

# THE PARKINSON'S update

SUMMER/FALL 2024

**ISSUE 80**

JOURNEY  
TO OWEN  
SOUND:  
TEAM IAN'S  
STORY  
*Page 8*

EMBRACING  
MINDFULNESS  
PATHWAY TO A  
BALANCED LIFE  
*Page 17*

2024 SPRING  
CONFERENCE RECAP  
*Page 14-15*

EXPLORING THE  
NORMALCY OF  
AMBIGUOUS LOSS  
*Page 4-5*

# FROM THE CEO'S DESK

It is hard to believe that we are half way through 2024. The sun is shining, warm weather has arrived; and for many, it's a time of relaxation. So much has happened over the past several months at PSSO. In May, our team was devastated by the sudden loss of our team member, Joanne Bernard. Each day continues to be a struggle, but we move forward knowing this is what she would want us to do.



Shelley Rivard

Through a partnership with Mitacs, Parkinson Society Southwestern Ontario (PSSO) has been able to fund four graduate students through the Graduate Student Scholarship Program. These students will receive funding of \$25,000 to continue their research programs (See pages 22-23).

This year our focus is on providing opportunities to build relationships and connections Closer to Home. This is made possible through the addition of our Community Engagement Coordinators last October. In the spring, we provided 4 conferences throughout the region, Owen Sound, Stratford, Fergus and Sarnia with all being well attended. We also host monthly webinars, have held a number of workshops, including a Carepartner workshop in Arthur. Coming this October, we will have our Fall Regional Conference in Kitchener on Saturday, October 26th.

We continue to offer our multidisciplinary approach to our support services. From support and exercise groups; Louder, Clearer offered by Speech and Language Pathologists; Music therapy through the Parkinson's Music Choir; as well as our Counselling Program, in partnership with King's University College at Western University we are here to ensure the well-being of those living with Parkinson's.

Summer is a time for walk preparations. Coming September 7th and 8th, we will be hosting 14 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. For those of you new to Walk for Parkinson's, come for the walk, but stay for the fun, entertainment, refreshments and time with family and friends as we support each other in the fight against Parkinson's disease.

Unable to walk, 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! All funds raised remain local in Southwestern Ontario.

My hope is that you will connect and get involved in all that PSSO has to offer in your community. You are never far from HOME with Parkinson Society Southwestern Ontario.

*Shelley Rivard*

Shelly Rivard, CEO

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.

✉ [info@pssso.ca](mailto:info@pssso.ca)  
🌐 [www.pssso.ca](http://www.pssso.ca)  
📘 [ParkinsonSocietySWO](#)  
📺 [parkinsonswo](#)  
📺 [ParkinsonSWO](#)

## MISSION STATEMENT

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

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

## BOARD

Brad Richards, Chair  
Alysia Christiaen, Vice-Chair  
Matthew Mitchell, Treasurer & Secretary  
Anthony Bender  
Kurt Berger  
Dr. Jeff Holmes  
Gary Pullam  
Bev Zaifman  
Dr. Mandar Jog, Honorary

## STAFF

**Shelley Rivard**  
CEO

**Igho Ogbobine**  
Data Operations Specialist

**Kevin Blondin**  
Marketing and Communications Specialist

**Michele Bucholtz**  
Executive Assistant to the CEO

**Michelle Pakulski**  
Information and Referral Specialist

**Stephen Owen**  
Community Engagement Coordinator, Central Region

**Heather Galloway**  
Community Engagement Coordinator, North Region

**Robin Arnott**  
Community Engagement Coordinator, East Region

**Samantha Grant**  
Community Engagement Coordinator, West Region

**Special Thanks to Volunteer Editor:**  
Neil Tenney

# LOVE AFTER LOSS: BRENDA AND ELM'S STORY

## BRENDA

My husband, Murray, was a dentist in the prime of his life, but that changed rapidly with his diagnosis at the age of 58. He lived with PD for 25+ years. We were able to enjoy the first ten years, but then the disease took over. I had been a nurse and am forever thankful for my training because I became his caregiver. His walking became difficult; falls started; he lost his ability to drive; his speech deteriorated. Agitation, dyskinesia became part of our routine and he eventually developed dementia. Still, he was a trouper and never complained.

We always attended support group meetings which became one of the most important parts of our lives. They gave us great information, love and support. The friends we met understood what was happening. Elm and Mary Jo were two of the friends we met at these meetings. When Covid-19 came along, the caregivers would meet separately on Zoom. Our caregiver meetings were so informative. We got to learn from each other's hardships, share information or just become friends. In any meeting, there are always people who stand out and you find yourself relating to them very easily. Elm was one of those people.

When I learned of Mary Jo's passing, I reached out to Elm because I knew and understood the loss he was feeling. We both had been with our loved ones for sixty years and needed to talk to someone who was feeling the loss to the same depth. We started walking and talking and learning about each other's lives apart from Parkinson's. It was a blessing to share stories and learn that we had much in common. We learned that we are kindred spirits and our walks became luncheons and our shared grief became wonderful stories to tell. We were laughing again. We started to do day trips around Guelph and it was clear to us that life had been on hold.

For many months our friendship grew. We planned outings with longtime friends and our friends kept telling us how happy we looked and how pleased they were to be in our company. Life continued to expand for us and when a planned vacation separated us for a few weeks, it became clear that love had been given to us again. We have been told that if you have had a great love, you are open for love again. I believe that to be true. Parkinson's took a great deal from Elm and me, but it also gave us one another. We are happy and our families are very pleased and happy for us.



## ELM

My wife, Mary Jo, was diagnosed in early 2014 with Parkinson's disease (PD). She was told in 2016 that her vascular form of PD did not respond well to levocarb and that dementia would likely develop. Both proved to be true. A major symptom was the occurrence of random "off" periods, which meant that she could never be left alone. Any activity became a risky endeavour. Even though we loved to travel to Vancouver to visit our younger daughter and her family, in November 2015, we learned that travel was no longer an option. I was fortunate to be able to look after her at home, never considering placement in long-term care, even pre-Covid. We moved from our home of 46 years to a condo in 2017 to avoid the use of stairs.

My role as caregiver was uplifted by attending monthly meetings of the Guelph PD Support Group for 3-4 years and by having PSWs come in twice a week for the last couple of years of Mary Jo's life. During Covid-19 lockdowns, the caregivers of the Support Group would meet separately over Zoom. It became clear that others understood and cared about my situation. Anything and everything was discussed in confidence, with understanding and acceptance. It was during these meetings that I noticed Brenda's wisdom and compassion when she talked about her caregiving of Murray.

A few months after both Murray and Mary Jo had passed away, after some emails of concern, Brenda and I decided to meet for a walk (with her dog) knowing we could talk freely about our grief. Our walks led to meals and then the desire to get together more and more. It soon became apparent that we had much more in common than caregiving. I soon started going to Brenda's every evening for dinner, though it took several months before we felt committed.

I think neither of us believed that we could or should love again. In the early days of seeing each other, I went away to visit my daughter in Vancouver for three weeks, and we knew that we did not want to spend another day apart. We have since enjoyed holidays together in Florida and Mexico. It is a blessing that our daughters and other family members as well as friends are so accepting and pleased with our close relationship. Every day is now a happy one and we constantly say how fortunate we are to have found each other.



# AMBIGUOUS LOSS

Ambiguous loss, a concept first articulated by Dr. Pauline Boss, professor emeritus at the University of Minnesota in the 1970s, refers to a type of grief that is unclear and lacks closure. Unlike definitive losses where the absence or death of a person is concrete and acknowledged, ambiguous loss create a situation where individuals are unsure whether to hold on or let go.

“Parkinson’s disease, or any neurodegenerative condition, results in a change to the future. The imagined future is forever altered often because of the unknown. For an individual living with Parkinson’s and their carepartner, life as a person without Parkinson’s is a past construct. Often people don’t feel they have permission to grieve this loss. They may feel disloyal. After all, the person they love and care for is still here, but with a different health diagnosis,” explains Dr. Miyasaki.

When asked about the challenges people can experience navigating the complexities of ambiguous loss, Dr. Miyasaki states, “Recognizing ambiguous loss, giving oneself permission to grieve and also giving oneself permission to still feel joy and hope is important. Sometimes, we forget that it is okay to laugh, to make plans, to find hope and joy in the every day.”



