “off” to “on” switch produces significant improvement of symptoms and those are the symptoms bothersome to the patient, then the patient is a good candidate to be considered for DBS.

There are no specific symptoms that we target as long as they are responsive to Levodopa. However, usually falls and marked gait problems and even tremor can be unresponsive to Levodopa. Tremor is not considered an exclusion criterion because despite its lack of response to Levodopa, it is the one symptom that DBS can improve. However, falls, gait problems, choking, swallowing, cognitive or mood, if not responsive to Levodopa, won't improve and can even worsen after DBS.

I hear people talking about certain chemicals or ingredients in food that I should avoid. What can you tell me about this?

There really aren't any chemicals or ingredients in foods that are toxic for Parkinson's disease. You may have heard the interaction of protein, which is definitely true. Levodopa is a large neutral amino acid and you have to be very careful to not consume any proteins with the pills for about an hour or so after. This is because many things such as beans, lentils, chicken, eggs and milk can interfere with absorption of Levodopa. Therefore, proteins should be taken at different times from Levodopa. Other than that, there is no requirement for certain chemicals or ingredients that you should avoid in Parkinson's disease .

I'm beginning to have swallowing difficulty and understand that this can be treatable. How would I go about being evaluated to get the necessary treatment?

Swallowing difficulty is a well-known problem in Parkinson's disease. This is evaluated by speech and language pathologists and your family doctor can make a referral to get an evaluation done. Bedside evaluation can be done for some who are significantly disabled and non-ambulatory, but this is not as good as having a full investigation done by a speech pathologist.

Most of the time the recommendation will be to modify the diet for patients with mild swallowing difficulty. For example, moistening dry foods or drinking thicker liquids are some simple things to be done. However, if swallowing difficulty progresses, the patient has to be prepared to take more aggressive measures which are recommended by the speech and language pathologist after the speech assessment is done.

If you have a question for **Ask the Expert**, please email info@pssso.ca. Although all questions will be considered, we cannot guarantee that your question will be published.



Kassie Harker, Education Coordinator

Kassie comes to PSSO with over 15 years of healthcare facilitation and education experience as a regulated healthcare professional. Working in a variety of healthcare settings and sectors has provided her the experience and knowledge in inclusively designed health and wellbeing promotion. Kassie is passionate about developing accessible and effective educational initiatives and opportunities that reduce barriers to accessing beneficial health resources and foster improved quality of life across all aspects of health and wellbeing. She is honoured to be a part of the PSSO team and develop educational events, information and resources to support the variety of Parkinson's journeys.

Graduate Student Scholarship Program

Parkinson Society Southwestern Ontario Graduate Student Scholarship Program is a strategic initiative to encourage young scientists to enter the field of Parkinson's research and to invest in research and training that offer promise for future work in the area of Parkinson's disease.

Through a partnership with Mitacs, PSSO has been able to fund seven graduate students through the program. These students will each receive funding of \$25,000 to continue their research programs.



RESEARCHER: Cody Caba, University of Windsor

PROJECT TITLE:

Regulation of Ubiquitin Specific Protease 8 (USP8) by AMPK-Mediated Phosphorylation

Parkinson's disease (PD) affects greater than 1% of people over 60 and is the second most common neurodegenerative disorder. PD diagnoses are predicted to double in the next 20 years, thus highlighting a critical socioeconomic need to identify the cellular components and pathways responsible for onset and progression. A major goal is to expand the available therapeutics and to develop novel prophylactic strategies. We have recently identified two enzymes, USP8 and AMPK, that interact and may be directly involved in PD-associated mechanisms. AMPK primarily functions as a metabolic energy sensor for cells, helping to regain homeostasis under low energy or stress conditions. AMPK may be linked to PD through its ability to orchestrate specialized autophagy, the removal of damaged cellular components. Similarly, USP8 is also a PD-associated target as it has been shown to contribute to the formation of Lewy bodies, the pathological plaques in the neuronal tissue of the brain—a hallmark of PD.

Using a multidisciplinary approach, my work aims to characterize the AMPK-USP8 interaction to determine its role in PD and associated cellular processes. We believe AMPK regulates the activity of USP8 directly. Such disruption contributes to pathological states resembling PD phenotypes. These novel findings will shed light on a new regulatory axis and a potential target system of significance to PD patients.



RESEARCHER: Madeline Gilchrist, Western University

PROJECT TITLE:

Developing Diagnostic MRI Biomarkers for Parkinson's Disease

PD is a progressive disorder that is known for its motor symptoms like slowness of movement and tremor. These symptoms are caused by the death of cells in the brain that produce the chemical dopamine. The symptoms of PD are extremely variable between patients, and there are many disorders that resemble PD in the early stages of the disease. This causes patients with similar disorders (e.g., essential tremor) to be incorrectly diagnosed with PD and referred to a movement disorder specialist for treatment. It is essential to improve the specificity of diagnostic tools available to physicians. This will prevent patients from receiving the wrong treatment, unnecessarily taking up limited spots to see specialists and being incorrectly recruited into clinical trials for PD which compromises the validity of the results.

Therefore, this study aims to identify biomarkers (i.e., indicators) of PD onset and progression that can be seen with Magnetic Resonance Imaging (MRI), which will help physicians differentiate PD patients from healthy people, as well as patients with essential tremor. Twenty patients from each patient group and twenty healthy controls will be recruited for this study. The MacDonald and Khan labs have developed a novel MRI technique to identify changes in volume and structural connectivity in the striatum and SNc/VTa. This reliably differentiates PD patients from healthy controls with unprecedented accuracy. As an extension to this research the current study will test the ability of this MRI technique to differentiate PD from other movement disorders with the hopes of providing physicians an accessible and reliable diagnostic tool.



RESEARCHER: Bahaaldin Helal, Western University

PROJECT TITLE:

Predictive Phenotyping of Alzheimer's and Parkinson's Disease from Multifactor Biomarker and Neuroimaging Data

Individuals diagnosed with either Alzheimer's disease (AD) or PD typically exhibit a distinctive profile of progressive impairments. AD primarily affects cognitive functions (e.g., dementia), whereas PD affects motor functions (e.g. tremor). However, in many cases, this symptomatic distinction is not apparent, because some AD and PD patients experience a mixture of cognitive and motor functions of varying severities. These observations have called into question our current definitions of AD and PD as being two separate diseases. An alternative framework proposes that AD and PD may represent extreme phenotypes of a continuum where mixed AD/PD subtypes lie in the middle. To test this, I will obtain longitudinal neuroimaging, protein pathology and clinical test data of AD and PD patients from the Alzheimer's Disease Neuroimaging Initiative (ADNI) and the Parkinson's Progression Markers Initiative (PPMI), respectively. Then, I will use a novel data integration technique, called similarity network fusion, to combine all the different data types, producing networks of patients who share common patterns in their data. I expect to see unique clusters of patients corresponding to the distinct disease subtypes. Overall, my findings may reveal novel links between the different mixed subtypes of AD and PD and their underlying mechanisms, ultimately leading to developing better intervention strategies for these diseases.



