THE PARKINSON'S UPDATE

WINTER/SPRING 2026
ISSUE 83

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Parkinson SOCIETY SOUTHWESTERN ONTARIO

A MAGAZINE FOR THE PARKINSON'S COMMUNITY OF SOUTHWESTERN ONTARIO

FROM THE CEO'S DESK


Shelley Rivard

As we begin 2026, it's a time to reflect on our successes and look ahead to what's next for Parkinson Society Southwestern Ontario (PSSO).

Thanks to your incredible support, **2025 was an outstanding year.** WALK for Parkinson's continued to grow, welcoming new and returning participants and raising an amazing **$575,000** in support of our mission. During Parkinson's Awareness Month in April, we introduced flag-raising ceremonies across the region, helping to raise awareness of Parkinson's disease and its impact on individuals and families. We also delivered four Living Well Conferences throughout southwestern Ontario, bringing education, connection, and Hope Close to Home.

Looking ahead, we are developing a new **strategic plan** that will guide PSSO over the next three to five years. With our strong focus on serving people affected by Parkinson's in southwestern Ontario, this plan will help ensure that we continue to meet the evolving needs of our community.

Education remains a cornerstone of our work. Through conferences, workshops, support groups, webinars, information packages, and one-on-one consultations with our Information and Referral Specialist, we help individuals and families connect to resources and feel supported every step of the way.

Our PEP Online for Community Caregivers program continues to make a meaningful impact by educating healthcare workers, improving care, and enhancing dignity for people living with Parkinson's in long-term care and retirement homes.

We are also proud to support local research through our **Graduate Student Scholarship Awards.** Thanks to our partnership with Mitacs, we've been able to expand the number of research projects we support, strengthening our commitment to advancing knowledge and care.

Wherever home is for you, we hope to see you at a conference, workshop, support group, or one of our Walk for Parkinson's events. With PSSO, you are never far from home.

As we move forward in 2026, we're excited to share what's ahead. Stay connected, stay safe and healthy — and remember, **we're in this together.**

Shelley Rivard

Shelley Rivard, CEO

✉ **info@psso.ca**
🌐 **www.psso.ca**
ParkinsonSocietySWO
parkinsonswo

MISSION STATEMENT

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

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APRIL AWARENESS

Parkinson's is often understood through what is visible, yet much of its impact remains unseen. Behind every diagnosis is a story shaped by emotion, resilience, and connection—stories that deserve to be heard.

With this we will begin our April awareness campaign, **Real Stories, Real Strengths** to remind the community that Parkinson's is touching every part of a person's life, in ways that are often invisible to others. We aim to help people understand not only the challenges faced by those living with Parkinson's, but also the quiet strength that carry them forward each day.

This year, we chose to focus on the people's personal journeys and shared experiences to make others feel less alone and that give them the hope to keep moving ahead even when the path changes. Members of the Parkinson's community generously shared their personal journeys, speaking about the small victories that mattered, the adjustments that allowed them to continue doing what they love in new ways, and the compassion they found in offering comfort to others navigating similar struggles. Their honesty created a sense of connection and reassurance, reminding those newly diagnosed that although life may change, hope, purpose, and meaning remain within reach.

On April 10th, we invite communities across southwestern Ontario to join us once again for our flag-raising ceremonies. These flags stand as symbols of unity and recognition, gently affirming to every person living with Parkinson's that they are seen, supported, and never alone.

And now, we invite you to share your own personal stories with us at **info@psso.ca**. Your stories strengthen our community and deepen understanding, helping others recognize the realities of living with Parkinson's. By sharing, you highlight the power of **Real Stories, Real Strengths.**

EVERY STEP BRINGS HOPE

On September 6 and 7, we celebrated the 30th Annual Walk for Parkinson's, three decades of community, compassion, and commitment to those living with Parkinson's. The PSSO team was moved by the continued generosity and dedication of clients, donors, sponsors, and supporters who walk with us year after year in the fight against Parkinson's.

In 2025, we raised over **$575,000!** Fourteen Walks across southwestern Ontario brought communities together to raise awareness, encourage others, and ensure no one faces Parkinson's alone.

To every participant, volunteer, donor, and sponsor, thank you. Your passion and efforts have made this year's Walk for Parkinson's an inspiring success. As our largest annual fundraiser, this event keeps funds within the community, directly supporting vital programs, services, and educational resources throughout southwestern Ontario.

Your contributions also help us expand into new communities, ensuring that hope, care, and connection are always close to home for individuals and families affected by Parkinson's.

From all of us at PSSO, thank you for walking with us. Your unwavering support strengthens our mission and gives hope to thousands across our region. We look forward to walking with you again on **September 12 and 13** at this year's Walk for Parkinson's!

2025 TOP WALKERS

Clare Poechman	$21,347.00
Scott Dunbar	$15,185.45
Bill Schafer	$12,606.77
Stuart Selby	$10,476.85
Jennifer MacNicol	$8,575.02
Chris Evans	$7,292.99
Carolyn Young	$5,833.47
Erica Miko	$5,515.69
Robert Ecclestone	$5,039.25
Tony Ryan	$4,468.90

THE **2025 WALK FOR PARKINSON'S** RAISED **OVER**

$575,000,

SURPASSING OUR **ORIGINAL GOAL!** ALL FUNDS GO BACK INTO THE **LOCAL COMMUNITY,** PROVIDING SUPPORT SERVICES AND RESOURCES FOR THOSE AFFECTED BY PARKINSON'S.

2025

WALK FOR PARKINSON'S SPONSORS

Toyota Motor Manufacturing Canada Inc.

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A DREAM REALIZED

By: Barb Myers and Ron Harrison

Have you ever known someone who could diagnose an engine problem just by hearing it drive by? Ron Harrison is one of those guys. The second of five kids, he grew up in his dad's shop. Selling Christmas trees at the age of 12 for a 25-cent commission. Pumping gas by age 15. Tinkering with motors and learning the shop talk all the while. Through high school, he worked in excess of 40 hours a week while still attending class – except for the early morning ones. He typically worked until midnight on whatever engines he could get his hands on.

Throughout the years, he worked for his dad's shop, Eric's Service Centre, in Stratford, Ontario, and in 2006, he bought the business from his parents and carried on with the name. Everyone loved the customer service at that garage. If you brought your car in for an oil change, you could count on it being topped up with windshield washer fluid, the hinges oiled, all lights checked, the tire pressure adjusted, and you'd likely get a ride to work if you needed one.

Ron loves cars.