.....  
Dr. Miyasaki conducts research in Parkinson’s disease and movement disorders. Her work focuses on Palliative Care for Neurology, communication, quality and novel care delivery. Dr. Miyasaki has authored several guidelines and quality measures for Parkinson’s disease and other movement disorders. She has over 160 publications in peer-reviewed journals and collaborates widely on an international basis.

## 6 QUESTIONS FOR EXPLORING YOUR PARKINSON’S-RELATED GRIEF

Grief is part of the human experience and a natural response to loss we experience. We meet grief regularly throughout our lives as we lose or say goodbye to what we hold dear, be it the people we love, the things and routines in our life that were important to us, or the plans or hopes we dreamed one day would come true. Grief is also part of the Parkinson’s disease (PD) journey as you experience changes to your body and life that you did not plan for or expect.

However, grief resulting from Parkinson’s-related loss can sometimes go unrecognized; you or others may recognize a change but not consider it a loss you are allowed to grieve. When you can identify your grief, you can begin to honour it. When you honour your grief, you can better understand your emotions and needs, and begin to chart a path forward.

### BELOW ARE SIX QUESTIONS TO ASK YOURSELF AS YOU START TO EXPLORE THE HONOURING OF YOUR GRIEF:

- 1. Do I feel pressured to ignore my loss or hold back my grief?**
- In an effort to live well with Parkinson’s, some people think they should always focus on the

positive and never on the disease-related loss they experience along the way or the grief they feel in response. Never creating space for your grief is like denying part of what makes you human. Give yourself permission to acknowledge and respect all the feelings that arise for you, the positive ones and the ones rooted in grief.

**2. Am I comparing how I feel about my losses? Am I judging how I am coping?**

A Parkinson’s-related change to your life can be a mere inconvenience for you, but that same change for someone else with PD can be experienced as a traumatic loss, and vice-versa. The changes you are forced to adapt to because of Parkinson’s will mean something unique to you, and your response to that change will be unique to you. Avoid comparing or judging yourself harshly about what you consider a loss or about the type of support you need to cope with it.

**3. What is my primary style of grieving?**

Some people grieve primarily through their emotions while others grieve primarily through their actions. Neither way is right or wrong and both have their benefits and drawbacks. Identifying your primary grieving style can help you better understand your approach to grief; it is what works for you. If you feel like your grief style is not working for you, it may help to seek extra support.

**4. What does my body need to navigate this grief I’m feeling?**

The feelings you experience from a PD-related loss don’t just sit in your heart or your head. Your body holds your grief too. When you are struck by a new loss or are having a day when you are remembering several losses, consider what your body needs to get through this difficult time. Your body may need rest or exercise, hydration or a nutritious meal, a hug or massage, space or fresh air, patience or forgiveness.

**5. To whom can I turn when I’m having a heavy grief day?**

Sometimes grief is just too much for one person to navigate on their own, so it helps to know whom you can call on for support. This might be a trusted family member, friend, or neighbour,

someone on your PD care team like a social worker, counsellor or support group, or members of your spiritual, civic or virtual communities.

If you are navigating this hard day on your own, consider what you would tell your best friend if they were going through what you are experiencing, and act as your own best friend as you grieve. Think about how you have navigated difficult times in the past and whether you can apply any of that wisdom to your grief today. Identify how you can show your mind, body and heart some compassion and tenderness. Reflect on whether a distraction from your grief might help right now or whether it might help to just cry.

**6. Who or what helps me feel like the whole person that I am, despite my loss?**

Having a chronic condition like PD can change the way you see yourself. Sometimes if PD-related losses accumulate, you might feel like important parts of your identity are also lost. Especially when you are grieving, it is important to remember that you remain a whole person and that you are still growing as a person, despite what has changed or been lost. Think about who or what in your life helps you feel like yourself, the whole you, and try to reconnect with whatever or whomever that is. If you are struggling with this, reach out to someone you trust or a member of your care team.

### HERE ARE TWO COMMON WAYS PEOPLE PROCESS THEIR GRIEF:

- 1. Intuitive Grieving:** People who are primarily intuitive grievers work through grief by expressing their emotions and talking about their feelings.
- 2. Instrumental Grieving:** People who are primarily instrumental grievers work through grief by asking questions, gathering information and completing tasks.

• **Tip:** Although you may have a primary style of grieving, most people fall along a continuum of these styles and not squarely within one or another. Some people think they are “doing grief wrong” if they are not crying enough or because they are “too emotional.” Again, there is no right or wrong way, but reach out for support if you feel stuck.



# COMMONLY ASKED QUESTIONS: NON-MOTOR SYMPTOMS

*\*Please note that these were questions asked during the 2024 Living Well Conferences; therefore more updated information may be available upon publication.*

**What is a Non-Motor Symptom and why are they important to discuss?** The term is used to distinguish between movement and non-movement symptoms. Non-Motor Symptoms can have significant effects on quality of life and don't respond to traditional dopamine-based Parkinson's medications (e.g.: Levodopa).

**Why am I drooling more than I used to?** Slowness of movement, a core symptom of PD, can affect the muscles responsible for swallowing, which causes you to swallow your saliva less frequently. Another contributing factor can be abnormal posture (stooping/bending forward of the neck) which leads to gravity contributing to saliva coming out of the mouth. It may be helpful to chew sugar-free gum or suck on sugar-free candy, which reminds you to swallow. (There is no specific benefit to sugar-free products; I just recommend them to avoid dental cavities or excessive sugar intake).

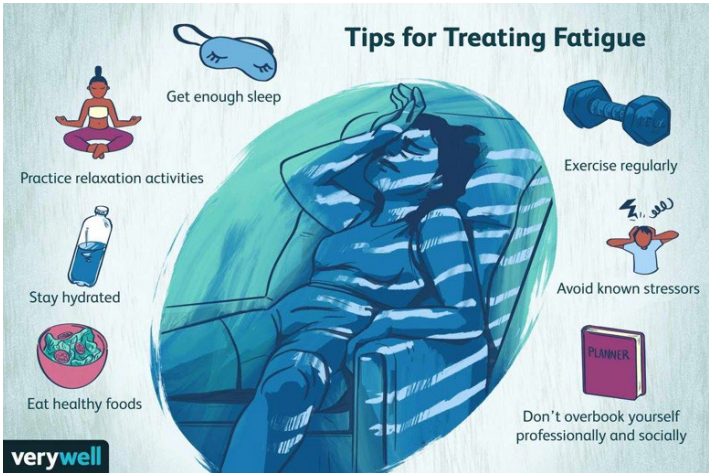
**I always feel tired after waking up. Can Parkinson's cause me to have trouble sleeping?** Difficulty with sleep is a common problem and complex to solve. The concern seen frequently is called rapid eye movement (REM) sleep behaviour disorder, which causes muscle paralysis to not happen. As a result, individuals can move their arms and legs while they are sleeping, sometimes physically



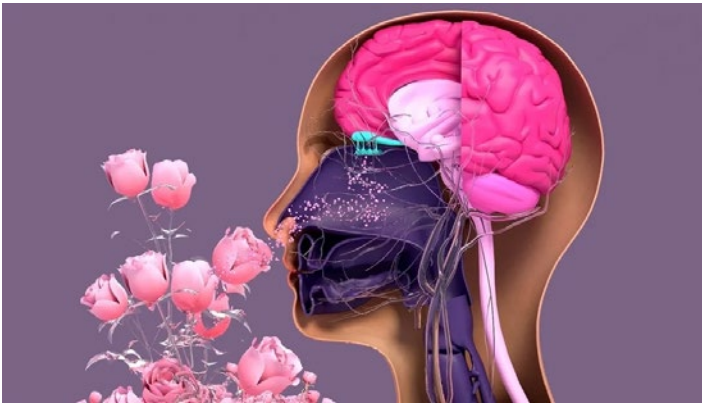
and vocally acting out dreams. I want to emphasize that not all limb movements during sleep are from REM BD. Treatment options include Melatonin, which is available over the counter at lower doses, or Clonazepam, which is a prescription medication. Please note the side effects of Clonazepam include drowsiness, an increased risk of falls in older people, and more.

**I have noticed my spouse will say there is a cat on the bed when we have never had one. What can cause this?** That falls under the classification of a Hallucination. Initially, this might be described as seeing brief flashes of something in the peripheral vision, like thinking you see a mouse out of the corner of your eye when watching TV. Over time, these images can become more clear and vivid, and people often describe seeing faces, people or little animals. Hallucinations can be a symptom of Parkinson's disease itself, or can be a side effect of medications.