RESEARCHER: Sarah Kearsley, Western University

PROJECT TITLE:

Investigating the Feasibility of Temporal Interference Stimulation for Humans

Deep Brain Stimulation (DBS) is a useful technique for clinicians and can be used to help improve symptoms of various neurological diseases, including PD. DBS involves implanting an electrode deep into the brain. This procedure has a small but serious risk of complications, such as hemorrhage and infection. Recently, a new stimulation technique, called temporal interference stimulation, has been developed. In the mouse, temporal interference stimulation can target deep brain structures without activating the overlying brain regions. This technique involves using two electric fields, that on their own do not affect brain activity. However, within a small region of the brain, where the two fields interact in the ideal way, the interaction of these fields can influence brain activity. While the work in mice is promising, whether it will work in humans is unclear, given differences in brain size and skull thickness. Using a combination of computational and experimental techniques, my research aims to investigate whether temporal interference stimulation will be feasible in humans. If so, this new stimulation technique may hold promise as a new treatment technique for people living with PD.



RESEARCHER: Benson Law, Western University

PROJECT TITLE:

Statistical and Ethical Implications of Pimavanserin Drug Trials Published with Unexplained or Missing Datasets on Parkinson's Disease

PD may present an array of symptoms, ranging from rigidity, tremors, psychiatric disorders and sleep issues. Levodopa remains the primary drug prescribed to manage PD. However, its use is accompanied by many side effects, one of which is PD psychosis. The complementary use of antipsychotic medications remains contested, with their use related to the worsening of PD. In 2016, a new medication called Pimavanserin was approved by the Food and Drug Administration (FDA) through their accelerated approval process, with the aim of overcoming prior shortcomings of antipsychotic medications. Many patients and their families may have heard about Pimavanserin and expressed interest in having it approved in Canada.

Although Pimavanserin performed well in drug studies initially, there are now questions emerging as to its safety and efficacy. An independent organization called the Institute of Safe Medicine Practices (ISMP) published a report in 2017 raising concerns as to the validity of the Pimavanserin drug trials. They cited that hallucinations (21.8%), drug effectiveness (14.9%), confusion (11.5%), and death (10.9%) as the most frequently reported adverse events related to the drug.

This project's primary aim is to examine in further detail the statistical rigour of Pimavanserin's drug trials. This will help to better understand whether Pimavanserin is safe for Canadians, and if it should be considered for approval as a treatment option. As well, a secondary aim of this study is to examine the utility and ethical implications of the FDA's accelerated approval process.



RESEARCHER: Samantha Marshall, Western University

PROJECT TITLE:

Mobile Brain Imaging and Mobility in Parkinson's Disease

Attention, an important aspect of human cognition, is needed for safe mobility and navigation through the environment. With age, the ability to move and navigate through the world requires greater cognitive resources. Previous brain imaging research in older adults and adults with PD have shown that mobility impairments are associated with reduced attention. However, previous research was limited to assessing attention while participants were immobile and/or in unnatural settings, such as the laboratory. This does not necessarily translate to what would occur in the real world. Mobile brain imaging techniques have made it possible to observe brain activity outside standard laboratory environments while participants are in motion. My research will use mobile electroencephalography (EEG) to compare brain activity across laboratory and real-world environments. In the naturalistic setting, participants will walk outside while their brain activity is recorded by a mobile EEG headband. Participants will be required to pay attention to natural occurrences in the environment, such as pedestrians, curbs, crosswalks and various forms of transportation. Brain activity will be compared between younger adults, older adults (with and without a history of falls) and adults diagnosed with PD. The findings from my research have the potential to expand current understanding of brain function in PD, human mobility and risk of falling, using real-world methods and technology.



RESEARCHER: Alaa Taha, Western University

PROJECT TITLE:

Indirect DBS Targeting Using Anatomical Landmarks and Machine Learning

DBS involves the constant delivery of electricity applied via electrodes to specific regions within the brain. It is performed to manage motor symptoms of PD like stiffness, slowness and tremor when medications become less effective. In DBS, deviations in more than 2 millimeters from ideal electrode position can lead to suboptimal therapeutic benefit (up to 60% difference in some cases). For some of the most common DBS targets used to treat PD (e.g., subthalamic nucleus), imaging acquired at the clinic pre-operatively does not allow for their clear visualization in relation to other surrounding regions. This makes it hard to accurately place DBS electrodes. It is like trying to plug in your charger with the lights turned off. In the same way you can navigate a dark room by identifying known landmarks (perhaps the edge of the table or chair), we plan to help surgeons find the DBS targets of interest by relating them to 32 points in the brain. This can be found very easily on pre-operative imaging (we call them anatomical landmarks). We also plan to use a powerful magnetic resonance imaging scanner (with a 7 Tesla magnet), available at the Robarts Research Institute in Western University, to develop an automatic tool to help find DBS targets in relation to the 32 landmarks. This tool will help surgeons that have lower quality imaging to still perform DBS with high degree of accuracy.

Thank You to our Research Partners!

The way to find a cure for any disease is through research and in 2022, PSSO is proud and thankful to partner with Mitacs, Equitable Life of Canada and Western University's BrainsCAN. Thanks to our research partners, it has been possible to fund a record number of scholarships this year with PSSO's Graduate Student Scholarship Program.

In partnership with Mitacs we were able to fund seven projects between Western University, University of Windsor and Parkinson Society Southwestern Ontario.



Equitable Life of Canada provided a \$10,000 education grant to help students advance their research towards an eventual cure for Parkinson's disease.



Our collaboration with Western University's BrainsCAN initiative led to the Mitacs partnership and also resulted in the highest number of Western research applications to date.



*If you are interested in becoming a Parkinson's research partner, please contact **Shelley Rivard** at shelley.rivard@pssso.ca or **1.888.851.7376 extension 201**.*

Carepartner Loneliness

Feelings of loneliness can be common among carepartners of individuals with Parkinson's disease. If you are struggling with loneliness, know you are not alone and that what you are feeling is completely valid. Changes to your typical routine after receiving a Parkinson's diagnosis can take time to adjust to. Juggling a new set of responsibilities as a carepartner while letting go of activities you previously engaged in, can lead to the development of loneliness. Acknowledging these feelings and taking action when they occur is critical to prevent your physical and mental health from being negatively affected.

The saying "you cannot pour from an empty cup" is especially relevant as a carepartner. Although it can be easy to place priority on your loved ones and their needs, neglecting yourself in the process can be harmful. The best thing that you can do for yourself and the individual that you care for is to ensure that you are caring for yourself first. In this article there are several recommendations on how to combat feelings of loneliness and boost your self-care activities.

Take advantage of support groups

Support groups are a valuable resource and can be especially beneficial for care partners. Spending time with other individuals who share similar experiences to you can offer validation that you are not alone in what you are feeling. While providing an outlet for support and advice, support groups additionally help you to connect and engage with others. Consider exchanging phone numbers with other members of the group whom you can call or visit in times of need. PSSO offers support groups across southwestern Ontario. Please reach out to find a group in your location (*see page 3*).

Asking for help and accepting it

Recognizing what you can and cannot do on your own and knowing when to ask for help is not a sign of weakness, but rather a key strength. When you recognize those early warning signs, reach out to your support system and ask for help. It is likely that your friends and family want to help you but they are unsure how. When someone asks if they can support you, be sure to say yes and be specific about what your needs are. Asking for assistance with some of your responsibilities can help offload your busy schedule and provide extra time for you. If your feelings of loneliness become overwhelming, consider the option of speaking to a professional about it. PSSO is here to support you and can assist you in getting connected to the help you need.

