THE PARKINSON'S UPDATE

WINTER/SPRING 2025
ISSUE 81

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Parkinson Society Southwestern Ontario

A MAGAZINE FOR THE PARKINSON'S COMMUNITY OF SOUTHWESTERN ONTARIO

FROM THE CEO'S DESK

MOVING FORWARD:

INSPIRING HOPE AND EXPANDING SUPPORT

Shelley Rivard

Happy New Year, everyone! I hope you enjoyed a wonderful holiday season and are excited for the opportunities that 2025 will bring.

As I reflect on 2024, it was a year of highs and lows. Financially, it was a strong year for PSSO, and I extend my heartfelt thanks for your unwavering support. The team worked tirelessly to increase programs and educational opportunities, bringing *Hope Close to Home* across southwestern Ontario. At our four spring conferences held in Owen Sound, Fergus, Stratford, and Sarnia, we welcomed more than 300 participants. The Waterloo conference in the fall was a sold-out event, showcasing the incredible demand for these initiatives.

In May, we faced a difficult loss with the passing of our team member, Joanne Bernard. All who knew Joanne were truly blessed by her presence. She will forever live on in the hearts and minds of all of us.

Looking ahead, PSSO is once again offering our Graduate Student Scholarship Program in partnership with Mitacs, and we eagerly anticipate receiving some outstanding research projects soon. Additionally, we have committed $100,000 for a two-year project with Dr. Jeff Holmes: iCare: Internet-Based Cognitive Behavioural Therapy for Caregivers of Individuals Living with Parkinson's Disease. You'll hear more about this impactful initiative in the coming months.

In 2025, our team will continue building on the relationships forged last year while focusing on fundraising to ensure a diverse and sustainable revenue stream for our organization. We'll be sharing opportunities to join our Hero of Hope Membership program, as well as seeking community grants and corporate partnerships. If you're interested in becoming a Hero of Hope or assisting with corporate fundraising, please don't hesitate to connect with me for more details.

As we deepen our community presence, our hope is to connect with as many of you as possible. Whether it's at local support groups, exercise programs, workshops, educational events, the Parkinson Golf Classic, or our annual Walk for Parkinson's, we look forward to seeing you throughout the year.

I encourage each of you to engage with your local PSSO community and explore all that it has to offer. Thank you for being an integral part of our PSSO family—your support makes everything we do possible.

Shelley Rivard

Shelley Rivard, CEO

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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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RECREATING MEMORIES

My partner Ian Coats and I decided that we needed to leave Oshawa where we had spent most of our working lives, and move to Guelph in the fall of 2020. It was a spur-of-the-moment decision. We managed to sell our house, downsize and move in two months during the COVID pandemic!

While we were quite ruthless with furniture that we knew would not fit into our new space, I was not willing to part with photo albums, diaries and trip journals. When we unpacked in Guelph, some of the bins that I moved contained memorabilia that I had not looked at in at least 20 years! In the four years that we have been here, we have been busy. Ian was diagnosed with Parkinson's disease. We are very grateful to attend Support Group meetings, Park 'n Dance, online webinars and exercise classes, as well as physio and medical appointments to learn all that we can. Also during this time Ian's mother and my father have passed on, although we both treasure the time that we were able to spend with each of them in their final years.

My father was diagnosed with dementia. Early on I tried to put my camera on a tripod in a corner of a room and record his stories. It really did not capture his spark. My daughter and her husband used a cell phone to record one or two of his humorous anecdotes at family dinners when Dad was still at the head of the table. This worked until the cell phone was lost. At a class run by the Alzheimer's Society I was given a book, "All About Me". It was designed to record as much as possible about a family member's personality to help future caregivers understand likes and dislikes, and their history. Some of the prompts got Dad talking about his teenage years working in his father's dairy during the war when at 14 he was required to do the job of a man.

When Dad was in Long Term Care we got into some spontaneous conversations and I grabbed pen and paper to write down whatever he said about his grandparents' houses in London, Ontario. We even looked up their houses on Google Earth to see if he could recognize anything on the street. Later when he was happier to sit and listen to stories, I read some of these 'jottings' back to him, and he would listen very intently and then often said, "Boy your memory is better than mine!"