Then, it started. A small tremor in his right hand. Delays in the medical system, coupled with the fact that men in their 60s typically often don't speak up about health concerns, add in the pandemic in 2020, and it took a while to get on the right track toward a diagnosis and medication. But it was Parkinson's disease, alright.
In December of 2020, Ron was forced into early retirement. Selling his shop was a difficult but necessary decision. It was time for him to focus on fixing his own machine rather than everyone else's.
Five years into the disease, Ron is still pretty lucky – as lucky as one with PD can be. His drug regimen allows him to golf three times a week with a group of buddies in the summer months. Usually only nine holes and always with a cart, but he still out drives most of them and has some of the best scores of the group, so he's doing okay, relatively speaking.

One of the blessings that has come from his early retirement – aside from attending all his grandkids' sporting events – has been tackling a lifelong dream of building a race car. And who better to do it with than his own son? Rod, who also owns his own business, has been able to juggle his schedule around his two busy kids and the challenges of operating Harrison Heating and Cooling, to assist in the build. Countless hours have been spent researching and sourcing the right car, and then all the parts to come up with the beauty that hit the tracks this summer for their first season of racing. They started out with a 1991 Ford Mustang Fox body. Original paint. Red. Mint condition. When you see it now, the only thing original is the paint. They've added an LS6.0 GM engine, a 2-speed Powerglide GM transmission, 10.5" wide slick tires on the rear with "skinnies" on the front, plus a host of other performance modifications. The rad is now in the trunk compartment along with the fuel tank, plus a few other goodies, to get weight off the front end to make room for an 80mm turbo up front. The stripped interior has a removable steering wheel and a roll cage. It's not made for comfort.

At peak performance this summer, they have reached speeds of 135 mph on a 1/8 and 1/4–mile track. That means the race is over in under 6 seconds. That's a lot of prep work to achieve these times, but it sure does put a thrill in the hearts of these two racing fans.
It never hurts to dream and dream big. Retirement may have been forced upon Ron, but if it had not been, would his dream have become a reality? What about you? Do you have a dream?

WINTER WELLNESS FOR PARKINSON'S:

Smart Nutrition Strategies for Energy and Strength

By: Sandra Venneri, RD, PHEc, NM, MAN

Registered Dietitian and Founder of Nutrition Bites — specializing in brain health, metabolic health, and making nutrition simple, practical, and "bite-sized."

In this Q&A, Sandra Venneri shares practical tips and strategies to help people living with Parkinson's stay nourished, energized, and independent during the winter months. From meal planning to energy-dense foods, her advice is designed to make nutrition manageable, enjoyable, and easy to implement.

How can people living with Parkinson's maintain good nutrition and hydration during the winter months?

Winter can make meals harder due to fatigue, limited mobility, or decreased appetite. Planning ahead is key:

Batch cooking: Make one meal for day one, have leftovers for day two, and freeze extra in individual containers.

Ingredient prep: Chop one ingredient per day (e.g., peppers, cucumber, tomatoes, or overnight oats) to keep meals and snacks ready.

Kitchen tools: Use crockpots or air fryers to reduce standing and cooking time.

Hydration: Drink warm teas, soups, and water throughout the day.

Energy-dense foods: Add avocado, guacamole, nut/seed butters (tahini, peanut, almond), lentil or bean purées, seeds (chia, hemp, flax, pumpkin), or Greek yogurt-based dips.

Tip: Prepping one ingredient a day keeps snacks and meals ready without feeling overwhelmed.

Comfort foods are appealing in colder months. How can someone enjoy them while staying healthy?

Soups, stews, casseroles: Add vegetables, legumes (like lentils), and healthy fats to boost calories and nutrients.

Protein timing: Redistribute protein throughout the day depending on medications — don't skip breakfast, but plan around medication needs.

Energy foods: Include whole grains, vegetables, and healthy fats at breakfast and in snacks.

Creative dips & dressings:
- Tahini or nut butter in salad dressings
- Greek yogurt mixed with seeds or nut butter as a dip
- Mashed avocado or guacamole for veggies or toast

Sweet and savory options: Slightly sweetened yogurt dips with nut butter or seeds can add variety and keep meals enjoyable.

Tip: Incorporating dips and spreads makes small portions more energy-dense and easier to eat.

What strategies help with grocery shopping and meal planning in winter?

Two-week grocery shop: Stock pantry staples like canned beans/lentils, frozen vegetables, whole grains, eggs, nut/seed butters, avocado, and healthy oils.

Week 1 vs Week 2: Use pre-prepped items during week one for quick meals; leave whole, unprepped foods for week two.

Meal services: Grocery delivery, Meals on Wheels, or prepared meal services help if getting out is difficult.

Meal organization: Combine batch-cooked meals with energy-dense add-ons to maximize nutrition and minimize effort.

Tip: Pre-pepping ingredients or using meal delivery can save time and energy while keeping nutrition consistent.

How can mobility or fatigue affect eating, and what strategies help?

Fatigue and limited mobility make standing and cooking difficult. **Use pre-chopped ingredients, crock pots, or air fryers.**

Eat short, frequent meals or snacks rather than large meals.

Gentle movement before meals may help stimulate one's appetite.

Add energy-dense foods (avocado, guacamole, nut/seed butters, lentil purées, seeds, Greek yogurt dips) to maintain calories with **smaller portions.**

Tip: Energy-dense foods can help maintain nutrition when appetite or mobility are limited.

What are the most important nutrition tips to keep energy up and support health through the winter months?

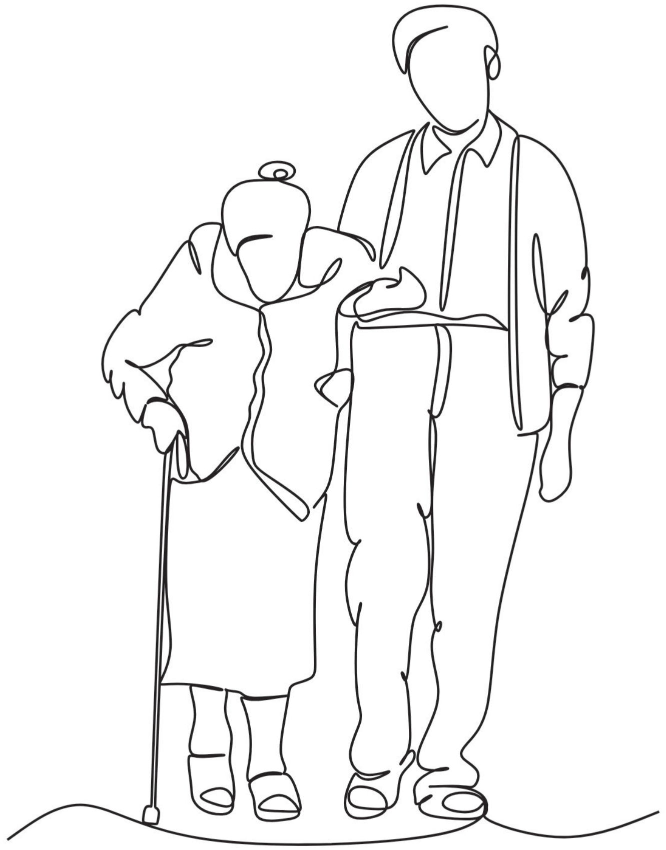
- Prioritize planning, batch cooking, and ingredient prep to make meals manageable and consistent.
- Use kitchen tools, grocery delivery, and pre-pepped items to save energy and maintain independence.
- Incorporate energy-dense foods: avocado, guacamole, nut and seed butters, lentil or bean purées, seeds, and Greek yogurt dips.
- Distribute protein thoughtfully around medications to support energy, digestion, and medication effectiveness.