Take time to self-reflect

When you start feeling lonely, take some time to check in with yourself. It is likely that when these feelings occur, your needs are not being met adequately. Whether you need a call with a friend, encouragement from a support group or a visit with family, bringing awareness to these needs will equip you with the tools to cope with these feelings. Taking regular breaks to breathe, to get some space and to reflect, can be a great first step in improving your self-care. If journaling interests you, set aside a few minutes each day or week to write down everything you're feeling. These journal entries can help identify triggers and early warning signs of loneliness.

Schedule time for yourself

While time away from your loved one may seem challenging and cause feelings of guilt, finding time to connect with others and connect with yourself is so important. If you have a busy schedule, plan ahead and allocate time for yourself. Use this time to meet with friends and family or engage in activities outside the home that you love. On days when you feel you are unable to leave the house, schedule phone calls or Zoom calls and engage in activities available to you.



Karlee Pringle has finished her first year of the Master of Occupational Therapy Program at Western University. Karlee has an interest in following a client-centered and strengths-based approach to practice, enabling individuals to engage in the occupations and activities that are meaningful to them.

Losing Words

Parkinson's Disease (PD) can cause several impairments in cognitive function, as it is a degenerative disorder of the brain. Some of these impairments include problems with finding words, where people can "lose" their words while talking, mix up wording or use the wrong words when speaking. Individuals with PD may increase their use of circumlocutions to accommodate for these word-finding problems. This involves describing characteristics of an object, event or action without specifically saying the exact name for that object, event or action. It can feel like the words you want to say are on the tip of your tongue, but you just cannot recall the precise word. For example, someone may have difficulty thinking of the word "glove" and may say, "what you wear on your hands to keep them warm" as a circumlocution. Word-finding problems can also include using empty phrases or pronouns, such as "it" or "him/her/them" instead of saying the name of the person or object. It is important to note that the words are not lost, as there is no evidence that vocabulary loss is a part of normal aging or PD.

As people age, it is normal for us to process information slower, have a reduced processing capacity, and struggle with word-finding. Chemical changes and memory abilities start to diminish, making it more difficult to retrieve words. Strokes, head trauma, tumors and dementia are also known causes of word-finding problems. With regards to PD, the reduction in dopamine which leads to motor deficiencies also causes cognitive impairments. Without enough dopamine, slowness of the working memory, motivation, attention and learning occurs. Together, this makes it challenging for individuals with PD to convey their intended words when they are communicating with others. There are different strategies that individuals with PD and their loved ones can use to alleviate these communication difficulties.

Individuals with Parkinson's Disease can:

- Read every day to increase their vocabulary and word fluency
- Match names to faces of their friends and family
- Practise how many words they can name starting with any letter of the alphabet
- Use crossword puzzles
- Name objects that they see around them
- Do aerobic exercises to allow more oxygen and nutrients to enter the brain. Exercise also allows brain cells to use dopamine more efficiently.

These are important steps to take for carepartners and individuals with PD, in order to stay connected with each other. If more care is needed, a Speech Language Pathologist can teach additional strategies to aid with difficulties in finding words. These same strategies are often used to treat individuals with aphasia who suffered from strokes, as they display the same cognitive impairments that reduce communication abilities. Overall, communication

should be treated as a partnership. With the right tools and strategies, communication can become more effective and less frustrating for those living with PD and for their loved ones.

Miranda Rodrigues is from Mississauga and is currently in her third year at Western University. Miranda is enrolled in the Health Sciences program with an Honours Specialization in Rehabilitation Sciences.

References: 1. <https://www.ageility.com/sites/default/files/inline-files/Common-Word-Finding-Problems-as-We-Age.pdf> 2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3049172/> 3. <https://choruscare.ca/communication-tips-for-aphasia/> 4. https://www.parkinson.ca/wp-content/uploads/Effective-Communication_2017.pdf 5. <https://www.parkinson.org/sites/default/files/attachments/Cognition.pdf> 6. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4684895/> 7. <https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Cognitive-Changes>

Carepartners and family members can:

- Choose times of the day when the individual with PD is not experiencing day-time sleepiness, anxiety or depression
- Minimize distractions such as the TV or radio
- Speak slowly, clearly and carefully
- Ask close-ended questions, so they can simply answer "yes" or "no"
- Use gestures and actions while speaking
- Be aware of the person's body language to determine their mood or emotions



Parkinson's and Pet Therapy

When one is diagnosed with Parkinson's Disease (PD), there can be an immense variety of emotions which arise within them, their friends and family. Such emotions in response to the depressive burden of a neurodegenerative disease can sometimes be more prominent than the physical and cognitive symptoms related to the disease itself. There are a variety of medical treatments (such as pharmacological treatments) and lifestyle modifications (such as exercise) which an individual can adopt to slow the progression of the disease. However at times, it may be one positive change to solve a different struggle in life that can have a chain reaction and be of indirect benefit to treating symptoms of a disease such as PD.

Animal Assisted Interventions (AAI) are an incredible representation of such effects. From horses to dogs or even a home aquarium with some fish, animals have been seen to complement and amplify the effects of other treatments present for a particular neurological disorder such as PD (Muñoz Lasa et al., 2015). If you think an animal could be of great benefit for yourself or a loved one with PD, there are multiple resources available. CertaPet (<https://www.certapet.com/>) may be a great place to start if you want to identify what's best for you through the advice of a mental health professional. They have an efficient 3-step process so you can identify the right emotional support animal for you and acquire the proper documents so the animal can be brought into regions where normal pets usually would not be allowed. You can also use CertaPet to get solely the documentation required to cover a pet you may already have.

Notably, dogs can have an incredible impact in the lives of people who struggle with PD. They can help with daily tasks or simply initiate lifestyle changes which help slow the physical symptoms in addition to cognitive impairments associated with PD.

Service dogs are one route which one could take to improve quality of life, as they can be not only a loyal companion but one who is trained to aid an individual with PD in specific ways. One individual explains how her service dog can help her initiate her first strides by pulling forward on a harness which she holds (Parkinson's Foundation, 2019).



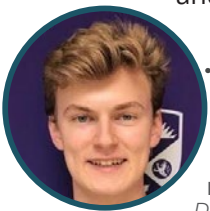
In the event she falls, her service dog can either alert someone of the incident if serious or, in minor cases, the dog can stand rigidly beside her and can be used as support for standing back up and regaining stability.

A fantastic resource if you would like to investigate potentially getting a service dog is Assistance Dogs International (<https://assistedogsinternational.org/>). They have three certified locations around Southwestern Ontario: Cambridge, Brantford and Oakville. Head to their website to find out about possibly getting a professionally trained dog that can help you daily with things such as walking, which can be impaired in PD patients.

If a service dog feels slightly too formal, don't worry. Please know even getting a dog which is not trained professionally can have huge benefits for PD patients, their family and friends. It is scientifically proven that dogs can have mental and physical benefits for a range of neurological disorders including PD (Boldig & Butala, 2021). Not only are dogs cute companions, but they also have energy and can initiate individuals with PD and their families to get outside for daily walks. Simply put, getting some exercise every day walking a dog has a chain reaction in improving mental health and fitness, lowering blood pressure and reducing stress. All of this can ultimately alleviate the severity and progression of PD symptoms (Boldig & Butala, 2021; da Silva et al., 2018; Kramer et al., 2019). One case study speaks about a woman who, after receiving a puppy, was able to set her mind on taking care of this dog, which reduced her depression (Zakeri & Bain, 2010). Over time as she walked the puppy daily, her walking and stability impairments from her early onset PD were alleviated to the point where she was able to reduce her medication!