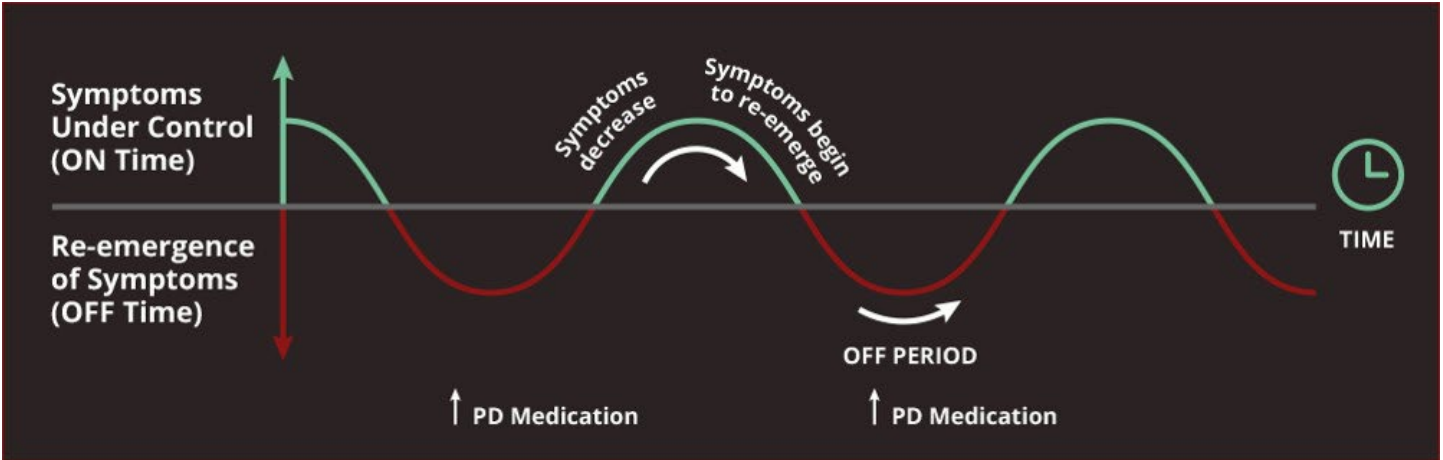
**How can I be referred to a neurologist, and why is it taking so long?** You can be referred to a neurologist by your family doctor or another healthcare professional qualified to make that referral (e.g.: a nurse practitioner, a fellow neurologist). However, I am sorry to report that many neurologists, such as myself, have a long waiting list as there is simply not enough of us out there. We also understand that every patient is different and has different preferences. Therefore, there may be a longer waiting list for the Movement Clinic in London or Toronto compared to your local hospital, but some patients prefer to wait for a specific doctor or specialist. It depends on your preference, but I hope that will change in the future with more neurology fellows graduating each year.



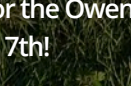
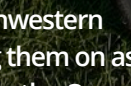
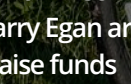
**Is there a way to tell if Parkinson's is causing issues when it comes to memory?** It can be difficult to determine if cognitive changes are caused by natural aging or something more serious. Dementia is the umbrella term for when memory or cognitive symptoms start to interfere with a person's ability to do things independently in day-to-day life. Dementia in people with Parkinson's is usually related to build-up of an abnormal protein which clusters into these abnormal structures that could be seen under a microscope (lewy-body dementia).



Dr. Lounsbury is a general neurologist practising in Sarnia. She attended Western University for undergraduate studies, and completed medical school and neurology residency training at the University of Ottawa.







# JOURNEY TO OWEN SOUND: TEAM IAN'S STORY

By: Barb Swanson

I don't remember first meeting Ian Shouldice. It feels like I've always known him. Neither of us could ever pinpoint our first introduction but we both remember our first date. I bumped into Ian on a summer afternoon in 2000. Later on, Ian phoned and asked me if I wanted to go to Anita's with him. Thinking Anita was someone Ian knew who was having a party, I accepted his invitation. He arrived at my door with a bouquet of flowers. It turns out Anita's was a Mexican restaurant.

Many phone calls, flowers, poems and outings later, I realized he was everything I wanted in a partner, and together we shared our lives for the next 22 years.

I remember being with Ian when he was diagnosed with Parkinson's disease in 2010. Neither of us knew what it was. I went to the Sarnia Public Library looking for literature on the subject and finding maybe two books total. We were fortunate that Ian became a patient of Dr. Jog at University Hospital in London. We also became acquainted with Parkinson Society Southwestern Ontario (PSSO). Now we had support – both medical and social.

We did our first Walk for Parkinson's in 2011. I went door-to-door in our neighbourhood asking for pledges. The next year we started soliciting pledges online too. The Walk was always a big priority for Ian.

Every year, a small group of family and friends would join us for the Walk along the waterfront in Sarnia, followed by lunch. We never missed a Walk, although we came to experience it differently. During the pandemic, we walked the track at the high school near our home. Over time, our Walk route became shorter. In 2021 we counted steps in our house as the Walk.

When Ian passed away in August 2022 I knew that he would want us to continue to walk. Ian's fight was now our fight. Last year is the first year we actually called ourselves Team Ian. My brothers, Cort and Larry, who both love to cycle, rode their bikes for two days to Sarnia, arriving the day before the Walk.

This year we plan to do the Walk in Owen Sound. I have been thinking about what Ian would want to happen to his ashes. Ian's father grew up in Lion's Head, and I have been remembering the stories he would tell about spending summers there as a kid: picking rocks in the fields, driving a tractor, going out on fishing boats, and homemade pies. When I learned of a scattering garden in Lion's Head, I knew it would be the perfect place. So this year, our team will walk in Owen Sound, before we scatter Ian's ashes in Lion's Head together.

Ahead of the 2024 Walk for Parkinson's, Barb's brothers Cort and Larry Egan are cycling to Owen Sound to raise funds for Parkinson Society Southwestern Ontario. Join us in cheering them on as they journey to join Barb for the Owen Sound Walk on September 7th!



## WHO ARE YOU WALKING FOR?

**SATURDAY, SEPTEMBER 7, 2024**

Brantford, Brant-Norfolk & Haldimand County  
– Mohawk Park

Registration 1:00pm, Walk 2:00pm

Goderich – Rotary Cove Pavilion #4

Registration 10:00am, Walk 11:00am

London & District – Springbank Gardens

Registration 10:30am, Walk 11:30am

Owen Sound – Bayshore Community Complex

Registration 1:00pm, Walk 2:00pm

South Grey Bruce & Hanover – Hanover Town Park

Registration 9:00am, Walk 11:00am

Stratford & 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 8, 2024**

Chatham-Kent – Kingston Park

Registration 12:00 noon, Walk 1:00pm

Grand Bend – The Grand Bend Legion

Registration 1:00pm, Walk 2:00pm

Oxford County – Roth Park

Registration 1:00pm, Walk 2:00pm

Port Elgin, Kincardine & Area – North Shore Park

Saugeen Shores

Registration 1:00pm, Walk 2:00pm

Sarnia-Lambton – Canatara Park

Registration 1:00pm, Walk 2:00pm

Windsor-Essex – Malden Park

Registration 12:00 noon, Walk 1:00pm

Visit [WalkforPD.ca](https://WalkforPD.ca) to Register or Donate.





# STRATFORD WALK SETS FUNDRAISING RECORD

2023 was a banner year for our largest fundraiser, the Walk for Parkinson's. Across our service area's 14 Walks, over \$544,000 were raised with nearly \$100,000 coming from Stratford. We continue to celebrate this amazing milestone.

When Barb Myers was first confronted with her partner Ron's Parkinson's diagnosis, she understandably needed time to process. But it wasn't long before the quiet reflection of this 20-year volunteer firefighter captain turned to tenacious resolve and she vowed to do something. She would find a way to increase awareness and raise funds for research into this disease. She reached out to Parkinson Society Southwestern Ontario.

The annual Walk for Parkinson's was the perfect vehicle for Barb to tap into her vast network and engage her friends and associates in the cause. She recalls informing her Facebook connections, letting them know her intentions, and being astounded by the immediate response of friends even from outside her immediate area. "Within minutes of posting, a team came together, and we started raising funds."

She and the other volunteers of the Stratford Walk team connected with private and corporate citizens in the area. "The generosity of this amazing community was incredible. Not unexpected, but still incredible", beams Barb.