With all of this collected material, I decided to enroll in an online course through the Oshawa Seniors Citizen Centres 55+ and learn how to create The Story of My Life with Shelley Weiss. Shelley's goal is "to guide, coach and inspire you to journal some of your life experiences…" On my first day of the ten weeks I wrote down my goals: to merge photos and handwritten trip journals; to tell the stories behind some of my family's heirlooms such as furniture that my father had built; and to collect memories of those who have gone like my grandparents, parents and friends who were such a big part of my life.

One class that I was not looking forward to was The Bucket List. Although Ian and I have shared some wonderful travels, we are choosing not to venture away from home for more than day trips, even in summer weather. Gone are our New Year's resolutions scheduling our dream trips. But Shelley had anticipated this! She led the class through the importance of a 'reverse bucket list' having us answer the question, "What have we done?" It turned out to be exactly as intended: a chance for Ian and me to feel grateful for the adventures and experiences that we have shared.

Shelley asked us, "What do you need to lead a purposeful life?" She hoped that we would try for twenty ideas and suggested that we should even set timelines, but I stopped at four ideas with no timelines. I loved the time that I spent thinking and writing during this online class. I have not completed The Story of My Life but I have recorded so many "magical moments that make me smile inside" and I even think that I can find the photos that would help me to illustrate these memories for others in my family. I can do the same with some of Ian's memories from work, from his family's cottage, and from his friends that we meet up with in person and for those too far away that we Zoom visit. These memories may not be important to anyone else, but writing is bringing joy to us!

__Laurie Ball__ graduated from the University of Guelph 50 years ago and has had a diverse career in social work and education. She has taught at the elementary and high school levels, in nursery school, and in online additional qualification courses for Queen's University. Laurie is a proud mother of two daughters and grandmother to two granddaughters. She and her husband, Ian, enjoy living in Guelph, just a short distance from the university campus.

DEMYSTIFYING DEEP BRAIN STIMULATION: YOUR QUESTIONS ANSWERED

Insights from Alaa Taha and Dr. Alfonso Fasano on the Benefits, Risks, and Innovations in DBS for Parkinson's Disease

INTRODUCTION

Deep Brain Stimulation (DBS) has revolutionized the treatment landscape for Parkinson's disease, offering significant improvements in quality of life for many patients. But for those considering this procedure, questions abound— how it works, who it helps, and what to expect before and after surgery.

To shed light on these questions, PSSO turned to two experts: Alaa Taha, a PhD candidate in Biomedical Engineering and facilitator of the DBS support group at Parkinson Society Southwestern Ontario, and Dr. Alfonso Fasano, a global leader in movement disorders and neuromodulation. Together, they provide a comprehensive overview of DBS, from the basics to the latest advancements, and help readers better understand this powerful intervention.

The Basics of DBS

Q: What is DBS, and how does it work?

A: Deep Brain Stimulation (DBS) is a surgical procedure in which electrodes are implanted in targeted areas of the brain to deliver controlled electrical impulses, much like a pacemaker for the brain. DBS is not believed to alter the progression of Parkinson's disease, and this remains an area of active investigation. For carefully selected candidates, however, DBS can significantly enhance quality of life by alleviating motor symptoms, such as tremors.

Q: Who might benefit from DBS?

A: Determining whether someone is a good candidate for DBS requires careful consideration by a specialized medical team. Since DBS is a surgical procedure, it involves risks and is not suitable for everyone. It is important to thoroughly discuss this option with your healthcare team and carepartners.

Q: How is life after DBS different?

A: Many individuals who undergo DBS report significant improvement in motor symptoms. This can include reduced tremors, better motor control, and often, reduced medication. However, adjusting to the therapy and getting the stimulation parameters right involves frequent hospital visits and working closely with the healthcare team to fine-tune the device for optimal results.

__Alaa Taha__ is a PhD candidate in Biomedical Engineering at Western University and facilitates the Deep Brain Stimulation support group at Parkinson Society Southwestern Ontario.

A Closer Look at DBS

Q: With which kinds of symptoms can DBS help?