LOVE, LOSS, AND CARE:

A Husband's Journey Through Parkinson's

Watching the woman you vowed to cherish and protect slowly slip away, not to a sudden tragedy, but to the slow, merciless theft of Parkinson's, is a crucible no wedding vow prepares you for.

I remember the easy grace of her movements; the way she danced in the kitchen, the swift, decisive way she tied a scarf. Now, every movement is a battle: the hesitant shuffle of her feet, the trembling hand reaching for a water glass, the mask of an expressionless face that holds back a storm of fear and frustration. It's a cruel irony that the very body and mind that I fell in love with has become her greatest adversary, and mine.
The vows, "in sickness and in health," become more than just words; they are an unbreakable tether, a silent, daily liturgy I constantly recite in my head. I've become the arms that steady her tremors, the voice that finishes the forgotten sentences or thoughts, the patience that absorbs the outburst of anger and grief that aren't really aimed at me. Every act of care, helping her dress, maneuvering the wheelchair, pureeing her favourite meal, is a small, agonizing reaffirmation of the promises I made from the day I fell in love with her.



The worst part is the loneliness of watching her essence recede. The disease doesn't just attack the motor skills; it chips away at the light, the spark, the her that I know and love. She's still there, flickering behind the fatigue and the rigidity, but the ability to easily connect, to share a spontaneous joke, to just be together without the shadow of the disease, has been diminished. I've found myself grieving the living, vibrant partnership we once had, even as I'm desperately trying to cling to the one we have now.

I'm trying to be a husband, a lover, a partner, but the reality is I'm a caregiver first. The line blurs until it disappears completely, and I'm mourning the loss of my own autonomy, the stolen spontaneity of our life, but I'm swallowing the resentment, because hers is the greater loss. I'm standing on the front lines, a shield against the cruel and harsh world, desperately trying to keep the disease from claiming the most vital parts of her soul, upholding my vow until the very end. Even while it's breaking me in the process, it's hard but watching the woman I love lose who she is, It's unlike anything else. I don't share this to scare you; I share this to bring attention and inclusivity to others. You're not alone. I see you, I hear you, and I understand you.

A SHORT COLLECTION OF CAREPARTNER ANECDOTES

By: Rob Barnett

When my wife, Dianne, was diagnosed with PD about five years ago, I remember our family doctor telling us that our journey as a couple was about to become progressively more challenging and that we needed to be mentally prepared for that. Both Dianne and I wanted to learn as much as possible about PD. Our educational journey started by talking to PSSO staff in London, attending monthly meetings at the PSSO office, and attending the Spring and Fall conferences with other patients and carepartners. PSSO has been extremely supportive overall, and we are grateful for all the shared experiences from other patients and their carepartners in the community.

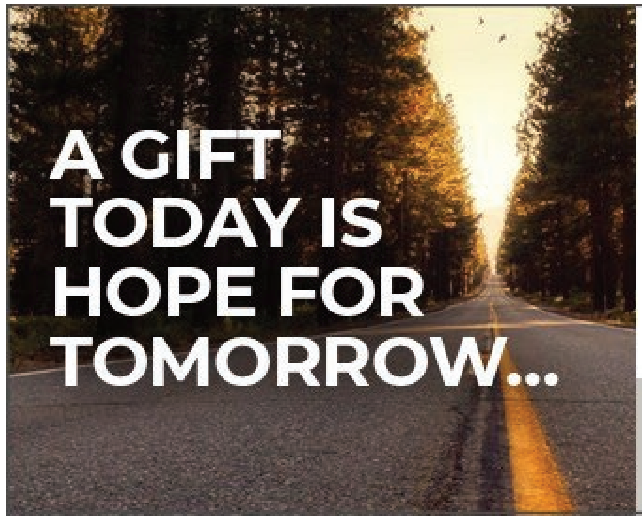
There are a multitude of resources available for carepartners assisting patients with PD, and I would like to identify a few important ones that have helped us. The most comprehensive reference I've found is the Parkinson's Canada PDF titled “Carepartnering: Managing Parkinson's Disease Together.” Another useful reference is the Parkinson's Foundation document “Carepartner Guide: A Practical Resource for Parkinson's Carepartners.” These are both excellent resources that provide detailed guidance for carepartners across a wide spectrum of patient symptoms and needs. Additionally, the PSSO office has organized carepartner support groups within southwestern Ontario, and I am a member of the London group. These sessions have shared a lot of useful information and difficult family experiences associated with PD, and we've all benefited from the discussions within our gatherings. I also wanted to mention that Dianne was referred to Alzheimer Society Southwest Partners by our family doctor (via an occupational therapist) because of the overlap of cognitive difficulty for both Alzheimer's and Parkinson's patients; Dianne has recently attended some of their patient services.

When Dianne first started taking Levodopa several years ago, she experienced periodic hallucinations and was certain she had seen children's faces and heard their voices. Initially, I reacted quite negatively to her hallucination descriptions and tried to dispel what she was telling me by insisting that she was likely hallucinating from her meds. However, after reading her face and eyes more carefully when she continued to hallucinate, I knew I needed to develop a better strategy. What I ended up doing was using a flashlight and going with her room-by-room, looking in closets and under beds to reassure her there were no other people in the house and to let her adjust to that gradually for herself. We've found this strategy helpful and still use it today.

Over the past two years, Di has struggled with her short-term memory, and this has resulted in a significant change in our lifestyle. When we're talking with friends, she'll often put me on the spot by asking me to recall names of people or places that she's thinking about, and one of my challenges is being ready for these conversational “hot potatoes”. My strategy with this is to at least try a few suggestions and sometimes ask her questions to help trigger her memory. This doesn't always work, but Di is seldom left hanging when neither of us can complete the thought.