.....  
*Stephen Owen is one of our four Community Engagement Coordinators, responsible for the Central Region (Oxford, Middlesex, Norfolk, Elgin, Perth and Huron).*

PSSO IN THE COMMUNITY - NORTH

## MEAFORD DANCING WITH PARKINSON'S:

PSSO launched our Meaford Dancing with Parkinson's program in November 2023 in partnership with Dancing with Parkinson's Canada. Since then, the group has grown significantly, supporting the mental and physical health of people in the rural community of Meaford. During classes, attendees practice researched-backed exercises designed to provide physical and emotional benefits, followed by social time with tea and cookies! We are thrilled to see how much this program has grown over the past six months.



Raising nearly half of the Stratford total was the team of Scott Dunbar and Bill Schafer. They were part of the fundraisers who worked their Stratford and area connections, culminating in fantastic results.

PSSO celebrated Stratford's success with some of the walking team at our recent Spring Conference in St. Mary's, expressing our deepest gratitude to the Stratford and area community.

The 2024 Walk for Parkinson's is again being held at Upper Queen's Park in Stratford. As you can probably imagine, the entire team is already plugging away on this year's fundraising efforts. We're looking forward to seeing what that community will do this year!

# MINDFULNESS AND PARKINSON'S DISEASE

On March 5, we hosted our "Mindfulness and Parkinson's Disease" workshop in Port Elgin. During the event, registrants were introduced to the concept of mindfulness by Social Service Worker Wanita Pelley from Anchor Counselling and Animal Assisted Therapy in Elmwood. We learned basic meditation skills to become mindful of our thoughts and help reduce stress and anxiety. We left the workshop with clear minds and new perspectives. We hope this introduction helps people incorporate mindfulness into their everyday lives.

PSSO IN THE COMMUNITY - CENTRAL



**From left to right:** Stephen Owen, Kaeleigh MacPhail (Woodstock Public Library), Rebekah Lindsay (Alzheimers Society Southwest Partners)

## UPPER THAMES TRIVIA NIGHT

In collaboration with Alzheimer Society Southwest Partners, our Trivia Night was convened by the Woodstock Public library and hosted at Upper Thames Brewery in Woodstock. UTB graciously provided space for the event and split the proceeds of the February Trivia Nights between AlzSWP and PSSO. Our thanks to Kaeleigh (WPL), Rebekah (AlzSWP) and Sarah (UTB) for an amazing fun-filled evening. \$200 were raised.

## OPEN MIC KNIGHT AT CASS

Orchestrated by College Avenue Secondary School (Woodstock) students and faculty, the open mic night event was a third-party fundraiser to raise funds for PSSO. Grade 11 student, Kylie, is following in her grandmother's footsteps in her fundraising efforts (see Pickleball tournament on page 12) for our organization. We are extremely thankful for the \$140 raised!



**From left to right:** Hannah Robinet (teacher), Natharie Dihansa, Isabel Hoekstra, Brian Mckenzie (teacher), Kylie West, Stephen Owen.





# PICKLEBALL TOURNAMENT

Held for the second year at the Flight Centre in Dorchester, the Pickleball tournament was a roaring success! A testament to the popularity of the tournament's cause, there was a waiting list of upwards of 20 players. Janet Noad and Vicki Carothers worked tirelessly to ensure a successful event. We were extremely grateful for the funds raised that day, and also to be able to raise awareness at the PSSO table. \$4,165.00 were raised.

## PSSO IN THE COMMUNITY - EAST

# COFFEE WITH A COP: AN IN-DEPTH MEETING WITH POLICE

Bringing Hope Close To Home means raising awareness and creating positive changes for people living with Parkinson's disease (PD). Police Officers play an important role in our communities, and in February, we were pleased that the Guelph Police Service hosted an information-sharing session with PSSO.

It all got started when PSSO staff approached Paul Hinchcliffe, an officer with Guelph Police Service's Community Resource Outreach department to discuss concerns from people with PD. The presentation of symptoms can make a person appear intoxicated and can lead to wrongful accusations of impaired driving and embarrassing, distressing interactions. The goal of this meeting was to share concerns and perspectives. PSSO will create more opportunities to speak with police officers in the near future.

Coffee with a Cop was well received by members, and news grew quickly. Many police departments across Southwestern Ontario followed suit and another Coffee with a Cop was held in Windsor, Ontario. Five members of the Windsor Police force joined clients of Windsor-Essex and spoke on mental health awareness and the appropriate

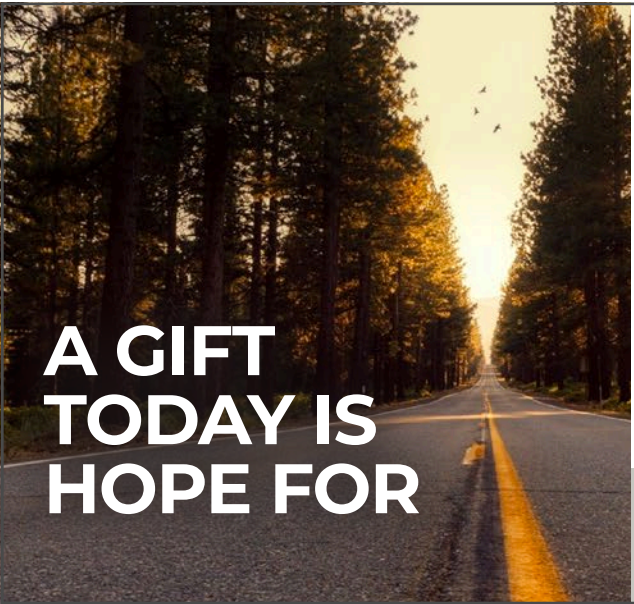


methods of interaction they use during traffic stops. A specialist from the fraud department attended to educate our members on common scams and fraud taking place and the best practices to avoid falling victim. They also emphasized what to do if you become a victim. "If there is an active threat or danger, never hesitate to call the police. If you are ever unsure call the non-emergency number and we would be happy to direct you to the appropriate officer for your concern".

Stay tuned for future opportunities to speak with your local police service!

## PSSO IN THE COMMUNITY - WEST

Over the past 6 months Parkinson Society Southwestern Ontario has been able to take part in many events in the West Region. We have been able to participate in 3 senior fairs/ community awareness events, as well as educational speaking opportunities with students in Restorative Care, Social Service Work and Nursing. PSSO has also been fortunate enough to be invited to participate in WE SERVE SENIORS. It is an organization that hosts meetings once a month in various cities across Ontario where organizations and professionals who assist in improving the lives of seniors connect with each other. Through this partnership members in the West Region have been fortunate enough to connect with professionals in Occupational Therapy, Police Service, and Financial Planning. Many more events have been planned for the upcoming year, and we are looking forward to many more opportunities ahead.



To leave a legacy is to sew 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.**





# THE 2024 SPRING REGIONAL PARKINSON'S CONFERENCES

## OWEN SOUND

### SPRING CONFERENCE RECAP

The Owen Sound Living Well conference was hosted on April 2 at the Bayshore Community Centre. With nearly 60 people in attendance at the event, it was wonderful to see the strong, supportive community blossoming in our North Region. The event featured presentations by Dr. Kelly Robb, a researcher from Wilfred Laurier University, and Michaela Harron, a registered dietitian from Collingwood. They spoke about novel research on the benefits of foot orthotics and how to get a balanced diet with Parkinson's disease. We also enjoyed a movement break with Rock Steady Boxing, as well as a delicious lunch. Special thanks go to Frances Morency for photographing the event. We look forward to hosting more events like this in Grey-Bruce!

## STRATFORD

### SPRING CONFERENCE RECAP

The Stratford & Area Living Well conference at the St. Mary's Golf and Country Club was an education event worth attending. With keynote talks by Dr. Angela Roberts of Western University and Dr. Heather Keller of Waterloo University. They spoke about Communication and Parkinson's, and Nutrition and Parkinson's, attendees left with great new knowledge. We recognized the huge success of Stratford's 2023 Walk for Parkinson's with a celebration cake. Pauline Shore led the Movement Break and an informative moderated Question and Answer session wrapped up our time together.

Made possible by:



## FERGUS

### SPRING CONFERENCE RECAP

Living Well with Parkinson's disease (PD) can mean different things to different people. Our Living Well conference in Fergus kicked off with a presentation from Alex Guennevig, Manager of Patient Services for the Wellington region. She gave us an overview of Home and Community Care Support Services (HCCSS) and the scope of services they provide, which are all covered by OHIP. Her presentation ended with a thoughtful discussion on system navigation, where we had the opportunity to share our thoughts and get some questions answered.