As Boldig and Butala (2021) state best in their review of pet therapy interventions, "Dog therapy and ownership is a safe and effective non-pharmaceutical option that may improve symptoms of chronic and progressive neurological conditions, patient psychology and enhance well-being." Every individual will struggle with PD in a unique manner, and all are at different stages in life. However, if a dog may seem like a resource which could be beneficial, don't be afraid to reach out to some of the organizations mentioned to explore the possibility further.

Finally, another great resource is The Service Dogs (<https://theservicedogs.com/service-dog-ontario/#where-can>) which outlines the different types of dogs that are trained and labeled in certain ways to treat a particular condition. They also outline the eligibility criteria for applying and give countless options on how to obtain the dog that would be best for your unique situation with PD. Hopefully some can be inspired to adopt a furry friend within their home and can feel optimistic that such an addition may be one of the best available options for fighting PD and slowing symptom progression!



Simon Hawke is from Vancouver, B.C. He is currently in his third year at Western University studying neuroscience and is interested in researching neurodegenerative diseases.

References: 1. Boldig, C. M., & Butala, N. (2021). Pet Therapy as a Nonpharmacological Treatment Option for Neurological Disorders: A Review of the Literature. *Cureus*. <https://doi.org/10.7759/cureus.16167> 2. da Silva, F. C., Iop, R. da R., de Oliveira, L. C., Boll, A. M., de Alvarenga, J. G. S., Gutierrez Filho, P. J. B., de Melo, L. M. A. B., Xavier, A. J., & da Silva, R. (2018). Effects of physical exercise programs on cognitive function in Parkinson's disease patients: A systematic review of randomized controlled trials of the last 10 years. *PLOS ONE*, 13(2), e0193113. <https://doi.org/10.1371/journal.pone.0193113> 3. Kramer, C. K., Mehmood, S., & Suen, R. S. (2019). Dog Ownership and Survival. *Circulation: Cardiovascular Quality and Outcomes*, 12(10). <https://doi.org/10.1161/CIRCOUTCOMES.119.005554> 4. Muñoz Lasa, S., Máximo Bocanegra, N., Valero Alcaide, R., Atin Arratibel, M. A., Varela Donoso, E., & Ferriero, G. (2015). Animal assisted interventions in neurorehabilitation: a review of the most recent literature. *Neurología (English Edition)*, 30(1), 1–7. <https://doi.org/10.1016/j.nrleng.2013.01.010> 5. Parkinson's Foundation (2019). <https://www.parkinson.org/blog/tips/service-dogs-for-PD> 6. Zakeri, N., & Bain, P. G. (2010). Sustained improvement in a patient with young onset Parkinson's disease after the arrival of a pet dog. *Journal of Neurology*, 257(8), 1396–1397. <https://doi.org/10.1007/s00415-010-5510-y>

Volunteers Needed - Support Group Facilitators

Looking for Support Group Facilitators in various locations across Southwestern Ontario

This position will work in conjunction with PSSO staff to provide education and support at monthly support group meetings to clients living with Parkinson's, their carepartners and family members. The Support Group Facilitator will provide leadership and create a safe and empathetic space for clients to share experiences, ideas and feelings. This role will also help address challenges, encourage the development of supportive relationships and provide an overall inclusive atmosphere where people can be themselves.

For more information, contact Meagan at meagan.warwick@pssoc.ca or 1.888.851.7376 ext. 207



Benefits of Aerobic and Resistance Exercises for Parkinson's Disease Patients

As we all know, exercise is recommended for everyone to improve their physical and mental well-being. For individuals with Parkinson's Disease (PD), physical activity can be even more beneficial by becoming an effective strategy to slow the progression of PD symptoms, such as leg tremors and instability.

Although the form of exercise to achieve the best outcome is highly individualized, generally a higher exercise intensity yields better outcomes. With regards to exercise, Yumi Kim and colleagues (2019) reviewed studies focusing on exercise benefits in PD. They concluded three to five sessions of approximately 20-30 minutes of aerobic exercise per week would be most beneficial. For some this frequency may be incredibly intimidating. There is absolutely no harm in starting at two sessions a week for 10 or 15 minutes and working your way up. Aerobic

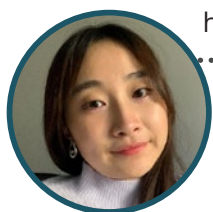
exercise can be as simple as walking at a steady pace, either outside or on a treadmill, maybe even adding an incline. Stairs are also an excellent resource for getting the legs working and raising the heart rate. Remember to challenge yourself. It's a good thing to be slightly out of breath, or as they say "to feel the burn", because this will ultimately return the most benefits. Another way to "feel the burn" is through resistance training, which can be accomplished through body weight, free weights (such as dumbbells) or resistance band exercises. Because symptoms are unique to everyone, one can target muscles accordingly. If someone with PD struggles with balance and walking, then they may prioritize their legs and core muscles for strengthening to hopefully alleviate some of those symptoms. If a debilitating hand tremor is present, maybe prioritizing the forearms, biceps, triceps and shoulder muscles would be most beneficial. Exercise is suggested during the "on" phase of one's medication cycle. It's always recommended to have supervision. Remember that every individual has their own unique set of symptoms with a unique degree of severity. Response to exercise will vary as well.

On page 17, there is an incredible summarizing table provided by Kim and colleagues (2019) for the recommended aerobic and resistance exercise regimens for people with mild to moderate PD. Note the Rate Perceived Exertion (RPE) refers to a 20-point scale that judges the intensity of an exercise, where 0 would be sitting still in a chair and 20 would be the most intense and strenuous exercise you would be able to perform. Here they recommend 13/20, meaning the exercise is more than moderately intense. One would certainly not be sitting still in a chair, but by no means is it necessary to push oneself to the absolute limit. You could also judge the intensity level of your workout by watching your heart rate (HR). If your maximum heart rate was 180 beats per minute (BPM), exerting yourself to 40-60% (72-108 BPM) of this maximum is recommended. One could track this on a treadmill which displays your heart rate while exercising. This would allow you to adjust your pace or to incline accordingly in order to reach the recommended heart rate which would be of most benefit to you. For resistance training Kim and colleagues suggest a resistance of 40-50% and over time up to 80% of your 1 repetition maximum (1-RM). This means that if a certain resistance weight was the weight at which you would be able to accomplish only one repetition, it is recommended to take 40-50% of this weight and do 8-12 repetitions with 1 to 3 times within a workout session.



	General Aerobic Exercise	General Resistance Exercise
How often?	3–5 days per week	2–3 days per week
How hard?	These activities should be performed at a moderate intensity. Moderate intensity of exercise is usually 13 on the 20-point RPE scale. An alternative way of measuring moderate intensity of exercise is 60%-80% HRpeak or 40%-60% HRR/V02R.	Pick a resistance between 40%-50% and up to 60%-80% of 1-RM.
How to?	Some options for activity include: <ul style="list-style-type: none"> • Ergometry (arm, leg or combined) • Walking (overground or treadmill) • Aquatics (including swimming) 	Resistance training activities mainly target major/ large muscle groups: <ul style="list-style-type: none"> • Weight machines • Free weights • Elastic bands
Overall considerations	<ul style="list-style-type: none"> • Overall progression should start with either duration or frequency, and finally progress intensity per tolerability of the person. • Rest your muscles 2- to 4-minute duration in between sets and muscle groups. • Rest you muscles for at least 1 day between strength training sessions. • Aerobic and resistance training can be performed on the same day as aerobic exercise training, depending on tolerability. • The exercise training should be undertaken during medication cycles or in an “on” state. 	