To make things a little easier in our kitchen, I recently took on the role of “chief cook and bottle washer”. Previously, Di was always the more active cook, but I enjoy cooking and have learned a lot from her over time. In spite of challenges that Di has encountered with PD, she still enjoys participating in the kitchen and wants to be right in there cutting vegetables, or stirring pots, and keeping an eye on food in the oven. My strategy here is to share the kitchen space and intervene only when I think safety may be a problem. This approach typically means that meals take a little longer to prepare, and although we sometimes get in each other's way, it's very important to Di that she does as much as she can. She gets great satisfaction from what she does in the kitchen.

Dianne Belfour-Barnett and Rob Barnett



PSSO IN THE COMMUNITY

This past year brought remarkable growth across our communities. Participation in programs and events reached record levels, accompanied by a significant rise in public awareness of Parkinson's disease. Much of this success stems from the active role of support group members in providing feedback and new ideas to help us keep offerings aligned with the needs of those we serve. By involving people living with Parkinson's and their carepartners in planning, we continue to strengthen the peer connections, which are the heart of PSSO's mission.

Owen Sound Dancing with Parkinson's group

Thanks to our dedicated volunteers, we held fourteen successful Walks, and forty support groups, both in-person and virtual, continue to flourish. Programming is also growing, for instance, PWR!Moves is returning to Orangeville in spring 2026, and a new exercise class is launching in Caledonia in March 2026.

Windsor Dancing with Parkinson's Participants

Partnerships are also opening exciting opportunities for movement. Supported by Caesars Windsor Cares, a Dancing with Parkinson's class launched at Cathy's Dance Studio in Windsor on September 8, 2025, paving the way for future collaboration.

Connections within the community remain strong, highlighted by gatherings such as the London Support Group potluck on August 16, 2025, and a well-attended lunch-and-learn in Wingham on October 21, 2025.

Across all areas, this progress reflects the dedication, collaboration, and passion of volunteers, facilitators, partners, and community members. Thank you for helping us grow, connect, and support one another throughout the year.

The Goderich Active Living and Wellness Fair

THE OVERLOOKED SENSE:

Why Regular Hearing Care Deserves a Place in Parkinson’s Care

By: Nashlea Brogan, Au.D

TEDx Speaker, Author, and Founder of Bluewater Hearing & Balance, Founding Member of Excellence in Audiology

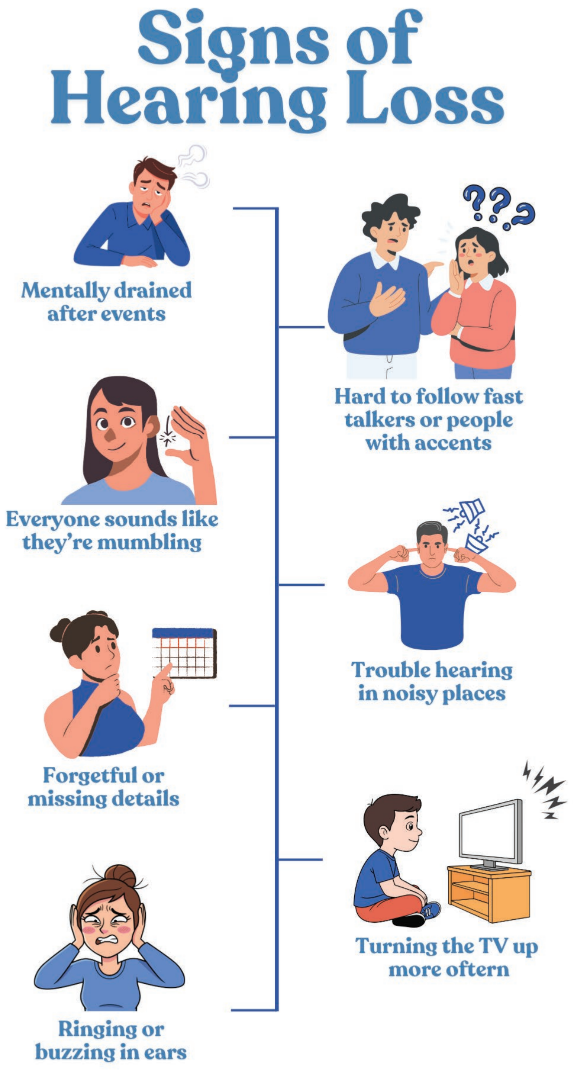
When we talk about Parkinson’s disease, the subject of hearing loss rarely makes the list. But it should.

I am an audiologist and someone living with a severe hearing loss. I’ve learned that changes in hearing often show up long before people realize anything is “wrong.” These changes appear slowly and affect our memory, energy levels, and ability to connect with others.

IT STARTS IN THE BRAIN.

Research shows hearing loss is more common in people with Parkinson’s and may even increase the risk of developing it. Yet, hearing care and having a hearing test are often delayed or never take place.

Hearing isn’t just about our ears, as most people believe. It’s happening in our brain, and it’s our brain that “hears” and processes the world of sound around us. When we deprive our brain of sound by delaying treatment, we may increase the risk of cognitive decline, dementia, having a traumatic fall, and social isolation. These are real consequences of putting it off that I see daily in the clinic.



WHAT ARE THE SIGNS OF HEARING LOSS?

- Feeling mentally exhausted after social events or appointments
- Struggling to follow fast talkers or people with accents
- Believing that others are mumbling
- Struggling to hear in noisy places
- Memory problems
- Needing the TV a little louder
- Ringing in the ear “Tinnitus”

These are all brain symptoms, not just ear ones, and they can quietly chip away at a person’s confidence and relationships with others.

WHY IT MATTERS FOR PARKINSON’S

For those living with Parkinson’s, communication already takes more energy. When hearing loss goes untreated, the brain is forced to work even harder. As a result, you can have increased listening fatigue, slower processing, and daily interactions can become more strained. One of my patients once said, “It’s not that I can’t keep up, it’s that the conversation keeps running away from me.” This is not a hearing problem. It’s a brain problem.

Next Steps:

- Make an appointment for a hearing test
- Treat any hearing loss as soon as possible
- Build regular yearly hearing check-ups into your Parkinson’s care plan

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THE HOLISTIC ADVANTAGE IN PARKINSON'S CARE

By: McKenzie Kim,

Certified Holistic Natural Nutritionist, CEO and Founder of Wild Wellness

A holistic approach to Parkinson's disease (PD) moves beyond medication alone, viewing the individual as a whole: mind, body, and spirit. This integrated model combines conventional medical care with complementary therapies to manage the full spectrum of symptoms and significantly enhance quality of life.