Next we heard from Terry Moore, neuromuscular physiologist, who demonstrated exercises specifically focusing on the health of the neck and back muscles for improving overall health and function. After lunch, we got moving again with Sarah Jane Burton and Leslie Fisher who run Park n' Dance in Guelph.

Our final presentation was by Christina Zahra Keating and Shannon Silva from Changing Tides Counselling. They covered navigating diagnosis, the benefits of movement and managing adaptations as our bodies change. By thoroughly discussing mental health, we were able to gain tools to cope with stress and grief, and share strategies to ensure that we are seeking help when we need it.

## SARNIA

### SPRING CONFERENCE RECAP

The final conference of the Living Well series took place at the Sunbridge Hotel and Conference Centre. PSSO was fortunate to welcome 115 participants to the event. We would like to thank Justine Davies and Khrista Boon for leading exercises throughout the day. Dr. Lounsbury (see Dr. Lounsbury's Q&A article on page 6-7) spoke on the topic of Non-Motor Symptoms and discussed characteristics of 12 symptoms and treatment options currently available. In the afternoon Angela Raffoul, RSW spoke on Chronic Pain Management. She was able to demonstrate the benefits of Tracking Activities, the Box Breathing technique, and the common causes of chronic pain.

## JOIN US FOR OUR FALL CONFERENCE



### OUR KEYNOTE SPEAKERS



**DR. ALFANSO FASANO**  
**Symptomatic treatment of Complicated Parkinson's Disease: What's New**



**DR. DEEPA DASH**  
**Sleeping with Parkinson's: Tips for Improving Sleep Hygiene**



**DR. KAYLENA EHGOETZ MARTENS**  
**Mobility, Falls and Freezing of Gait**

**SATURDAY,  
OCTOBER 26, 2024**

10:00 am to 3:00 pm  
Registration starts at 9:00am

#### PLACE

**DoubleTree by Hilton**  
30 Fairway Rd S, Kitchener

#### COST

\$50 per person  
for in-person or virtual

**Register at [pssso.ca](https://pssso.ca)**



# CAREPARTNER WORKSHOP, ARTHUR

In June, we hosted our Carepartner Workshop in the charming town of Arthur. We were pleased to welcome over 30 carepartners from our North and East regions for a day of learning and support. The workshop featured informative and interactive presentations, a delicious lunch, and most importantly, the opportunity for carepartners to connect with each other over shared experiences.

Our first presenter was Laura McDonald, from Canadian Mental Health Association (CMHA). Laura provided an interactive presentation on caregiver burnout and practicing self-compassion. She asked participants to think about their many responsibilities as carepartners, and consider ways to lessen their load. We learned how to assess our own stress level, and recognize when we need support. Her presentation encouraged participants to share their personal feelings about their roles as carepartners. We are so grateful to Laura for helping us create a safe space for our carepartners to feel heard and valued.

After enjoying thoughtful discussion over lunch, participants learned to mime from Dr. Kimberly Francis from the University of Guelph and two research students, Emily Fleming and Isabelle Kirby. They are examining the therapeutic benefits of miming for people with Parkinson's disease using techniques informed by Barbara Salsberg Mathews, founder of Mime Over Mind and professional mime who has PD. She has visited several support groups throughout the region to spread the word, and has been quoted in local and international publications, including the Davis Phinney Foundation and Parkinson's Europe. Barbara trained Emily and Isabelle to lead her workshop to help develop a protocol for a larger research study. They adapted the workshop for carepartners to encourage fun movements, imagination, all while explaining how these techniques could be incorporated into the everyday routines of people with Parkinson's and carepartners. Who knew that balancing a peacock feather in your hand could help improve balance, or that a flow ring could help broaden our range in motion?

We extend our gratitude to everyone who helped us make this workshop possible, including Never Enough Thyme for our wonderful lunch, the staff at Arthur Arena for accommodating us, our presenters for engaging and informing us, and most of all the carepartners who spent the day with us.

## Knockout-PD IN LONDON



Location:  
**DAMIAN WARNER FITNESS  
CENTRE-NORTH**  
755 Wonderland Rd. North  
London

**OPEN  
HOUSE**  
September 27th



**Push Back Parkinson's Together**  
knockoutpd@neuphysio.com  
(519) 434-3881

SUPPORTED BY:



JOIN us for a great workout to combat Parkinson's Disease and improve quality of life through non-contact boxing classes, offered 5 days per week.

\* THIS IS A PAID ADVERTISEMENT



## EMBRACING MINDFULNESS: Pathway to a Balanced Life

Mindfulness, a practice rooted in ancient traditions, has gained contemporary recognition for its profound benefits in managing stress, chronic pain, and enhancing overall well-being. At its core, mindfulness is the practice of being fully aware and accepting of the present moment. Jon Kabat-Zinn, a pioneer in mindfulness-based stress reduction (MBSR), identifies seven pillars of mindfulness: non-judging, patience, beginner's mind, trust, non-striving, acceptance, and letting go. These principles offer a roadmap for achieving inner peace and balance.

Mindfulness is not merely a philosophical concept but an evidence-based approach with tangible benefits. Research over the past 35 years has demonstrated its effectiveness in managing chronic pain. Mindfulness reduces pain perception, lessens the need for pain medications, and alleviates psychological distress such as depression, anxiety, and worry. By fostering a mindful awareness of our experiences, we can change our relationship with pain, viewing it with curiosity and non-judgment, rather than resistance and fear. This shift can lead to long-lasting improvements in both physical and emotional well-being.



Wanita Pelley is a Registered Social Services Worker and owner of Anchor Counselling and Animal-Assisted Therapy in Elmwood, Ontario. She uses animal assisted therapy and mindfulness therapy to support people of all ages.

Incorporating mindfulness into daily life can be simple and practical. One can start with mindful breathing, paying full attention to the breath's rhythm without trying to change it. Engaging in everyday activities with focused attention is another effective practice. For instance, while washing dishes, notice the sensation of the water, the texture of the soap, and the sound of the scrubbing. This focused awareness can transform mundane tasks into moments of mindfulness.

Guided meditations can also be beneficial. Many resources are available, including apps and online platforms, offering guided sessions that range from a few minutes to longer practices. Additionally, spending time in nature, listening to the sounds of the environment, and observing the beauty around us can enhance mindful awareness.

Mindfulness is not about escaping reality but embracing it fully. It teaches us to live in the moment with acceptance and without judgment. By adopting mindfulness practices, we can cultivate a balanced, healthy life, equipped to handle stress and pain with greater resilience and calm. The journey to mindfulness starts with a single moment of awareness, leading to a lifetime of benefits.



# PSSO HARNESSSES TECHNOLOGY FOR EDUCATION & SUPPORT

Parkinson's disease (PD) affects people physically, emotionally and socially. New opportunities for education have been made possible by technology.

**Education at your fingertips**

Parkinson Society Southwestern Ontario (PSSO) uses many digital platforms to spread essential resources and information. From interactive modules to online webinars, people can access a multitude of knowledge from the comfort of their own homes. An eight-part course called the Parkinson's Education Program (PEP) Online explores several facets of Parkinson's disease (PD), such as symptom management, communication techniques and medical therapies. This intuitive web-based platform gives carepartners and medical professionals the resources and information they need to offer the best care.

**Key Programs**

**GETTING CONNECTED**

The GETTING CONNECTED Parkinson's Referral Program helps healthcare professionals connect individuals with Parkinson's disease and their carepartners to PSSO at any stage of the disease. This program provides people with Parkinson's and their carepartners with the necessary information and support. It bridges the gap in the system by connecting clients with information, support, and community resources, thus aiding both clients and healthcare professionals.

**NEWLY DIAGNOSED SERIES**

A Parkinson's diagnosis can be overwhelming. Take time to learn about its physical and emotional impacts.

Our Newly Diagnosed 4-part series helps you start your journey to living well with Parkinson's. Topics include: getting the news and sharing the news, types of grief and loss, self-care, Parkinson's 101, and living well with PD. Connect with others diagnosed within the last 2 years and access tailored resources.