Overall, exercise is highly recommended for individuals with PD. More specifically, moderate aerobic exercise and resistance training that target major muscle groups can enhance motor functions and diminish symptom progression. Implementing something such as exercise into your daily or weekly routine can be difficult and intimidating, so having guidance on what will be most beneficial to you is important! Talk to your family doctor about what is a safe level of exertion for you or find a local gym with a trainer or a physiotherapist who could guide your exercise regimen. Luckily, certain cities have exercise and support groups specifically for individuals with PD. Look at the Parkinson Society Southwestern Ontario website for potential groups and programs near you!



<https://psso.ca/programs-services/support-and-exercise-group-listings/>

Yunyi Yan is a third-year Kinesiology and Psychology double-major student. She is passionate about neurological disorders and hopes her work can help people.



Simon Hawke is from Vancouver, B.C. He is currently in his third year at Western University studying neuroscience and is interested in researching neurodegenerative diseases.

References: 1. Ellis, T., & Rochester, L. (2018). Mobilizing Parkinson's Disease: The Future of Exercise. *Journal of Parkinson's disease*, 8(s1), S95–S100. <https://doi-org.proxy1.lib.uwo.ca/10.3233/JPD-181489> 2. Kim, Y., Lai, B., Mehta, T., Thirumalai, M., Padalabalanarayanan, S., Rimmer, J. H., & Motl, R. W. (2019). Exercise Training Guidelines for Multiple Sclerosis, Stroke, and Parkinson Disease: Rapid Review and Synthesis. *American journal of physical medicine & rehabilitation*, 98(7), 613–621. <https://doi-org.proxy1.lib.uwo.ca/10.1097/PHM.0000000000001174> 3. Kwok, J., Kwan, J., Auyeung, M., Mok, V., Lau, C., Choi, K. C., & Chan, H. (2019). Effects of Mindfulness Yoga vs Stretching and Resistance Training Exercises on Anxiety and Depression for People With Parkinson Disease: A Randomized Clinical Trial. *JAMA neurology*, 76(7), 755–763. <https://doi-org.proxy1.lib.uwo.ca/10.1001/jamaneurol.2019.0534>

WEBINAR

Parkinson's Disease & Gut Health: The Microbiome Connection

Presented by **Sara Lodge, RHN, NNCP**

Join us on September 21 at 11:00 am to discuss Parkinson's disease, brain health, gut health, support, education on the gut microbiome, gut-brain axis, foods to eat and foods to avoid.

For more information, visit www.pssso.ca/events



Slow and Steady Wins the Race:

Get the Most Out of Your Day With Energy Conservation

Everything we do in a day requires energy. Whether you are sitting and reading a book or playing a game of soccer, the body uses energy to get things done. Parkinson's can affect daily energy use in different ways. Whether it be wearing OFF times, daytime sleepiness or sleep attacks, rigidity, dyskinesia or tremors, a constellation of symptoms contribute to increased baseline energy expenditure, leaving less energy to do other activities throughout the day. This makes it important to figure out how an individual can capitalize on the time they are functioning best in order to get things done on a day-to-day basis. However, this does not mean rushing to check off all the items on a to-do list when we are feeling our best. Energy conservation involves adapting the way you go about your day to reserve energy for heavier tasks, and make use of lighter tasks when energy levels are low. The key concept of energy conservation is sustainability. By using intentional strategies that redistribute energy to optimize participation in activities during the day, an individual can engage in the activities they need to do, want to do, or are expected to do.

An easy way to implement effective energy conservation is through remembering the 4 P's: planning, prioritizing, positioning and pacing.

Planning ahead sets us up for success! Planning involves looking at all the tasks or activities you need to do or want to do for the week, and scheduling them in a way that allows for balance in energy expenditure. For example, alternate heavy and light tasks throughout the day so that your body has the opportunity to recuperate after completing an activity that requires more energy. These alternating tasks can also be planned to line up with the cycle of ON and OFF times, so that you do not find yourself having to complete a larger task at a time when medication is losing its effect.

More tips for **prioritizing**:

- Identify non-negotiables. Some parts of your day might not be flexible, such as appointments. Ensure some flexibility around these non-negotiable activities for an opportunity to rest.
- Have a back-up plan. Symptoms can be unpredictable. Sometimes activities may have to be cancelled or moved. Respect your body and consider other options to your plan.

The 4 P's of Energy Conservation

PLAN



Spread out larger tasks throughout the week.

Alternate heavy and light tasks.

PRIORITIZE



What needs to be done today? What can wait?

Begin with your most important tasks.

Rest before you feel tired.

Listen to your body and respect your limits.

Take your time!

Avoid bending or reaching too much.

Maintain an upright posture.

Sit when you can.

PACE



POSITION



More tips for **planning**:

- Don't overschedule. Ensure your plans are doable for you!
- Group similar tasks together. Reduce the amount of travelling within the home or in the community by scheduling activities within the same vicinity to be completed together.

Prioritizing helps ensure you get the important things done. A helpful way to do this is to sort the tasks you need to get done versus those you would like to get done. Starting with those that need to get done, rank them by importance or by urgency. What needs to be done today? What can wait, but should be done within the week? This can create the basis of your plan for the week, and the “nice-to-do” tasks can fit in where possible.

Positioning is key to optimizing how well your body tolerates activities. Maintaining good ergonomics (i.e., comfort and efficiency) may help prolong the amount of time you are able to engage in an activity and minimize the risk of injury.

Pacing is a reminder that completing day-to-day tasks is not a sprint - it's a marathon! Avoid feeling the need to rush through tasks, or to constantly be productive until you fatigue. Schedule ample time to complete activities and intentionally plan for break times before you reach exhaustion. This comes from the concept of chunking, which involves breaking up large tasks into smaller achievable “chunks” of tasks.

This helps to make large tasks less daunting and to foster a sense of success with each achievement. Every victory counts!

As a whole, energy conservation has to do with recognizing and respecting your body and its needs. These intentional strategies of planning, prioritizing, positioning and pacing can help you find the balance between work, rest and leisure in order to get the most out of your day!



Samantha Lau has finished her first year of the Master of Occupational Therapy program at Western University. Samantha has a particular interest in the interactions among an individual's mind, body and environment. Samantha understands the importance of taking a holistic approach to help clients participate meaningfully in their daily lives.

More tips for **positioning**:

- Sit down for tasks whenever possible. A significantly higher amount of energy is required to maintain an upright standing position.
- Avoid tasks that require significant coordination/bending/reaching when you are feeling fatigued. It may increase your risk for falls.
- Balance the load when lifting a heavier item. Avoid straining one side of the body.

More tips for **pacing**:

- Maintain a slow and steady pace. Don't rush!
- Avoid holding your breath when completing more strenuous tasks. Practise pursed lip breathing (breathe in through your nose for two seconds, then out through your mouth for four seconds).
- Listen to cues from your body when you start to fatigue.
- Ask for help when you need it. You might need assistance with some tasks, and that is okay!



Dylan Murphy, Special Events Coordinator

Dylan joined the PSSO team in January 2022. As Special Events Coordinator, Dylan is in charge of the planning and execution of fundraising events, including Walk for Parkinson's and the Parkinson Golf Classic. Dylan recently completed a Graduate Certificate in Sport and Event Marketing from Fanshawe College, where he specialized in all aspects of Event Management. Prior to this, Dylan studied at Laurier University, where he earned a Bachelor of Music degree in Cello Performance.