A: DBS of either the subthalamus (STN) or globus pallidus (two different brain targets) can help motor fluctuations (ups and downs of the medications), as well as levodopa-induced dyskinesias. It usually provides a benefit similar to levodopa, which is why the neurologist would typically assess you off and on levodopa. For instance, if gait does not improve with levodopa, it will not improve with DBS. Two exceptions to this rule: speech can be worsened by DBS even when levodopa helps; and tremor responds well to DBS even when medications don't help. Another brain target (thalamus) can be treated with DBS, which only helps tremor.

Q: How has DBS surgery progressed in the last 10 years?

A: Neuroimaging techniques, such as MRI, have greatly improved, leading to increased accuracy of lead placement. The speed of the procedure has also improved. In some cases, patients can be asleep for the entire duration.

Q: Can DBS be monitored virtually?

A: Yes, we can access and program some devices in a very reliable and safe manner. Each time a virtual visit takes place, the patient has to allow it with a two-step procedure. While this feature is not always available, generally all devices can be accessed by a dedicated patient controller, allowing the health professional to suggest changes within previously programmed ranges.

Q: How do I decide between DBS and other interventions available to me?

A: The decision takes time and in-depth discussion with the healthcare provider and family. There are four types of neurosurgery for Parkinson's, but two are popular and adopted on a large scale: DBS and MRI-guided focused ultrasound. The latter is attractive because it allows brain surgery without incision, making it ideal for frail patients. However, DBS is adjustable, can be done bilaterally in one go, and allows more effective targets, such as the STN and globus pallidus. Thus, MRI-guided focused ultrasound is mainly used to treat tremor on one body side.

Q: Are there any risks associated with DBS?

A: Yes, like any medical procedure. There are three types of adverse events: surgical, hardware-related, and stimulation-induced. Surgical adverse events can occur during the procedure, such as stroke, infection, or seizure. Hardware-related issues include malfunctioning, breakage, infection, etc. Finally, stimulation-induced adverse events are caused by the spread of electricity to unintended areas, producing neuropsychiatric problems, such as pulling, tingling, speech disorders, mania, etc.

Surgical risks are mostly not reversible but are quite rare (~1%). Hardware-related problems are fixable, as with any piece of hardware, and the stimulation-induced ones are reversible by means of reprogramming.

CONCLUSION

DBS continues to offer hope and relief to many people living with Parkinson's disease. As highlighted by Alaa Taha and Dr. Alfonso Fasano, this innovative therapy comes with its benefits, risks, and considerations, requiring thorough evaluation and collaboration among patients, caregivers, and medical teams. By staying informed and consulting with specialists, individuals can make empowered decisions about whether DBS is the right path for their Parkinson's journey.

For more information and resources on DBS and Parkinson's disease, visit PSSO.ca.

__Dr. Alfonso Fasano__ is a global leader in movement disorders, specializing in advanced treatments that improve the lives of people with Parkinson's disease. He serves as Chair in Neuromodulation at the University of Toronto and University Health Network, where he co-directs the Surgical Program for Movement Disorders at Toronto Western Hospital. Dr. Fasano has authored over 450 scientific publications and is a pioneer in cutting-edge neuromodulation techniques.

ART VS. APATHY: HARNESSING CREATIVITY TO CONQUER PARKINSON'S CHALLENGES

Creativity in the Face of Challenge

Art has a way of transcending limitations and becoming a powerful tool for self-expression, connection, and healing. For those living with Parkinson's, the creative process can also serve as a vital counterweight to some of the condition's most challenging symptoms, such as depression, apathy, anxiety, and more. In this feature, we explore how two talented artists, Harry and Barbara, have harnessed their passion for photography and painting to navigate the hurdles of Parkinson's and continue to find joy, meaning, and purpose in their craft.

While Barbara finds inspiration in her studio and through her global connections, Harry turns to the great outdoors and his love for nature photography. Though their art forms differ, both artists share a profound understanding of how creative pursuits can lift the spirit, restore hope, and help navigate the ups and downs of Parkinson's.

WHEN HARRY MEETS APATHY

In our Parkinson's Support Groups we often engage in conversations about the non-motor symptoms that folks living with the disease experience. Apathy is one of the symptoms that not all individuals experience, but it's a very real complication that Harry encounters from time to time.

Harry is an accomplished nature photographer who enjoys venturing out with his camera, capturing eagles, wolves, owls and other wildlife. "I shoot wildlife for fun, but no animals are hurt or killed because of my hobby", smiles Harry when describing the joy he feels in the outdoors. "I get strange looks of confusion and dismay when I respond, 'eagles' to people who see me in camouflage and ask what I'm going to be shooting."