Parkinson's affects far more than movement; it commonly involves non-motor symptoms like anxiety, depression, sleep issues, and digestive problems. A holistic plan directly addresses these 'invisible' challenges, which medication may not fully control. For the body, practices like Tai Chi, yoga, and specialized exercise programs are profoundly beneficial. They are scientifically proven to improve balance, stability, flexibility, and gait, reducing the risk of falls and preserving physical function.

Mind-body interventions such as meditation and mindfulness help manage the chronic stress and anxiety that often exacerbate motor symptoms. By calming the nervous system, they promote emotional resilience and can lead to better sleep. Furthermore, focusing on nutrition, like a Mediterranean-style diet rich in antioxidants and incorporating supplements such as probiotics for gut health, supports overall brain and systemic health.

Ultimately, this comprehensive, person-centred strategy empowers the individual with PD, giving them a greater sense of control and actively involving them in their own wellness journey. By treating the interwoven physical and mental health issues simultaneously, a holistic approach offers a more robust path to maintaining independence and well-being.

NAVIGATING PARKINSON'S:

A Physician's Personal Story with Deep Brain Stimulation

By: Stephen Nantes M.D.

I am a 71 – year – old semi-retired Kitchener Family Physician who has for nine years been diagnosed with Parkinson's disease. Three years ago, I had Deep Brain Stimulation surgery at Toronto Western Hospital and a lot of you may be asking yourselves how I navigated Ontario's Health Care System in order to have this surgery performed.

First of all, I am lucky to have had a very fine Family Physician, Dr. John Pope, who looked after me in 2016 when I sought his advice shortly after I developed a tremor in my left hand and left foot. He kindly referred me to a local neurologist in Cambridge, Dr. Dwight Stewart, who after first examining me, told me that I didn't quite meet the criteria for PD and he arranged that I have a brain MRI test performed. He continued to follow me every 3-6 months. After a few years had passed by, my balance slowly worsened, my left arm didn't swing properly, and my tremor became more obvious, it was concluded that I indeed had PD.

I was started on various medications including a trial of Sinemet, but nothing seemed to control the tremor which was becoming increasingly troublesome and embarrassing. Although I had barely heard of DBS surgery in my 35 years of Family Practice, in 2019 I met a man from California with PD who had just recently had DBS surgery. He told me how marvellous it was at controlling his tremor and now he was able to reduce the dosage of all his PD medication by half.

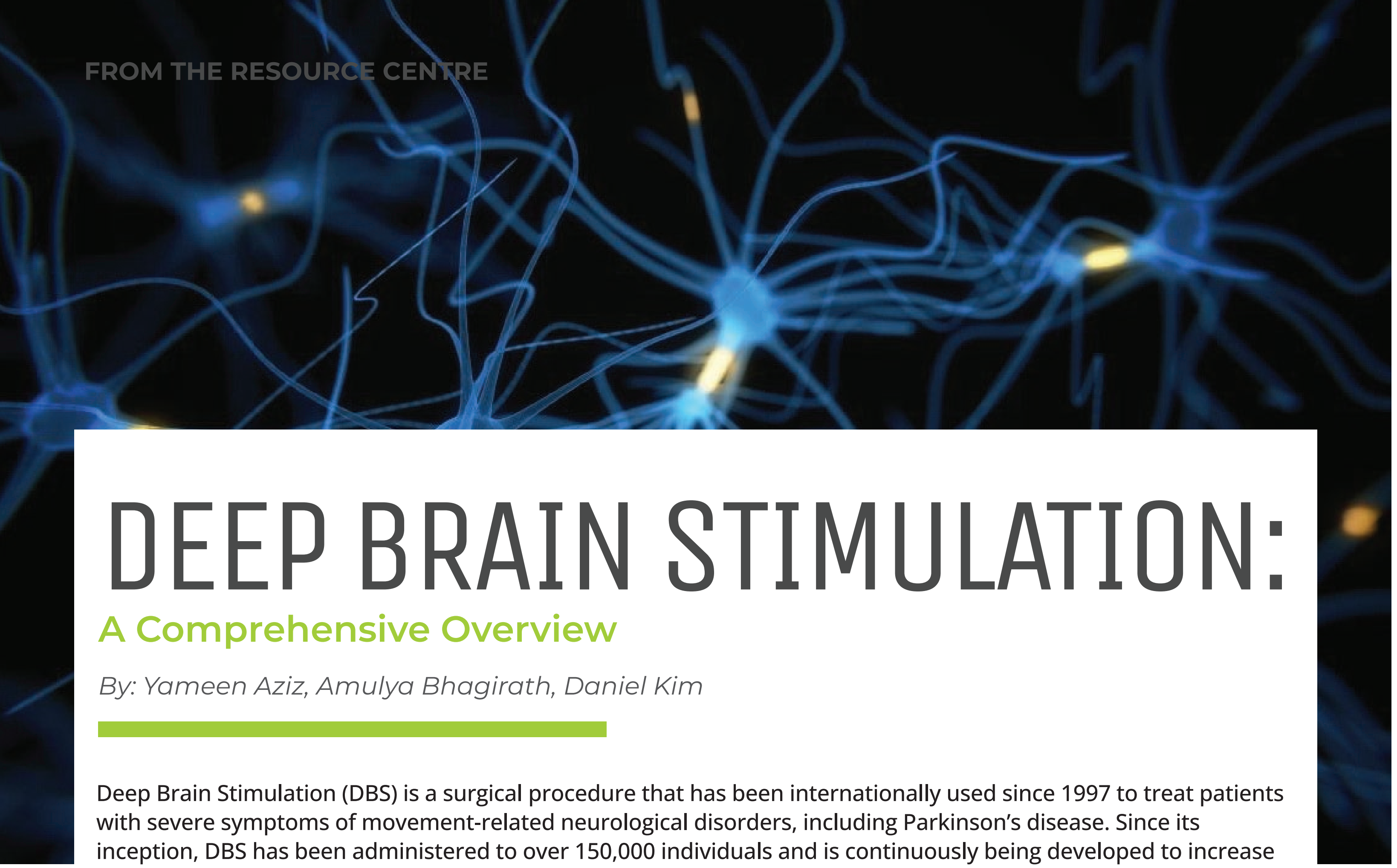
That encounter sparked enormous interest in me for DBS, so I went online to do some research. I discovered that Ontario offered two venues where they performed DBS surgery: at Toronto Western Hospital and at London Health Sciences Centre. On my next visit with my Neurologist, I told him about my encounter with the gentleman from California and asked him if he would consider referring me to TWH Movement Disorders Clinic. He agreed. I knew that the wait list would be long, first for a more recent brain MRI, and then for the actual visit with their neurology clinic team headed by Dr. Alfonzo Fasano.