Tips to Help Manage Anxiety

Anxiety is a common non-motor symptom of PD, affecting approximately two out of five people with Parkinson's. Though a noticeable increase in anxiety most likely occurred with your first acknowledgement of PD, motor-symptoms such as stiffness, slowness of movements and tremors, as well as receiving your official diagnosis, anxiety can actually be one of the first signs of PD. Research suggests that anxiety might not be a psychological response to the illness, but rather the result of chemical changes within the brain. If you have managed anxiety, such as Generalized Anxiety Disorder, Anxiety Attacks, Social Avoidance and Obsessive-Compulsive Disorder prior to a diagnosis of PD, you may in fact have been experiencing the first symptoms of the disease. It is often not connected to PD until the motor symptoms of PD are present. For those who experience anxiety after their diagnosis, it is important to discuss this with your physician to ensure that effective interventions are added to your treatment plan.

Types of Anxiety

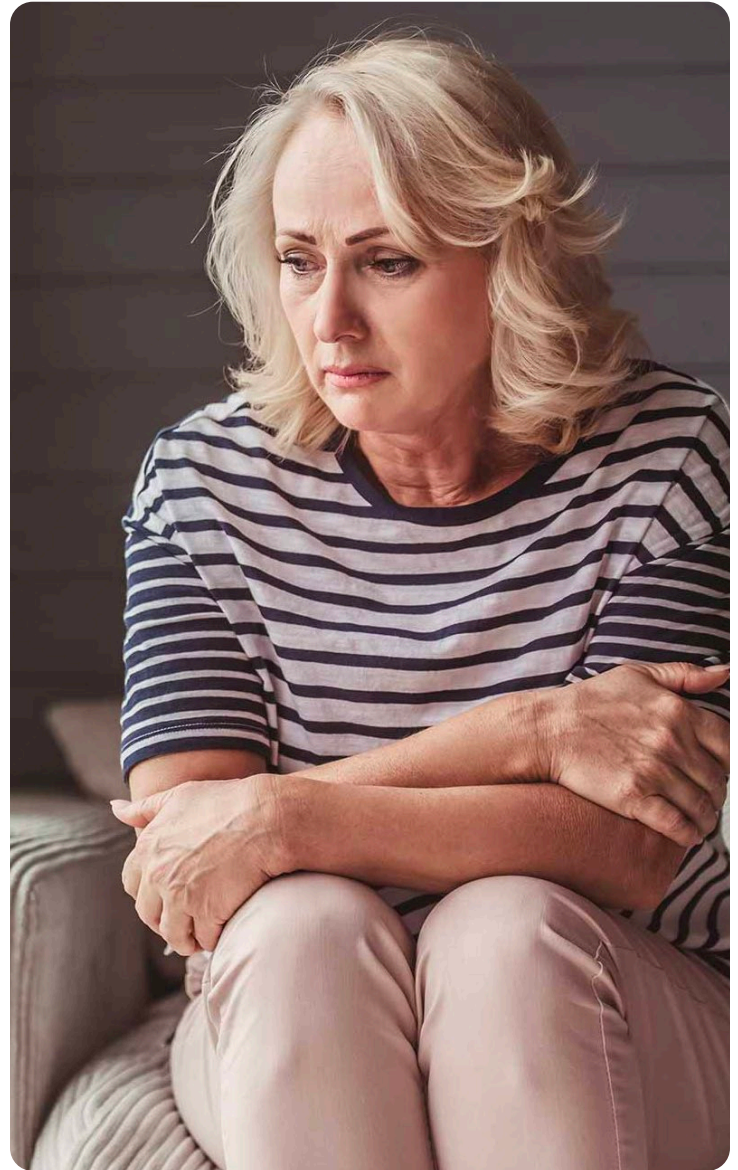
Approximately 40% of people with PD will experience anxiety in their lifetime. The following briefly outlines how anxiety may appear in people with PD.

Generalized Anxiety Disorder (GAD): Persistent and excessive worry about a number of different things, an overall feeling of nervousness that seems out of proportion to what is actually happening. Physical symptoms include nausea, heart palpitations, trouble breathing (perhaps leading to hyperventilation), swallowing, sweating and increased tremors.

Panic Attacks/Panic Disorder: Sudden onset of intense physical and emotional distress, you may feel you cannot breathe, or are having a heart attack. The distress can be so concerning that you feel you are having a medical emergency. The sensations often subside quickly, within a few minutes, but they can last up to one hour, especially during "off" times. Left untreated, panic can lead to agoraphobia and an inability to leave the house, at least on your own.

Social Anxiety Disorder: A sense of fear or embarrassment, which could be due to PD symptoms, that can leave you avoiding everyday social situations for fear of being scrutinized and judged negatively by others.

Obsessive-Compulsive Disorder (OCD): Unwanted thoughts, ideas or sensations (obsessions), for example fear of germs, that makes you feel driven to do something repetitively (compulsions). In the case of germs, you may repeatedly wash your hands or avoid crowded places. The compulsions are put in place to alleviate the anxiety produced by the obsessions.



Repetitive behaviours, such as hand washing, checking on things or cleaning, can reach a point where the need to continually act on the compulsions significantly interferes with your daily activities and social interactions.

Tools for Managing Anxiety

Anxiety can lead to avoidance and can impact your quality of life and overall well-being. To help you manage, there are a number of tools you can include in your day:

Mindfulness: “Mindfulness means paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.” — Jon Kabat-Zinn. When you are anxious, your mind is generally focused on the past, future or worst-case scenarios. Taking a moment or two to focus on the present can help calm the mind. Mindfulness activities can help you do this. There are a variety of mindfulness exercises, including yoga and meditation. Here are two brief exercises that can get you started.

Three Senses

Simply notice what you are experiencing right now through three senses – sound, sight, touch. Take a few slow breaths and ask yourself:

- 1) What are three things I can hear? (clock on the wall, car going by, music in the next room, my breath)
- 2) What are three things I can see? (this table, that sign, that person walking by)
- 3) What are three things I can feel? (the chair under me, the floor under my feet, my phone in my pocket)

Belly Breathing

- 1) Sit in a comfortable position.
- 2) Put one hand on your belly just below your ribs and the other hand on your chest.
- 3) Take a deep breath in through your nose, and let your belly push your hand out.
- 4) Breathe out through pursed lips as if you were whistling.

Do five times ... go at your own pace!

Talk About It

Talking helps. Reach out to a trusted friend, your physician or a counsellor/therapist for support. Talking about your situation and experiences and sharing negative emotions with someone you trust can be healing. Studies have shown that talking about it reduces stress, strengthens your immune system and reduces physical and emotional distress.

Medication

For many, medications are a last resort to managing anxiety. However, if your anxiety is affecting your quality of life, speaking to your physician about options may be the next step to consider.



Written by Cathy Messenger. Volunteer, London

Nutrition

Eating a balanced diet, staying hydrated and limiting alcohol and caffeine are at the foundation of supporting a diet that will help reduce feelings of anxiety. Complex carbohydrates such as those found in whole grains (unprocessed oats, brown rice, etc.), legumes, vegetables (broccoli, green beans, etc.) and fruit help to maintain even blood sugar levels, a process that creates feelings of calm. Sources of magnesium such as nuts, seeds and leafy greens and foods rich in zinc such as cashews and egg yolks have also been linked to lower levels of anxiety.