**Speech and Language**

**LOUDER, CLEARER**

You may notice people asking you to repeat yourself more often as speaking clearly becomes harder. PD can affect speech volume, tone, rhythm, and rate, often leading to softer speech, less emotion, and slurred or mumbled words. PSSO offers group sessions led by speech-language pathologists, where you can learn and practice skills for louder, clearer speech in a relaxed, social setting both in-person and virtually.



**PARKINSON'S MUSIC CHOIR**

The Parkinson's Music Choir offers a unique and holistic approach to supporting individuals living with Parkinson's disease. Through Vocal Intonation Therapy and therapeutic singing, participants engage in vocal exercises and singing activities that not only address speech and respiratory challenges, but also promote psychological well-being and social interaction. With the cost covered by Parkinson Society Southwestern Ontario, individuals can access this program without financial burden, allowing

them to reap the physical, emotional, and social benefits of music therapy.

**COUNSELLING PROGRAM**

A long-standing partnership with Kings University College (at Western) results in incalculable benefits for everyone involved – most importantly those who access counselling services. Through this collaboration, social work students offer free, short-term counselling to individuals affected by PD. They enthusiastically utilize their training and education to effect positive change. Sessions are solution-focused – the client's concerns are heard, but the focus is on utilizing compassion, empathy, and empowerment to draw out the strengths already present in the person. Counsellors are trained in the basics of Parkinson's, recognizing that the client is the true expert in their own story, including diagnosis and symptoms. Counsellors are not advice-dispensers, but rather listen with care, asking thoughtful questions that allow someone to explore their own strengths and solutions. What about confidentiality? Conversations are strictly protected and may only be broken in the event of disclosure of imminent harm, historic/ongoing abuse, or subpoena. The exception to that rule is that because counselling is provided by students engaged in their own learning, from time-to-time, they will seek guidance from a supervisor, many of whom have decades of experience in the field. Students may, in broad strokes, using no identifiers, and maintaining the privacy of our clients, seek advice. This is for the own growth. We encourage anyone experiencing anxiety, depression, grief, or any other challenges associated with PD to access counselling



.....  
*Elsa Susan Mathew is a placement student from Conestoga College in Management of Community Services. She holds a Bachelor's degree in Sociology and a Master's degree in Business Administration with a specialization in Human Resources.*  
.....

via: [pssso.ca/programs-services/counselling-program/](https://pssso.ca/programs-services/counselling-program/) or call 519.652.9437 EXT 206 in September.

**MONTHLY WEBINARS**

PSSO holds webinars which explore a variety of topics such as "Fraud in the Community," or "Successful Workplace Navigation." To stay up to date on upcoming webinars, please contact us.

Our dedicated team is here to assist you. You can contact us toll-free at 1-888-851-7376 or locally at (519) 652-9437 or email us at [info@pssso.ca](mailto:info@pssso.ca).

**CONNECT WITH US & STAY INFORMED**

Parkinson Society Southwestern Ontario is dedicated to supporting the Parkinson's community. Staying connected is vital! Reach out to us to keep the spirit of community alive and prevent loneliness. Let's stay united and strong together!

[pssso.ca/stay-informed/](https://pssso.ca/stay-informed/)

[pssso.ca/contact-us/](https://pssso.ca/contact-us/)

Whether you were connected with us through GETTING CONNECTED, "Connect with Us," or "Stay Informed," benefits for clients include but are not limited to: connecting with individuals with Parkinson's to information, community programs, and support services, providing education resources through the Parkinson's Update magazine, E-News, conferences, webinars, and workshops; providing quality publications on upcoming and ongoing research; and offering access to a toll-free information and referral line: (519) 652-9437 or 1 (888) 851-7376 EXT 204 or by e-mail [info@parkinsonsociety.ca](mailto:info@parkinsonsociety.ca)



# CYBERSECURITY AND CYBER-ENABLED CRIME TARGETING SENIORS

As the digital world expands, there is an increased threat of cyber crimes. With the convenience of online commerce, shopping and communication, older adults are drawn into the digital world, often without the same level of caution or technical knowledge as younger generations. Cyber criminals exploit this vulnerability in many ways and use tools to spoof legitimate organizations to convince seniors to hand over their hard-earned funds.

According to the Canadian Anti-Fraud Centre (CAFC) in 2023, Canadians reported losing more than \$572 million to fraud. It is estimated that only 5 to 10 percent of victims report their frauds to law enforcement or to the CAFC. In 2023, Canadians lost over \$309 million to investment frauds, with many of the frauds involving cryptocurrency. These schemes lure victims with the promise of guaranteed financial opportunities and “quick cash,” convincing people to invest in fake investment ventures. Most often the target of these frauds are seniors, who lose on average 33 percent more than the other demographics.

Another common method is phishing, which is when criminals use tactics to trick their victims into giving personal information or clicking on dangerous links. Criminals send their victims unsolicited emails, text messages, phone calls or pop-ups advertisements pretending to be from legitimate organizations such as financial institutions, businesses or government agencies. These often request personal information or direct the recipient to a fake website designed to steal login credentials, passwords and/or bank account information. Seniors unfamiliar with such tactics may inadvertently provide information, leading to identity theft or significant financial losses. No one should ever download and use remote entry software or provide access to their devices or computers.

Fraud prevention, education and awareness are crucial to protect yourself and loved ones from cyber-enabled crime. Get Cyber Safe is an educational website about adopting cyber security practices, such as securing your devices, accounts

and connections by using strong, unique passwords, enabling two-factor authentication, and being skeptical of unsolicited phone calls and emails.

Families and caregivers also play a vital role in safeguarding seniors. Open communication about online activities and potential threats can help seniors feel comfortable about seeking help or advice. Additionally, utilizing cyber security tools such as anti-virus software and secure browsing practices can provide an added layer of protection.

## WHAT CAN YOU DO TO HELP PROTECT YOURSELF AND YOUR LOVED ONES:

**Do your research and educate yourself.** The Canadian Anti-Fraud Centre should be your first stop. They provide information on the emerging frauds and ways to protect yourself. Most financial institutions and police services also have information on how to protect yourself from cyber crime.

**Slow down and be cautious.** Criminals who engage in cyber-enabled fraud tend to apply a sense of urgency to their victims. By rushing their victims, they force them to make decisions quickly with the hope that the victims do not become suspicious. If you feel pressured or suspicious, consider not proceeding with the request.

**Do not be afraid of asking for help.** Many people do not understand the complexities of the Internet and online activities. Criminals may attempt to exploit this lack of knowledge to target victims online. Criminals often target the same victims repeatedly, even after successfully victimizing them. Remember, if you become a victim of a fraud or know someone who has been a victim, contact your local police service to report the crime and report it to the CAFC at 1-888-495-8501 or online on the Fraud Reporting System, even if a financial loss did not occur.

Understanding the risks of online fraud is essential. Through education, vigilance and support, we can be better protected in the ever-evolving landscape of cyber-enabled crimes.



Dylan Innes is a Provincial Constable with the Ontario Provincial Police in South Bruce.

# EFFECTIVE NAVIGATION OF TRAVEL AS AN INDIVIDUAL WITH A DISABILITY

Travelling with a disability can be an incredibly fulfilling, smooth and enjoyable experience with careful planning and the right resources.

**Before you Travel:** It is important to plan ahead by researching your destination thoroughly to ensure it is accessible. Look for hotels, restaurants, and attractions that can accommodate your needs, and inform them in advance about your specific requirements, e.g.: using a wheelchair or walker. Planning appropriate transportation ahead of time will also assist in a smooth travel experience. There are many rental/ transportation companies who outline accessible options to book prior to arriving to your destination. Finally, ensure you have the appropriate travel insurance to cover any medical emergencies that may arise and have medical documentation on hand (doctor's note, list of medications, etc.).

**What to Bring:** When travelling with medication, it is important to let your doctor know that you will be away and for how long. This will enable them to provide you with a doctor's note that details your condition, date of diagnosis, the necessity of the medication and contact information. In order to cross borders, your medication needs to be in the original packaging with the prescription label intact. Ensure that you bring photocopies of prescriptions should you require a refill while travelling.

**Crossing an International Border:** Upon arriving at the international borders, be prepared to declare your medication and provide the necessary documentation that states the condition the medication is treating, dosage, and frequency. Keep in mind that not all medications can be taken to all countries. Foreign Canadian Representatives can go through your list of medications and inform you of the classification (legal or illegal) as well as the allowed dosages. A list of Foreign Canadian Representatives from other countries can be found on the Government of Canada's website.