In the spring of 2021, I was seen by Dr. Fasano and his team; after a few visits where I was neurologically accessed and my gait, balance and tremor was videotaped. Dr. Fasano sat down with me and told me he thought I would be an ideal candidate for DBS surgery. The final steps, however, were to have a five-hour testing session with their Clinical Psychologist followed by a one–hour telemedicine video call assessment with the team's Psychiatrist, and then, finally, a consult with Dr. Lozano. He is the Neurosurgeon whose team would perform the intricate seven–hour operation, six hours while I was awake to install the electrodes deep in my brain, plus one hour to install the stimulator device itself under the skin of the right side of my chest.

The entire team met in the spring of 2022 and concluded that I was indeed an ideal candidate for DBS surgery; October 24, 2022, was set for my surgery.

I was both thrilled and excited about having the surgery while at the same time, frightened to death! The odds were good that there would be few or no surgical complications. However, the stakes were high if there was a major complication, such as a major bleed or serious infection, the outcome could be catastrophic. Luckily, I had a fantastic result, and was even sent home the very next day after the surgery. I was given three months' time to heal, and then, in January 2023 I was reassessed and the device was programmed and turned on. Within three seconds, my tremor was instantly gone! I had the regular five weekly sessions to fine-tune the device, and now I have a new lease on life!

Dr. Fasano and his team see me every six months, and tweak some minor slurred speech or balance issues. All in all, I can say the entire experience has been life-altering. Even my golf game has improved and I am eternally grateful!



DEEP BRAIN STIMULATION:

A Comprehensive Overview

By: Yameen Aziz, Amulya Bhagirath, Daniel Kim

Deep Brain Stimulation (DBS) is a surgical procedure that has been internationally used since 1997 to treat patients with severe symptoms of movement-related neurological disorders, including Parkinson's disease. Since its inception, DBS has been administered to over 150,000 individuals and is continuously being developed to increase its efficacy and broaden the scope of its usage.

The objective of DBS is to implant electrodes deep within the brain, near structures like the subthalamic nucleus (STN) or the internal globus pallidus (GPi), that are often associated with motor-related disorders. These electrodes create electric fields that stimulate nearby neurons at a specified frequency. The electrodes are then connected to a microcontroller, placed under the skin near the collarbone.

The procedure itself begins with a brain scan, typically a CT or MRI, to determine which regions of the brain need stimulation to eliminate tremors. Local anesthesia is applied to the scalp to reduce pain, but the patient is kept awake for the neurosurgical team to test the effectiveness of the electrodes in certain locations, or to observe how symptoms are mitigated with changes in frequency. Oftentimes, the patient is given a task, like playing the violin, to focus on fine motor control throughout the procedure.

Small holes, known as burr holes, are made in the skull to navigate thin leads into the correct region(s) of the brain. Oftentimes, one lead, equipped with several electrodes on its tip, will be placed in each hemisphere of the brain. The orientation and spacing of the electrodes will be modified during the surgery to create the optimal total electric field.

Once the electrodes have been placed, the patient is administered general anesthesia in order for the surgical team to embed an Implantable Pulse Generator (IPG) in the chest cavity. A thin wire is guided underneath the skin from the electrodes and is connected to the IPG, which, when programmed, will be able to control the frequency of the generated electric fields.

Over the next several weeks, the patient will meet recurringly with their neurologist to determine the correct frequency schedule for the IPG. Depending on the specifications of the patient's symptom progression, stimulation may be constant or at times of need only.

During outpatient procedures, the battery of the device may need to be replaced or charged, in which another surgical intervention is required. During these routine procedures, small modifications may be made to update the device according to new standards that may have been developed in the time between replacements.

However, not all patients are eligible for use of DBS as the criteria for this advanced neurological procedure is specific to the individual. Ideal participants have had Parkinson's for at least five years, continually experience dyskinesia or motor fluctuations despite medicine management, and respond well to Levodopa. DBS is used when various other Parkinson's medications fail to provide adequate symptom management.

Participants should also be in good health, as DBS is quite an invasive surgery. Participants should have no underlying illness that could interfere with the administration of DBS or its functioning post-surgery; they should have no neurological impairment or uncontrolled mental illness that would affect recovery as well. Age is another factor as those over 70 usually have increased surgical risk.

Despite its efficacy, DBS treatment does present some of the inherent risks associated with brain surgery, but most of which are unlikely. According to longitudinal research from Fenoy et al., Surgical risk includes infection (1.7% of patients), seizure (0.3%), and device malfunction (1.7%).

Post-surgery also has some risks but are again in a very low percentage. The same study explains loss of treatment (1.4%), discomfort from the device (1.4%), and the need for surgical correction (up to 2.6%) are all possible but very unlikely.

Nonetheless, further research is integral to advancing DBS treatment and specifically curating it to the individual. For example, research from Gimsa et al., identified that inert electrodes that do not corrode are essential. Furthermore, because of iron's neurotoxicity, stainless steel electrodes should not be applied. Hence, one way of progressing DBS treatment is possible by reducing the side-effects and risks through research.

To look into DBS advancements, it is cardinal to first look at how it was developed in the past to understand what can be ameliorated.

DBS is a surgical treatment with decades of neurological research supporting its development. The history of DBS can be traced back to the early 20th century when a Canadian-American neurosurgeon by the name of Wilder Penfield discovered that electrical stimulation could influence brain activity during epilepsy surgeries. This eventually led to the groundbreaking discovery that stimulating certain areas of the brain could control seizures, movement, and sensations of the patient.

In 1987, DBS was fully developed and functionalized by a French neuroscientist, Dr. Alim Louis Benabid, which was performed by applying high-frequency electrical stimulation to the subthalamic nucleus or the globus pallidus internus.

The first official clinical DBS treatment was administered in 1993 and proved to be more effective and less harmful than lesioning procedures such as pallidotomy and thalamotomy, which were destructive and caused permanent brain damage.

In 2002, DBS was officially approved by the FDA to treat Parkinson's disease and became a globally standard treatment for Parkinson's.

Since then, DBS has continued to evolve and made significant improvements especially in terms of: Precision; with the incorporation of fMRI and CT scans, safety; with the recent innovation that adjusts the stimulation levels based on real-time brain signals, and versatility; with now a wider range of applications to treat neurological conditions.

Currently, researchers are working on a method of non-invasive DBS by using focused ultrasound or magnetic fields, and using AI to improve the precision of the stimulation. However, it is also important to note that DBS is often the last resort as a treatment and should only be performed when all non-invasive treatments such as medication, physical therapy, and ultrasound have all failed.