Exercise

Not only is exercise an effective means to manage symptoms of Parkinson's, but it also has a calming effect due to the changes in your brain chemistry that occur during exercise. Your body will release dopamine and endorphins (naturally occurring morphine), both feel-good chemicals.

Walker Profile: Margaret Borges

Margaret Borges began participating with Walk for Parkinson's in 2018. Diagnosed with Parkinson's in 2012, she was looking for a way to take action and raise awareness. Even during the pandemic, Margaret stayed active and planned a 5km walk around her neighbourhood with her children. She trained all summer. During the walk, neighbours would stop them and ask what they were walking for. Margaret was happy to share her story with them and raise awareness for Parkinson's.

Margaret shares with me that the main reason she is involved with Walk for Parkinson's is to "educate people on how the disease affects people differently." She adds, "There are no typical symptoms of Parkinson's disease." For example, Margaret does not have a tremor, one of the more common symptoms associated with Parkinson's, but she deals with other symptoms, such as fatigue.

Parkinson's has changed Margaret's daily living, but she insists on staying positive and finding solutions for any problems that she encounters. For example, instead of getting frustrated with not being able to tie shoelaces, she made the easy switch of purchasing shoes with no laces. Margaret notes that time management is important, so she gives herself extra time to complete tasks and to get ready in the morning. During our conversation, she shares a phrase that she finds helpful: "Parkinson's lives with me, I don't live with it." In other words, she is in control, not the disease.

Parkinson Society Southwestern Ontario has helped Margaret by providing her with information and access to exercise programming. Margaret began the Rock Steady Boxing program in May, and has already begun to see progress. After only one month of participating, Margaret has noticed that her posture has improved! She mentions, "The program helps me mentally and physically, and even though I'm tired afterwards, I always look forward to the next session." Margaret enjoys connecting with other people living with Parkinson's, and her husband is able to participate with her as well. She says, "The program is a lot of fun and hard work, and every week is different."

Margaret encourages other people to get involved with Walk for Parkinson's in order to educate themselves, friends and family members about the different ways Parkinson's affects people. "The more you know, the more you understand," she says, "and there is always something new to learn."

Margaret is looking forward to returning to the in-person Walk for Parkinson's event this year with her team, the Night Warriors. When I asked her about the team name, she mentions that she came up with it after dealing with insomnia, a common Parkinson's symptom. She says, "The name Night Warriors came to mind, as I see myself as a fighter and I don't give up."

Written by Dylan Murphy, Special Events Coordinator





REGISTER TODAY!

walkforpd.ca | 1.888.851.7376

SATURDAY, SEPTEMBER 10, 2022

Brantford-Brant County – Mohawk Park

Registration 1:00pm, Walk 2:00pm

Goderich – Rotary Cove Pavilion #4

Registration 10:00am, Walk 11:00am

London and District – Springbank Gardens

Registration 10:30am, Walk 11:30am

Owen Sound – Bayshore Community Complex

Registration 1:00pm, Walk 2:00pm

South Grey Bruce and Hanover – Hanover Town Park

Registration 8:00am, Walk 10:00am

Stratford and Area – Upper Queen's Park

Registration 9:30am, Walk 10:30am

Waterloo Region – Kiwanis Park

Registration 10:00am, Walk 11:00am

Wellington-Dufferin – Centre Wellington Sportsplex

Registration 10:00am, Walk 11:00am

SUNDAY, SEPTEMBER 11, 2022

Chatham-Kent – Kingston Park

Registration 12:00pm, Walk 1:00pm

Grand Bend – The Grand Bend Legion

Registration 1:00pm, Walk 2:00pm

Oxford County – South Gate Centre

Registration 1:00pm, Walk 2:00pm

Port Elgin, Kincardine and Area – North Park, Saugeen Shores

Registration 1:00pm, Walk 2:00pm

Sarnia-Lambton – Canatara Park

Registration 1:00pm, Walk 2:00pm

Windsor-Essex – Malden Park

Registration 12:00pm, Walk 1:00pm

WHO ARE YOU WALKING FOR?

Join us on
**September 10th
and 11th at your
nearest location.**

Come for the walk, but stay for the fun, entertainment, refreshments and of course social interactions that we have undoubtedly missed. Walks will follow local public health regulations.

Participate

Go to walkforpd.ca and register today!

Form a Team

Form a team with family, friends and co-workers! Remember, you don't have to walk at the same location in order to be a team.

Collect Pledges

Collect pledges online at walkforpd.ca or in person using the pledge form. Pledge forms can be downloaded from walkforpd.ca or call 1.888.851.7376.

Volunteers Needed

Walk for Parkinson's Event Day Volunteers
(various locations)

This position will work in conjunction with PSSO staff and the Volunteer Planning Committee to support the annual Walk for Parkinson's. The event volunteer will arrive at the designated walk location in their geographical area and will participate in various tasks that support the overall success of the event. This event will not only raise awareness about Parkinson's, but will also strengthen the community connection to Parkinson Society Southwestern Ontario.

**For more information, contact Meagan at
meagan.warwick@pssso.ca or 1.888.851.7376 ext. 207**





2022 Parkinson Golf Classic in partnership with Rembrandt Homes

On June 1, Parkinson Society Southwestern Ontario held the 2022 Parkinson Golf Classic in partnership with Rembrandt Homes at West Haven Golf & Country Club. Thanks to the generosity of our sponsors and participants, we were able to raise over \$90,000! These funds help to ensure we can continue to provide programs and services to those living with Parkinson's in Southwestern Ontario. In addition, some of these funds will help fund seven Graduate Student Research Projects, each at \$25,000 (see pages 8-11).

At dinner, we had the pleasure of welcoming guest speaker Chad McGahan to speak about his journey living with Early Onset Parkinson's disease. Chad spoke eloquently about how Parkinson's has affected him, and how PSSO has helped him every step of the way.



PSSO Updates

PSSO gratefully acknowledges the Ontario Trillium Foundation for its funding of the Community Engagement and Volunteer Coordinator (CEVC) project for the 2022/23 year. This project is aimed at bolstering volunteerism within our organization, while providing additional services to help support groups, providing educational and programming opportunities and supporting the mental, physical and emotional wellness of our clients, their families and carepartners.

Ontario
Trillium Foundation



Fondation Trillium
de l'Ontario

An agency of the Government of Ontario
Un organisme du gouvernement de l'Ontario



Meagan Warwick, Community Engagement & Volunteer Coordinator

Meagan has taken on a brand new role at PSSO as Community Engagement & Volunteer Coordinator. She has many years of experience in the non-profit sector working with children and youth, and has been coordinating volunteer engagement for the past eight years. Meagan is very passionate about working with diverse groups of people and creating inclusive spaces in our community.

2022 SPRING REGIONAL PARKINSON'S CONFERENCE

The Spring Regional Parkinson's Conference on May 7 at the Best Western Plus Walkerton Hotel & Conference Centre was offered both in-person and virtually. Thank you to Dr. Galit Kleiner, Dr. Tiago Mestre and Dr. Mandar Jog for sharing some of their expertise on Parkinson's.