Apathy shows up in one of two ways for Harry, either presenting a hurdle when he's planning on going out on a photography excursion or at other times as he contemplates sitting down at his computer to edit the images he has captured. "I know I need to edit but I just can't get myself motivated to get to my software." When he does, however, he becomes laser-focused, and he doesn't have any difficulty sticking with the task, whether it's a shorter edit or a more involved and time-consuming process.

Knowing this about himself, he takes it in stride, realizing that he eventually will get around to diving into the part of the process that brings him joy and an immense sense of accomplishment. The walls of his home are adorned with the glorious products of a passion that extends to landscapes, lakeshores and old barns, a testament to tenacity in the face of apathy.

***Harry Schut** – Tracey Blackmore, Blackmore Media*

When Harry brought up this topic up at a recent 'Coffee Klatch' Support Group, he explained that he considers the apathy he experiences to be different from how he views depression because the events are usually short-lived. For him, although apathy can leech into periods of general malaise, it's usually related to a specific activity and generally isn't long-term.

There are roadblocks and there are hurdles and Harry sees apathy as the latter, choosing to wait patiently until the time is right to take another run at it. "I don't get frustrated at myself. I get frustrated at the apathy itself, knowing from experience that it'll pass, and I'll eventually accomplish the task if I just wait for the right moment to activate."

And that's a great attitude to have.

Follow @harryschutphotos on Instagram. All photos (except family) for sale. A portion of proceeds to PSSO.

Abandoned Beauty – *Mansion at sunset, Harry Schut Photos*

Hoooo are You? – *Great Horned, Harry Schut Photos*

Reflecting on Lunch – *Bald Eagle, Harry Schut Photos*

Winged Get Away – *Bald Eagle in flight - Harry Schut Photos*

BARBARA'S BRUSH WITH PARKINSON'S

Barbara Salsberg Mathews has been creating art for as long as she can remember. "Making art is my way of processing the world and communicating with others," she shares. After a long career as an artist, teacher, and mime, Barbara retired with plans to dedicate herself to her art full-time, showing and selling her hyper-realistic acrylic paintings.

Then came her Parkinson's diagnosis.

The symptoms crept in slowly—tremors, a weakening arm, and chronic pain while holding a brush. "The thought of not being able to paint made me very depressed," Barbara admits. "Every time I tried to paint, nothing I did looked like it used to." A large unfinished canvas sat untouched for two years, a painful reminder of what she thought she had lost.

But Barbara wasn't ready to give up. Gradually, she began to adapt her approach to art. She accepted the changes Parkinson's brought and found new ways to create. "I harnessed my tremor, turning it into my servant to do my shading," she explains. "I also used an artist's folding stick to support my weak hand. My style became looser than my earlier hyper-realistic one, and I learned to let it be what it wanted to be."

Barbara's artistic resilience is matched only by her determination to support others in the Parkinson's community. In 2020, she began collecting global perspectives on life with Parkinson's, culminating in her book, What Parkinson's Feels Like. The project brought together dozens of descriptions from people in ten countries, paired with Barbara's illustrations created using watercolour, ink, acrylic, and digital tools.

"These descriptions reminded me that I'm not alone, and for that, I'm extremely grateful," she reflects. Today, Barbara continues to paint, write, and even use mime as a therapeutic tool for others with Parkinson's, proving that creativity knows no bounds.

What Parkinson's Feels Like was published by Parkinson's Europe and is available for free as a digital download on their website. The paperback version is available on Amazon with all profits donated to Parkinson charities.