DEEP BRAIN STIMULATION:

A Comprehensive Overview - Continued

Dr. Martin Duennwald, a researcher who received his doctorate from the University of Cologne, Germany, and completed his postdoctoral training at Massachusetts Institute of Technology (MIT), states that “[DBS] tends to be invasive, expensive, and an extremely specialized surgery that comes with associated risks”.

Dr. Duennwald is an expert in molecular biology and is currently investigating the effects of protein misfolding in neurodegenerative diseases such as Parkinson’s at Western University. In an interview, Dr. Duennwald noted that it is important to recognize that “efficacy is still limited for DBS” and hopes for a more “accessible and broader treatment, which [could] apply to a larger population and help more people”.

This is unfortunately true as DBS is a costly procedure, often reaching tens of thousands of dollars, making it inaccessible for many patients, particularly the elderly who may have limited financial resources.

Additionally, while DBS does an exceptional job at restoring motor controls and alleviating symptoms such as tremors, bradykinesia, and stiffness, it is less effective for non-motor symptoms of Parkinson’s. Cognitive impairment, autonomic dysfunction, and sleep disturbances have been proven to be less responsive to DBS treatment, which highlights the limitations of the treatment pointed out by Dr. Deunnwald.

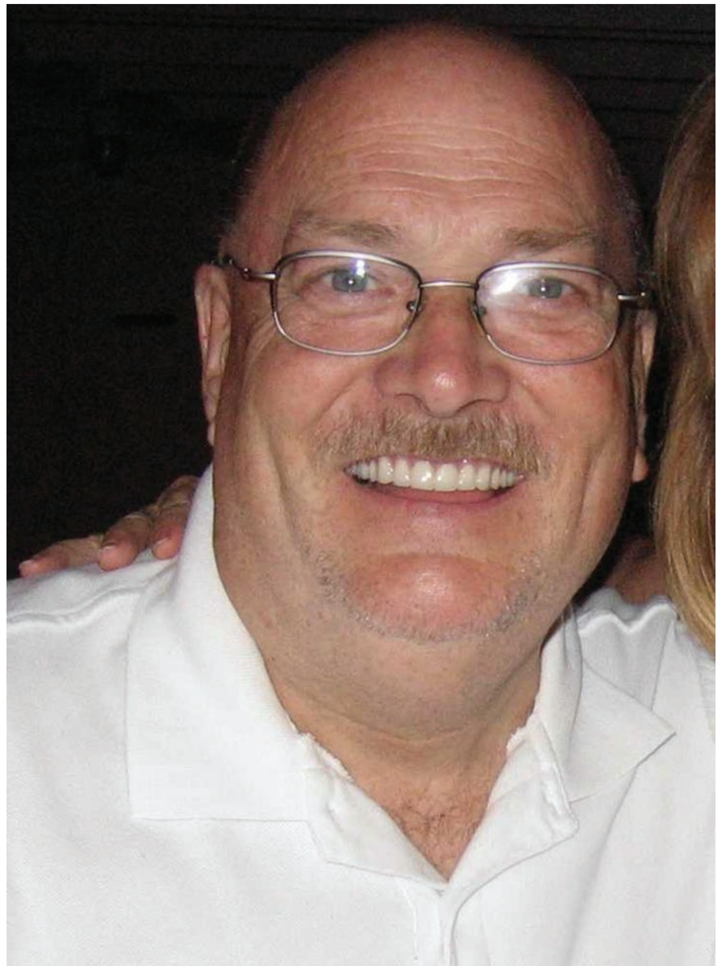
However, despite the drawbacks of the treatment, when asked about any personal experiences with DBS, Dr. Duennwald responded that he had a connection with a neurosurgeon, Dr. Matthew Hebb, who performed several DBS treatments to PD patients and stated that “it seemed to make a huge difference in the patients he had treated”.

“Since there is so little we can do for PD patients,” Dr. Duennwald states, “even regaining motor functions [will be] a great aid to patients suffering from Parkinson’s”. This is especially true with the limited treatment options we currently have for neurodegenerative diseases such as PD, and many patients have expressed satisfaction with the DBS surgical procedure with a 92.5% satisfaction rate and 95% recommendation rate.

Undoubtedly, DBS has transformed the lives of many patients suffering from the symptoms of Parkinson’s and revolutionized the field of neurology and neurosurgery. And with the continued advancements in technology and research, the future of DBS appears promising with the potential to become even more effective to a growing number of patients.

VOLUNTEER SPOTLIGHT

Bill Robson



We are celebrating the contributions of a dedicated volunteer, Bill Robson, who is stepping down from his role as Facilitator of our Cambridge Support Group. We are extremely grateful for the imprint he is leaving on PSSO – an impact that extends far beyond the meetings he has led.

Through engagement in informative, educational, and often difficult discussions, Bill consistently demonstrated a remarkable ability to lead. As a person with PD, his own lived experiences, coupled with what he’d learned from being a carepartner to his wife, enabled Bill to bring unique insight into the conversation. The Cambridge Support Group maintains 15 to 25 regular attendees, including people living with Parkinson’s disease, carepartners, as well as other community members.

Each month, Bill consistently attended Community of Practice meetings, where Support Group Facilitators check in with one another, sharing topics and valuable tips. We will never forget Bill’s description of the “300-pound door" people need to walk through upon their first meeting. He explains that as participants develop meaningful connections with peers, the initial weight becomes lighter.

He intentionally structured support group meetings to include a ‘check-in' — letting participants take turns sharing their recent experiences. While encouraging group members to speak openly, Bill would actively listen, guiding meetings according to what was shared in the group. His meetings would conclude with a ‘check-out’ where he’d encourage participants to share the “nuggets of knowledge” they’d gained and the steps they would plan to take toward self-care.

During Community of Practice debriefs, the Community Engagement Coordinators would often comment on the numerous ways in which Bill’s words had enlightened them or shifted their mindset. Although Bill's time volunteering with us is coming to an end, we will remember his words as we continue to support our community.

ARTS4PD:

Connecting Parkinson's and the Arts

By: Rebecca Barnstaple

Introducing Arts4PD - A platform to help connect people with Parkinson's with arts-based supports and facilitate arts prescribing for healthcare providers

Did you know that participating in various art forms, like singing or dancing, has been shown to have specific benefits for people living with Parkinson's disease? A recent article by leading neurologists entitled "If Art Were a Drug: Implications for Parkinson's Disease" reviews research on the impacts of arts engagement and concludes that arts-based interventions have the potential to reduce motor- and non-motor symptoms, and may also address issues of self-esteem, foster personal problem-solving, and augment holistic well-being through empowerment. This paper also calls for more research on dosages and symptom - specific benefits in order for the arts to be included in routine patient care (Gros et al, 2024).