Funding for this conference is made possible by a grant from the James Goreski Private Foundation

Support Provided By:

abbvie



THE
PARKINSON'S
UPDATE

25

Volunteer Profile:

Lynn Tomlinson



When Lynn Tomlinson retired in 2016 from her career as a kindergarten teacher, she knew volunteering was in her future. She had plans to perhaps return to the school and help, or look for opportunities in her community. She never dreamed she would one day become a facilitator for a Parkinson's support group. In fact back then, Lynn didn't even know such a group existed.

In 2017, Lynn was diagnosed with Parkinson's. She had known for a while that something wasn't quite right. She was experiencing stiffness and tremors and mobility issues, but it wasn't until she moved to Leamington, after retiring, that she found a doctor who understood. During that time, she was also seeing a physiotherapist for a shoulder problem who, upon hearing of the diagnosis, became a tremendous source of support for Lynn. She realized that Lynn needed to talk to others who were travelling along this same journey and suggested the local Parkinson's support group.

When Lynn discovered what was occurring, she was reluctant to be in public. She felt self-conscious and experienced high anxiety when leaving the house. But thanks to the incredible support of her husband Alan, she did venture out to the support group where she made immediate connections and realized it was a safe place to be – everyone was going through something similar. And they understood.

In 2018, when she learned the current facilitator was in the process of stepping down, she realized she had found her volunteer role. Given that she spent a lifetime teaching and helping others, this just seemed like a natural fit. Now Lynn is supporting others while also supporting herself, by learning what is available to improve quality of life and by remaining active. Of course COVID presented a few challenges, Lynn made sure that everyone remained connected during that time, computer or not. Four area support groups got together for Zoom meetings. Email updates were sent regularly, but Lynn would be on the phone, checking in and providing information to those who either did not have Internet service or needed additional supports. For Lynn, everyone was part of this group and needed to know the information that was available.

She has also been instrumental in bringing in a variety of informational speakers to the support groups. She enjoys researching new activities to introduce to the members. It is important to Lynn to help others and to learn and to share as much information as possible.

Lynn's family is also supportive of her journey. Her sister-in-law, Veronica, volunteers at the annual Walk for Parkinson's and takes the walk with Lynn. In 2019, her then 87-year-old mom travelled from Nova Scotia to join Lynn at the Regional Parkinson's Conference.

Lynn also understands the need for self-care and exercise. An avid reader, Lynn enjoys walking through the many conservation areas her community has to offer. With the use of walking poles, she has also been able to increase her stability and balance. As a result, she is able to remain outside longer. Lynn and Alan also enjoy camping throughout Ontario. Not always comfortable in public areas, for Lynn this mode of travel offers a home away from home where she can still see the beauty of the province but come "home" to her own space – wherever they are. Lynn is also very active in her community. She sits on the board of directors for her condominium complex and participates in the Parkinson's choir.

As a facilitator Lynn notes that an open mind is essential in order to welcome the varying perspectives the members bring. She feels being a good listener and sometimes hearing beyond the words to promote good conversations and understanding is a needed skill when supporting others.

Her work as a facilitator is interesting and rewarding and has brought her many new friends over the years. While she does plan to continue, she would also like to get more involved in Parkinson's advocacy work. "I've accepted I have this disease and know it will get worse and I wouldn't wish it on anyone. I'd like to do my part to help make a difference – to educate, help others understand and advocate for what is needed or what needs to change, to work toward ending Parkinson's disease."

In Memoriam

We offer our sympathy to the families whose loved ones have passed away between January 1, 2022 and June 30, 2022.

Janneke Baan	John DeGroot	Rick Hodgkinson	Sandra McCann	Betty Roelofson
Kathleen Batson	Keith Deline	Don Hoffarth	Gene McCarthy	Charles Ruttan
Oswald Baum	Eric Deman	Larry Hossack	Dorothy McElhone	George Schafer
Herbert Beitz	Roland Demers	Helen Hovius	James McFadden	Anthony Schincariol
David Bell	Armine Dennie	Hsueh-Hai Huang	Peter Menzies	Hartland Sealey
Lanrick Bennett	Stanley Ditner	Frederick Hubbs	Russel Merrifield	Inge Serschen
Malvina Betteto	Allan Douglas	Thomas Huff	Lyle Moffatt	John Shatto
Dwight Brady	Harold Dube	Joanne Hugill	R. Lee Montgomery	Mary Simpson
William Brennan	Gloria Dubeau	Jack Hunter	Mary Morrissey	Edythe Smith
Ken Brobyn	Cal Evans	Allen Hutt	Dianna Lynn	Penny Stevenson
Clement Brown	Leonardo Fazio	Masud Jawaid	Moser-Paleczny	Ken Suggitt
Harriet Brown	Jack Garrett	Mabel Johnston	James Neill	Larry Sullivan
Ron Brown	Ted Garrity	Ivor Johnstone	Derek Nielsen	David Thain
David Carter	Bob Giegerich	Beatrice Jolley	John Nixon	Johann Thiessen
Shirley Christian	Jeffrey Gill	Frances Kempf	Hugo Noorenberghe	Claire Anne Thorup
Eva Comartin	Nada Giovinazzo	Louis Keresztyen	Ray Northgate	Stefani Tichbourne
Patricia Coulthart	Stephen Goff	Harold Kilimnik	Helen O'Brien	Isabel Ward
Jim Crawford	Ray Goodwin	Rosemary Kopf	Joan O'Connor	Mary Weber
Richard Crawford	Alex Gramada	Christopher Lachance	Jacqueline Padfield	Neil Webster
Tim Crooks	Lloy Grose	Dorothy Lesperance	Theresa Pastorius	Gail White
James Cruickshank	Diane Halpin	Jerry Levitt	Vonda Pearson	Ed Willshire
Tony Cucinelli	Gerard Harren	Robert MacIntosh	Roy Pletch	Jeff Willsie
Janine Ann Currie	Janice Harris	Wendy Mackay-	Milan Podhorsky	Paul Witheridge
Kerry D'Arcy	Joan Harris	Robinson	David Pyatt	JoAnn Wolfs
Jim Darrach	Suzanne Hatchard	Mushtaq Mall	Dave Rader	Edward Wright
Robert Dawdy	Helen Hegan	Bessie-Belle Marshall	Tom Read	
Eleanor Day	John Highgate	Wayne Matheson	Marvin Recker	

We make every effort to include all members who have passed away. We sincerely apologize if any individual was inadvertently omitted from the above list. Please call and let us know if we have missed anyone and we will include their name in our next issue.

PEP

Parkinson Education Program
for Community Caregivers

ATTENTION: MEDICAL PROFESSIONALS

The Parkinson Education Program (PEP) for Community Caregivers is an online educational series offered to better equip healthcare professionals in providing excellent care to individuals living with Parkinson's disease.

Get your PEP Certificate today!

It's free and makes a difference in the Parkinson's community.

www.peponline.ca



BECOME A HERO OF HOPE

Our Membership Program

By becoming a member, you join as a Hero of Hope. Your monthly gift makes hope possible. You not only provide sustainability for services and Parkinson's programs including research, but you also invest in the lives of people with Parkinson's in our community.

Simply fill out the form on our website
psso.ca/how-to-help/hero-of-hope/ or
call 1.888.851.7376.



WHO WILL YOU WALK FOR?

September 10th & 11th

Details at walkforpd.ca or call **1.888.851.7376**

Walks will follow all local public health guidelines.

Parkinson SOCIETY
SOUTHWESTERN
ONTARIO

Register today at walkforpd.ca
f ParkinsonSocietySWO ✓ ParkinsonSWO