Barbara Salsberg Mathews

1. No Energy Shadows: *"Parkinson's feels like I'm on 1% and can't find my charger." By @SethGillman, UK*

2. Puppet Jerked Around: *"Parkinson's feels like I'm a puppet on a string. My limbs are tied by strings that no one can see nor control, except by my master - Parkinson's." Illustration inspired by descriptions from David Sangster, 42, Diagnosed, 2011, Greater Manchester, England Sossie, Diagnosed, 2022, Buckinghamshire, England*

3. Calm Storm: *"Sometimes when I look calm on the outside, there's a storm going on inside me which people can't see." Nina Juncker, Diagnosed in 2020 at age 47. Berlin, Germany*

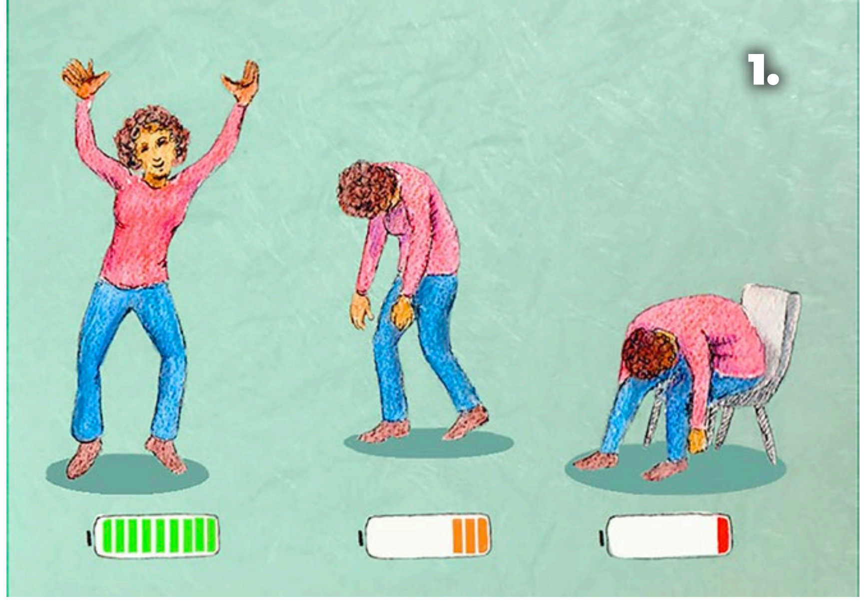
4. Slow Man Fast Coloured: *Parkinson's is like living life in slow motion. Simple tasks seem to take forever. Putting your socks on in the morning can be a major challenge. I always wear brightly coloured ones to make me smile. It's very satisfying when you finally manage to pull them up." Dave Clark @DaveClarkTV Yorkshire, England*

5. Olympic Sport Getting Dressed: *Getting dressed in the morning is like an Olympic sport." Ceri Price, Diagnosed in 2020. 65 years of age. Swansea, South Wales*

6. Grey Mist: *"Parkinson's is like a grey mist, floating towards me from behind to take me down. Sneaking up in an insidious way, trying to put me to sleep, rolling me up in a tight ball, kicking me under the couch so I roll off to the corner with the dust bunnies." Barbara Salsberg Mathews, Diagnosed in 2020, Guelph, Ontario, Canada*

7. Clockwork Bear Toy: *"Parkinson's makes me feel like a clockwork toy. A dose of levodopa winds me up, then I slowly wind down until the next dose." Matt Couchman @Tremr8 Diagnosed in 2016. Lives in Norwich, UK*

8. Living in a Salvador Dali Paiting: *"Parkinson's feels like I'm trapped in a Salvador Dali painting. Everything is heading downward. Nothing is floating, just getting heavier and heavier." Liz Voogjarv, 68 years old. Diagnosed 8 years ago at age 60. Lives in Canada*



THE HEALING POWER OF ART

Through photography, painting, and countless other forms of self-expression, art becomes a lifeline for people like Harry and Barbara. It's a reminder that while Parkinson's may pose challenges, it can never extinguish the human spirit—or its ability to create beauty in the face of adversity.

WALK FOR PARKINSON'S

WITH SMILES ON, WE WERE WALKIN'

This past September we hosted our annual Walk for Parkinson's events all across southwestern Ontario. Over the two days, our 14 walk locations hosted more than 1800 participants and raised over $525,000!! It truly was amazing to see all these communities gathering to support the walks and each other. In particular, those who walked on the Saturday through wind and rain with smiles on their faces, were very impressive and embodied exactly what these events are all about.

We are so thankful for all the support these events get from our great sponsors, numerous hard-working volunteers and, most importantly, YOU! Every dollar raised provides *Hope Close to Home* for those affected by PD in our local communities.