If CBSA (Canadian Border Services Agency) believes a person may be intoxicated and they claim that they are experiencing symptoms of PD, OPP/Paramedics are often called to assist CBSA with further assessment. It is helpful if you have the appropriate documentation showing proof of diagnosis, and this information can be easily confirmed with a couple phone calls or inquiries if necessary. If officers still feel the need to obtain a breath sample, they will conduct this right at the border, but often there are several key factors missing. Furthermore, don't hesitate to connect with CBSA if you have further questions about border crossings, as they are the experts. Call 1-800-461-9999 for support.



Jim Kennedy is a duly registered member of the Travel Industry Council of Ontario and an active member of the ACTA (Association of Canadian Travel Agencies). Prior to becoming a Travel Concierge, he was a public speaker for Stress Management Workshops.

## TIPS AND TRICKS FOR THE BEST EXPERIENCE WHILE TRAVELLING

- **Mobility Aids:** Bring portable mobility aids like foldable wheelchairs or walkers that are easy to transport.
- **Rest Periods and Tailored Itinerary:** Schedule regular rest periods to avoid fatigue. It is best to plan these around your ON/OFF Times or during times of the day you are most active. Be open to changing plans if something isn't working out as expected.
- **Health Check:** Have a check-up with your doctor before travelling to ensure you're fit for the journey.
- **Pack Smart:** Bring all necessary medications, a list of your medical conditions, and contact information for your healthcare providers in your personal item/carry-on to ensure they are with you at all times.
- **Accessible Adventures:** Seek out accessible tours and attractions that cater to your interests.



# Introducing Our 2024 Parkinson Society Southwestern Ontario GRADUATE STUDENT SCHOLARSHIP RECIPIENTS

The Parkinson Society Southwestern Ontario Graduate Student Scholarship Program is dedicated to fostering the next generation of Parkinson’s disease researchers. By providing up to \$25,000 CAD to exceptional graduate students, we support innovative research and training aimed at uncovering new insights into Parkinson’s disease (PD). This year, we are proud to introduce four outstanding scholars whose groundbreaking work holds great promise for advancing our understanding and treatment of PD.

Through the dedication and innovative research of Juan, Mojtaba, Nate and Viveka, we move closer to unraveling the complexities of Parkinson’s disease. The Parkinson Society Southwestern Ontario is honoured to support these promising young scientists in their quest to improve the lives of those affected by PD.



**RESEARCHER:**  
**Juan Jurado**, Western University

**PROJECT TITLE:**  
**Oxidative stress-induced Nrf2 misfolding in Parkinson’s disease**

Oxidative stress and aging are the primary risk factors for Parkinson’s disease (PD). The protein Nrf2 is particularly important in fighting oxidation and the associated damage in the brain as it activates antioxidant enzymes. Nrf2 is regulated by another protein called Keap1. These two proteins can be damaged under excessive oxidative stress conditions and thus contribute to neuronal death. In my study I will delve into how exactly Nrf2/Keap1 malfunction contributes to PD. I will study the different expression levels, localization and activation of Nrf2/Keap1 in brain samples of PD patients using biochemical approaches and microscopy. Furthermore, by using well-established PD cell models co-expressing Nrf2/Keap1 with the PD-associated protein  $\alpha$ -synuclein, we will study their interactions in PD. Cannabidiol (CBD), one of the main non-psychoactive molecules of Cannabis sativa, is a strong antioxidant that may mitigate the damage to Nrf2/Keap1, activate the Nrf2 pathway and thus slow down or even prevent neurodegeneration in PD. In summary, our study will elucidate the Nrf2 and Keap1 pathway in PD and assess CBD as a potential therapeutic for PD.



**RESEARCHER:**  
**Mojtaba Sharafkhah**, Western University

**PROJECT TITLE:**  
**Examining neural substrates of freezing of gait with structural MRI in patients with Parkinson’s disease**

Parkinson’s disease (PD) is the second most common and fastest-growing neurodegenerative disease in the world. PD is characterized by both motor and non-motor symptoms. One significant motor symptom is freezing of gait (FOG), where patients experience sudden, involuntary interruptions in walking. FOG affects about 50% of PD patients, leading to falls and fractures. Unfortunately, there are no effective treatments for FOG, necessitating more research to understand its underlying mechanisms. Dopaminergic pathways, especially those involving the striatum—a part of the basal ganglia—and midbrain regions like the ventral tegmental area (VTA) and substantia nigra pars compacta (SNc), are crucial in the pathophysiology of FOG. Previous studies have shown MRI abnormalities in the striatum, VTA, and SNc in PD patients with

FOG. However, these studies are limited in evaluating whole responsible brain regions in FOG versus specific subregions. The current study addresses this gap using advanced diffusion MRI (dMRI) techniques to examine specific subregions within the striatum and midbrain responsible regions between PD patients with and without FOG. Participants are recruited from the Parkinson’s Progression Markers Initiative (PPMI) database and categorized based on their FOG status (PD-FOG and PD-nonFOG). A novel parcellation technique is run on baseline MRI of all patients to evaluate the integrity of parcellated striatum, VTA/SNc compared to the integrity of the whole striatum, VTA/SNc between PD-FOG and PD-nonFOG patients. Focusing on subregions rather than whole regions, this study aims to uncover specific structural differences linked to FOG, potentially leading to objective prognostic MRI biomarkers and therapeutic targets for this debilitating symptom.



**RESEARCHER:**  
**Nate Rothery**, Western University

**PROJECT TITLE:**  
**Developing a prognostic model for freezing of gait in Parkinson’s disease**

This research project introduces a method to predict the onset of Freezing of Gait (FOG), a debilitating motor symptom in Parkinson’s disease (PD), by leveraging Magnetic Resonance Imaging (MRI) and machine learning. FOG significantly reduces patients’ quality of life, and unlike other PD motor symptoms, FOG is notably resistant to treatment. Current therapeutic strategies are often ineffective because little is known about the underlying causes of FOG, and researchers are working on models to determine who is likely to develop FOG. Previous attempts at predicting FOG onset using neuroimaging alone have not been accurate enough for clinical use. To address this, our project focuses on analyzing changes in brain structure and connectivity, particularly in regions associated with motor, cognitive and sensory functions, which are commonly disrupted in patients with FOG. By identifying these alterations, we aim to develop a robust predictive model for FOG onset. This research has the potential to transform clinical practice by enabling personalized medicine approaches and improving the selection process for clinical trials. Identifying patients at risk of developing FOG can enhance trial efficiency and reduce costs. Moreover, this research could pave the way for new therapies designed to prevent, delay or modify the progression of FOG, ultimately improving outcomes for patients with PD.



**RESEARCHER:**  
**Viveka Pimenta**, Western University

**PROJECT TITLE:**  
**Investigating Parkin Oxidation and its Impact on Parkinson’s Neurodegeneration**

Parkinson’s disease (PD), a devastating neurodegenerative condition, is becoming increasingly prevalent in our aging population, yet the events leading to neuron death remain unclear. Current treatments aim to alleviate symptoms, but none address the cause of neurodegeneration, leaving a cure for PD elusive. Disease progression is marked by significant neuron loss in the brain region responsible for mobility, caused by oxidative damage to the neurons’ energy-producing mitochondria. During oxidative stress in PD, the enzyme parkin prevents cell death and neuron loss. However, the structure of parkin is inherently vulnerable to oxidation, and its protective role in PD requires recruitment to a highly oxidizing environment. The objective of this research is to determine the mechanism and consequences of parkin oxidation at the molecular and cellular levels. Understanding parkin oxidation in relation to its neuroprotective activity is essential for identifying the events that link oxidative stress to the death of motor neurons. This groundwork has the potential to advance the development of new and effective PD treatments aiming to slow neurodegeneration. In partnership with Parkinson Society Southwestern Ontario, this work aims to boost community awareness of scientific findings and provide an underserved population with educational resources to strengthen support systems.





## RESEARCHERS STUDYING EFFECTIVENESS OF LASER LIGHT THERAPY AS TREATMENT FOR PARKINSON'S

Researchers at the University of Windsor hope to shed light on a possible novel treatment for Parkinson's disease, thanks to the donation of a device that uses lasers to stimulate the brain.

Canadian manufacturer Theralase Technologies has donated equipment for a ground-breaking clinical study into photobiomodulation as a treatment for Parkinson's. Photobiomodulation, or PBM, uses low-level light to stimulate cells and promote healing.