In response to this call for research, and to help address the lengthy gaps many people face before seeing a neurologist, researchers at the University of Guelph have designed a platform to help connect people with PD with arts-based programs in their communities and across Canada. The platform also aims to give doctors and other healthcare workers the tools they need to feel more comfortable prescribing arts-based programs for PD. Based on a social prescribing model, Arts4PD is intended to act as a virtual link worker – a resource that connects across medical and community partners, facilitating engagement with personally meaningful, non-clinical services that can support social connection. Social prescribing is already well-established in the UK and is showing enormous potential to transform healthcare in Canada. For more information, check out the Canadian Institute for Social Prescribing (CISP) website: **https://www.socialprescribing.ca/.**

Arts4PD (arts4PD.com) is launching this spring, and is a free service with an option to participate in research on the benefits of engaging in creative arts for people with PD. You can use the platform to find programs that match your interests, with in-person and online options available for many locations. It is hoped that this project will increase the visibility of arts-based programs for people with PD, support the development of arts-based health supports, and accelerate access to these programs across Canada.

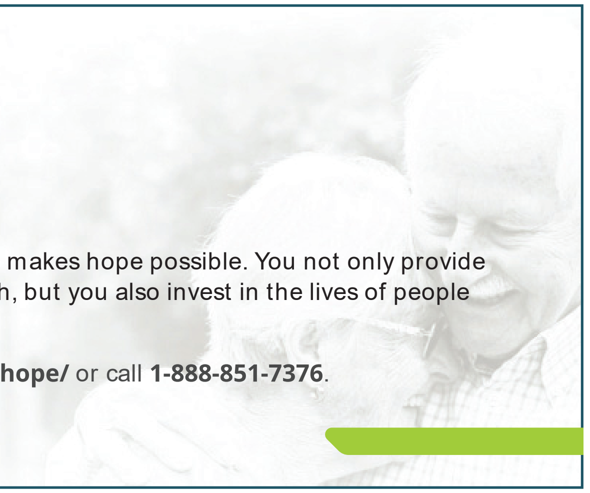
Arts4PD was made possible by a New Frontiers in Research Fund Exploration Grant.

IN MEMORIAM

We offer our sympathy to the families whose loved ones have passed away between June 1, 2025 and December 31, 2025.

Mary "Dianne" Atkinson
Jim Barbour
Jerrold Beech
Sharon Biekx
Keith Bridge
Paul Brown
Maria Brum
Jon Campbell
Velma Card
Agostinho "Carolino" Carolino
John Clements
Clayton Crow
Maurice "Moe" Demeulemeester
David DeVogelaere
Camillo DiPasquale
Katherine "Kathy" Dutot
William "Bill" Fetter
Mark Fetter
Ron Flood
Marsha Fraser
Paul Galloway
Heilla Gordon
Pasqualina Greco
Mary Grelik
Morley Hardy
George Hayman
Antonia (Toni) Hendrikx
Beverley Hoffman
Tom Horton
Derek Hudson
Robert "Bob" Hystead
Gord Jamieson
Gerald Jantzi
Grant Jones
William Jones
Alexandrina "Ina" Kapshey
Janet Kerr
Bob Kett
Doreen Lacey
John Lauwereys
Eric Law
Ron Lee
Maurice L'Heureux
Doreen Marchuk
Kenneth "Hugh" McCaughey
Harold McKnight
Larry Miehm
Ray Millson
David Moody
Robert Moss
Susan Nicolson
Leonard Norris
William "Bill" Norton
Dee Preikschas Brown
John Prendergast
John Ransley
Sean Rea
Shirley Regan
Darlene Ropp
John Rutgers
James Robert "Rob" Salts
Audrey Sambrano
Earl Schneider
Susanne Skinner
William "Bill" Stacey
William "Bill" Stover
Richard Tessman
Anita Thiessen
Diane Vale
Mary Vernon
Robert (Bob) Vollick
Brian Wadel
James "Jim" Whaling
David "Dave" Williams
Martin Withenshaw
Glen Workman

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 **psso.ca/how-to-help/hero-of-hope/** or call **1-888-851-7376**.

THIRD PARTY EVENTS

WHAT IS A THIRD PARTY EVENT?

A fundraiser organized by you, with Parkinson Society Southwestern Ontario as the beneficiary of the funds raised

STEPS TO HOST A THIRD PARTY EVENT:

1 Plan your event! Have an idea, location, date, time and supplies to make your event come to life! Don't forget to name your event!

2 Contact Parkinson Society Southwestern Ontario to share the information of your event. This gives us the opportunity to share our support and appreciation!

3 Share your event marketing materials and our team would love to re-share it! We can re-share social media posts, or add marketing material to our monthly e-news!

4 Host the event! Whenever possible, a PSSO staff member would love to attend your event!

IDEAS FOR THIRD PARTY EVENTS:

- Walk/run
- Sports tournament
- Bike-a-thon
- Concert
- Trivia/bingo night
- Bake sale
- Step challenge
- MANY MORE!

LET US KNOW ABOUT YOUR THIRD PARTY EVENT!

✉ events@psso.ca ☎ 519-652-9437 x 208

THIS APRIL, EXPERIENCE INSPIRING SPRING CONFERENCES HAPPENING ACROSS SOUTHWESTERN ONTARIO!

LIVING WELL

WITH PARKINSON'S

GODERICH

Knights Of Columbus Community Hall
10am - 3pm

Mary Jenkins
Living Well with Parkinson's Disease

Angela Roberts
Staying Connected: Cognition, Communication, and Everyday Life in Parkinson's Disease

April 1st

CALEDONIA

Caledonia Lions Community Centre
10am - 2:30pm

Philip Millar
Feeling Tired Without Slowing Down: Exercise, Fatigue and Parkinson's Disease

Markie Ryckman
Living Well with Parkinson's Disease: How Occupational Therapy Can Help

April 15th

LEAMINGTON

The Roma Club
10am - 3pm

Christopher Langley
Urologic Manifestations of Parkinson's

Mercedes Phalavong
Navigating Community Supports and Preparations with a Chronic Illness

April 21st

WOODSTOCK

South Gate Community Centre
10am - 3pm

Jack Scott
Lend Me Your Ears: Optimizing Communication

Martin L. Duennwald
Oxidative Stress in Parkinson's Disease: How Rusty Proteins Impair Brain Cells

April 24th

Sponsored by:
abbvie

To learn more about these educational opportunities and to register, visit ***psso.ca/events***