Make sure to mark your calendars for September 6 and 7, 2025, for the next Walk for Parkinson's. We will be looking for volunteers in the coming months to join our local walk committees and help with the planning process. If you are interested, please reach out to your regional Community Engagement Coordinator or to our main office. We are already looking forward to a great weekend again next year and cannot wait to Walk for PD with you! See you out there!!

WE'RE **THRILLED** TO SHARE THAT THE **2024 WALK FOR PARKINSON'S RAISED OVER**

$525,000!

EVERY DOLLAR WILL GO DIRECTLY TO SUPPORTING THOSE AFFECTED BY PARKINSON'S IN OUR COMMUNITY.

2024 TOP WALKERS

1. Clare Poechman	$17,665.00
2. Scott Dunbar	$13,685.34
3. Christine Scheer	$11,643.34
4. Stuart Selby	$9,756.76
5. Grant Bourner	$9,124.77
6. Robert Ecclestone	$7,828.74
7. Chris Evans	$7,718.50
8. Don Sararas	$6,023.85
9. Carolyn Young	$5,777.11
10. Erica Miko	$4,608.54

2024 WALK for Parkinson's Sponsors

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HOPE IS CLOSE TO HOME:

Strengthening Support, One Community at a Time

Since joining the team in fall 2023, Parkinson Society Southwestern Ontario's four Community Engagement Coordinators (CECs) have been busy bringing support and resources to people living with Parkinson's and their carepartners across southwestern Ontario. Each CEC has worked hard to expand services and foster strong community ties, providing a network of local programs and new opportunities for connection. Here, our CECs share their recent highlights and achievements, showing how together, we're making support more accessible, personalized, and *close to home*.

HEATHER INNES - NORTH REGION

Heather has been working to expand our programming and reach remote communities. In 2024, we began two new exercise programs, a Dancing with Parkinson's class in Meaford and a chair yoga class in Kincardine. We continued to operate support groups in Goderich, Kincardine, Hanover, Owen Sound and Meaford, and began a new support group in Port Elgin. We hosted six workshops in this region throughout 2024 on topics including mindfulness, medical assistance in dying, and falls prevention. Heather attended many community events including volunteer fairs and seniors' fairs throughout the region. She gave presentations on Parkinson's disease to retirement homes and community clubs to raise awareness and expand our community. Her long-term goal is to increase access to programs and services for people impacted by Parkinson's further north on the Bruce Peninsula. In 2025, we are excited to host the North Region Spring Conference in Walkerton on April 23. Stay tuned for more events happening in our North Region this year!

ROBIN ARNOTT - EAST REGION

Since joining PSSO in the Fall of 2023, Robin has immersed herself in her region to do her best to identify needs and steer programming in directions that will provide the most meaningful support possible. Robin has had the opportunity to initiate new community connections, such as the annual Coffee with a Cop meetings with the Guelph Police Service, inviting people affected by PD, carepartners, community members, and police officers to have open discussions about fraud, mental health, and what happens when a person with PD is wrongfully accused of impaired driving.

To ensure a multidisciplinary approach to care, she has built relationships with CMHA Waterloo-Wellington, CMHA Haldimand-Norfolk-Brant, Ontario Caregiver Organization, Ontario Health at Home, and the YMCA of Three Rivers. Recognizing the need for exercise programs for people with PD in rural areas, she has developed Chair Yoga in Simcoe and is working on creating more fitness programming which will be announced soon! She's played a crucial role in furthering our educational programming by multiple webinars, hosting a large, well-attended Fall Regional Parkinson's Conference in 2024, and she is bringing her 2025 Living Well Conference to Brantford.

Robin believes it is an honour to support people with Parkinson's disease and their carepartners. She invites all community members to stay in touch with her. You are welcome to book a meeting, give her a call, or shoot an email to share what's on your mind.

STEPHEN OWEN - CENTRAL REGION

In his inaugural year, Stephen has focussed on relationship-building, connecting with our dedicated volunteer Support Group facilitators, filling in as needed, and getting to know our groups' attendees. Some groups in the Central Region are currently without facilitators and, while actively searching for facilitators, Stephen provides support. He's engaged in Coffee Klatch, Carepartners, London, Tillsonburg and at a LTC home. 2024 has found him involved in programs and services, a spring conference, fundraising efforts, webinars, workshops, and an awareness campaign to town councils. He has presented PSSO in Lambton Shores, South Huron, Woodstock, Stratford, Tillsonburg, Ingersoll, Blandford-Blenheim, Norfolk County and Strathroy.