"We're excited to begin the very first randomized placebo-controlled trial on laser light therapy in Parkinson's patients," said Kinesiology professor Anthony Bain, who is leading the study. "We are especially grateful to be collaborating with Theralase on the project, and for their generous donation of the lasers."

Dr. Bain is working with professors Dr. Sean Horton, Dr. Paula van Wyk and Chad Sutherland, all from UWindsor's Faculty of Human Kinetics. They are collaborating with Windsor chiropractor Luigi Albano of Walkerville Chiropractic.

People with Parkinson's often experience tremors, but as the disease progresses, they may struggle with walking and talking, and can experience memory loss, chronic pain, fatigue, depression, anxiety, loss of the sense of smell and other non-motor impairments.

PBM is a promising therapy, Dr. Bain said. "Preliminary studies and animal experiments exploring the use of PBM in Parkinson's disease have demonstrated positive outcomes, including potential improvements in motor function and a reduction in symptoms."

While PBM is considered an experimental therapy, it is non-invasive with few side effects.

Specifically for this study, Theralase has designed and manufactured a pair of devices that wrap around the head. One contains four low-temperature lasers, or cool lasers, that apply low-level light that permeates the skull. The other is a placebo device containing very low-powered lasers that do not permeate the skull.

As is common in double-blind studies, neither the patient

nor the researchers know which device is which, ensuring the reliability of the research findings.

The research project—the subject of study by PhD student Brooke Shepley—is additionally funded by Parkinson Society of Southwestern Ontario and the WE-Spark Health Institute.

To learn more about the study, contact [Anthony.bain@uwindsor.ca](mailto:Anthony.bain@uwindsor.ca) or phone 519-253-3000, ext. 4069.



Sarah Sacheli is an award winning writer/ editor and is currently the Communications Coordinator at the University of Windsor. She is working alongside Brooke Shepley and her fellow team of PhD students, who brought this project to the clients of PSSO.

## VOLUNTEER FACILITATOR SPOTLIGHT

Volunteer facilitators are the backbone of our Support Groups. Their presence is seen when the groups gather each month. However, it is their dedication to planning, organizing presenters, sourcing snacks and attending monthly Community of Practice meetings with PSSO staff that you may be less familiar with. It is with extreme gratitude that we recognize two of the Central Region's Support Group Facilitators.



**CATHERINE MCBRIDE**

St. Thomas' Support Group is in great hands with Catherine! The group she facilitates meets at St. Thomas Seniors' Centre. The group's participants benefit greatly from Catherine's focus on bringing in guest presenters to talk to them when she can find someone in her area. At Christmastime she had a music group, Yukes of Hazzard, entertain the group's participants. Catherine's passion for the Parkinson's community shines through as she facilitates fantastic conversations with the group. The St. Thomas Support Group meets on the second Tuesday of each month at 2pm. Connect with PSSO to join the St. Thomas Parkinson's Support Group.

**KERRY JARVI**

Dropping in on Kerry Jarvi at Woodstock's Support Group is always a treat because of the way she smoothly and efficiently runs meetings. Driven by her experience with a close family member who had Parkinson's, Kerry's desire to make connections with folks in the Parkinson's community is evidenced in her sparkling eyes and welcoming smile. Kerry chooses to devote the volunteer hours her employer, the City of Woodstock, grants her to facilitate the group. Each month she leads engaging and informative conversations. The Woodstock Support Group convenes at Chartwell Oxford Gardens on the last Monday of each month at 1:30pm. Contact PSSO to get connected with the group.





IN MEMORIAM

We offer our sympathy to the families whose loved ones have passed away between December 1, 2023 and June 30, 2024.

Lobba Albano	Theresa DeVogelaere	Liz Hewitt	Maria Ramalheira
Richard Archer	Ron D’Hulster	Kurt Hougesen	Stewart Reynolds
Joan Attwood	Jim & Karen Dickison	Oscar Hudon	Shirley Richards
Bill Ball	Imelda Drake	John Jones	Jean Robbins
John Barnes	Don Edgar	Hyo Kim	Norm Robertson
June Bell	Timothy Edwards	Joanne King	Don Ross
Joanne Bernard	Eva Marlene Fagan	Leo Labadie	Anne Salters
Ronald Billings	Barry Fay	Jean Lassaline	Joe Scandinavo
Bradley Boyle	Heather Feick	Jack Legault	Ron Schiedel
Veronica Bozek	Diana Figg	Jake Levesque	Dan Serbert
Frank Breier	Linda Firman	Mary Loree	Robert Seyler
JoAnn Brodie	Donald Forward	Dan Lucio	Hal Sharpe
Mary Broome	June Funck	Lorna MacEachern	Carmine Sim
Herbert Campbell	Mike Fyfe	Audrey MacIntyre	Joan Sinclair
Suzanne Tang Koon Cheong	Lois Gabel	John MacIsaac	Gerald Skinn
Ralph Clark	Charles Gardiner	Isabel Mandich	Nancey Slatter
Bill Sr. Clawsie	Patty Gardner	Antonio Matos	Donald Slumskie
Brenda Clingersmith	Wayne Garner	Mary Lou Matteucci	Costas Spanos
Gary Cook	John Gillis	Michele McComb	Clyde Spencer
Peter Cook	Nellie Goossens	Marilyn McCracken	Frank Stojdl
Carol Crossman	Donna Graham	Mike McIsaac	Domenico Stramacchia
Gus Cuthbert	Martha Gubbels	John McMahon	Irene Thomas
Joseph De Quick	Louise Hachman	Gail Monk	Len Tighe
Johan De Schiffart	Scott Halpenny	Ruby Montgomery	Jim Tsujita
Brigida De Sousa	John Hamilton	Harvey Postma	Margaret VanderKaden
Claus Demczynna	Mary Hendrix	Ted Powell	Gwen Weston
Mary Dennis	Katie Hesch	Stuart Radke	Alan Yardley

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.

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 [pssso.ca/how-to-help/hero-of-hope/](https://pssso.ca/how-to-help/hero-of-hope/) or call 1-888-851-7376.

WE REMEMBER

Joanne Bernard

In this world, certain people shine bright and Joanne Bernard was one of them. Joanne started her time with Parkinson Society Southwestern Ontario as a volunteer because of her personal passion for the cause. In August of 1998, she began her career when she was hired as the Coordinator of Volunteer Development and Administration working on things from support groups to fundraising walks.

From that day forward until May 4, 2024, Joanne remained committed to the organization serving for 25 years. She exemplified a strong commitment to the mission, was a team player and was a talented and professional leader. She was always thinking about and advocating for putting people with Parkinson’s first.

Although Joanne was truly passionate about her work, she lived a balanced life of serving in the community and putting her family first. Her daughters Hannah and Sara were her pride and joy. She was proud of her girls and their accomplishments. When I turned on her computer after her passing, there was a picture of her and the girls as the screensaver, a gentle reminder of what she valued most.

Joanne was kind and caring, and had a great sense of humour. Joanne’s quick wit brought us all laughs and smiles in our time together as a staff team. She had the best one-liners.

Joanne was a mentor. She always made time for others. She was there to offer a listening ear when you needed and she would share from her experiences and had a positive perspective to share.

Anyone who knew Joanne is forever blessed.

Losing Joanne has left a huge hole in our organization. Although Joanne was taken way too soon, she will be forever in the minds and hearts of everyone in the Parkinson community of Southwestern Ontario and beyond.

— Shelley Rivard







## WHO WILL YOU WALK FOR?

### SATURDAY, SEPTEMBER 7, 2024 .....

Brantford, Brant-Norfolk & Haldimand County –  
Mohawk Park

Goderich – Rotary Cove Pavilion #4

London & District – Springbank Gardens

Owen Sound – Bayshore Community Complex

South Grey Bruce & Hanover – Hanover Town Park

Stratford & Area – Upper Queen's Park

Waterloo Region – Kiwanis Park

Wellington-Dufferin – Centre Wellington Sportsplex

### SUNDAY, SEPTEMBER 8, 2024 .....

Chatham-Kent – Kingston Park

Grand Bend – The Grand Bend Legion

Oxford County – Roth Park

Port Elgin, Kincardine & Area –  
North Shore Park Saugeen Shores

Sarnia-Lambton – Canatara Park

Windsor-Essex – Malden Park

For more information  
please visit [walkforpd.ca](http://walkforpd.ca)

**parkinson** SOCIETY  
SOUTHWESTERN  
ONTARIO