SAMANTHA GRANT - WEST REGION

Over the past year, PSSO has been a part of many positive strides towards bringing education and supports to the West Region!

Cathy's Dance Studio and Steppin Up Dance Co. joined as new locations for 12-week Dancing with Parkinson's programs in Windsor and Petrolia. We were also happy to Welcome Back Melissa Vincent from Bayshore Therapy! She facilitated in-person Louder-Clearer programs to a total of 45 clients over the course of eight weeks.

Our first annual Living Well Conference hosted 124 participants in Sarnia to learn more about the management of non-motor symptoms. A special thanks to Dr. Lounsbury, Angela Raffoul, Justine Davies and Khrista Boon for sharing their expertise with everyone! In 2024, five educational workshops were held focused on dental/hearing, speech and language, the correlations between dementia and PD, carepartners effectively navigating medical systems and assistive devices throughout the West Region.

PSSO was also fortunate to be included in 20 workshops and Expos across the West Region where we have connected with Specialists and organizations to further strive towards bringing HOPE CLOSE TO HOME! Many wonderful opportunities are planned for 2025 and we cannot wait to welcome you!

Looking Forward Together

As we look ahead, our CECs are excited to continue strengthening connections, expanding services and bringing innovative programs to each community. With your ongoing support, PSSO's vision of accessible, personalized care across southwestern Ontario continues to grow stronger every day. Together, we are making *Hope Close to Home* a reality—one step, one connection and one community at a time.

CARING FOR YOURSELF WHILE CARING FOR OTHERS

Carepartners play a significant role in supporting the various needs of their loved ones. With the busyness of caring for others, it can lead to caregivers putting themselves on the back burner. To continue showing up for others, it is crucial that carepartners also take care of themselves. This article highlights some self-care strategies to think about and how they might be applicable to your routine.

BUILD IN REGULAR BREAKS FROM CAREGIVING

It is critical to build in regular breaks from caregiving to ensure you remain at your best. It can be hard to find time, but even just taking a few minutes to step away from your caregiving responsibilities can help you take care of yourself. If you have additional support to assist you, do not hesitate to ask for help so you can give yourself a moment to recharge.

CONNECTING WITH OTHERS

Being a caregiver can cause feelings of isolation. It is important to connect with others to talk about your situation. Support groups are a great way to relate to other experiences and feel well supported. Connecting with others through a support group or maintaining social connections can provide you with a sense of community, so you are not alone in your experience.

SELF-COMPASSION

It is important to be kind to yourself as you are experiencing normal reactions to a situation that is ever-changing. It can be easy to jump to self-criticism when we fail or make mistakes. As a carepartner it is important that you give yourself grace and be kind to yourself. Especially while navigating a multi-layered situation while caring for your loved ones.

DETERMINE ACTIVITIES THAT MAKE SENSE FOR YOU

It is important as a carepartner that you take time for yourself and integrate activities into your routine that work best for you. Self-care activities look different for everyone, so make sure you choose activities that leave you feeling refreshed and recharged. Whether it is going for a walk, reading a book, getting coffee with a friend, or meditation. It is crucial to choose activities that don't feel like a chore, but rather something to look forward to as well. Integrating a few moments of self-care activities in your daily routine can make all the difference. Choose what feels the best for you!

__Aliesha Murphy__ is in the fourth year of the bachelor's of Social Work program at King's University College. Aliesha entered into social work for their passion to help others and to seek positive change in their community.

WHEN CAREPARTNERING ENDS

Loss and grief are a part of the caregiving journey, leaving caregiving in the final stages frightening and stressful. As a carepartner to someone with Parkinson's, you have likely experienced grief throughout your caregiving time. You've witnessed your loved one lose their mobility, independence, identity, facial expressions and voice—each loss compounding until your grief becomes the final loss.

Your emotions are natural, and there is no right or wrong way to grieve. The critical thing to remember is to give yourself permission to feel and experience all the emotions that accompany grief. You may have heard that with time, your grief may get smaller. However, through my studies in thanatology, I have learned that grief does not diminish with time, but instead remains the same, and the space around grows bigger (as pictured in Figure 1). As time passes, we grow around the grief, learn to adapt, and grow through the experience.

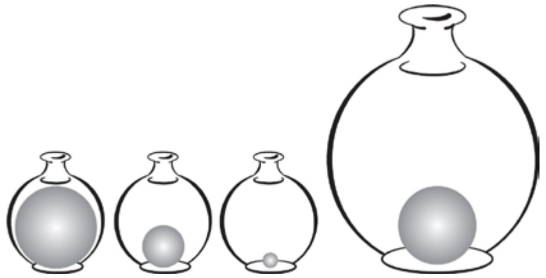


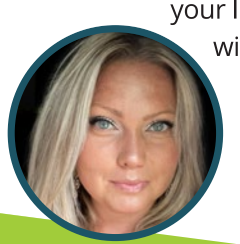
Figure 1.
Source: Tonkin (1996, as cited in Nugus, 2011)

More than likely, caregiving has profoundly impacted the person you are today. If your caregiver role is over, you may need to re-establish relationships with friends and family. Just as you have navigated different stages with your loved one through Parkinson's, you will also navigate this chapter in your life.

HERE ARE SOME SUGGESTIONS:

1. Consider continuing with your support group until you transition from identifying as a carepartner.
2. Start a hobby you did not have time for while caregiving.
3. Join a grief support group or counselling; a hospice in your area may offer free services.
4. Consider making a keepsake, like a memory book with pictures and stories.
5. Re-evaluate your relationships, think about where you have been and where you wish to go and create small goals to move forward.

When carepartnering ends, many things start to change, but the love and memories you have with your loved one will be a part of you forever. By honouring the person you cared for and healing your grief, you can put your life into its new context, allowing you to move forward with purpose while keeping their legacy alive in your heart.



__Natalia Pavlovets__ is a fourth-year social work student at King's University College pursuing a minor in Thanatology, which is the study of death and bereavement.

"EEYORE" HELPED EDUCATE OUR GRANDCHILDREN ABOUT PARKINSON'S

My husband, Dale, was diagnosed with Parkinson's in November of 2023, having shown subtle symptoms for a number of years prior.

We live in a large multi-generational home and have the good fortune of sharing it with our son and daughter and four of our grandchildren, ranging in age from 8 to 12. At the time of his diagnosis, Papa, as we all know him, had no problems talking about Parkinson's and sharing his explorations and discoveries with our family as we began this precarious adventure into the "PD World".

Grandchildren had been popping in and out of our lives daily for years, but after initial discussions concerning Papa's Parkinson's diagnosis, we noticed that our grandchildren's' visits slowed significantly and became shorter in duration. Our circle (including another son, daughters-in-law and four more adult grandchildren and extended family) expressed concern and confusion as to how PD will impact Papa's future.

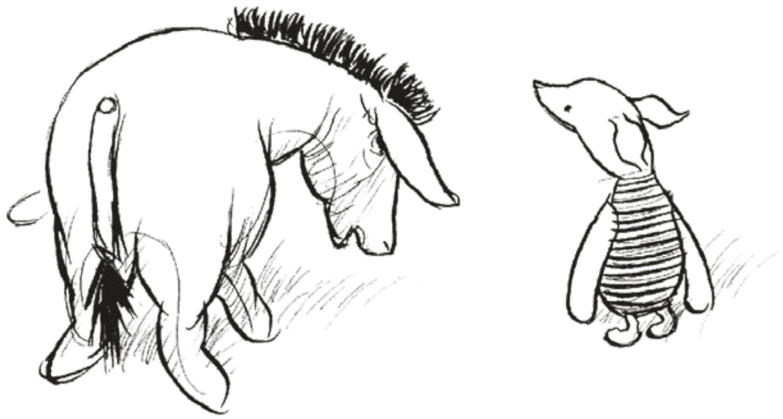
Parkinson's was an unfamiliar, uninvited entity taking on a life of its own within Dad/Papa's safe space...an intruder in our home and in our conversation.

What is this Parkinson's and what do we do now?

Well that is the question, isn't it?

Recognizing that the entire family has Parkinson's now, our immediate challenge became sharing our PD plight with the determination to lighten our outlook, embrace what we have as a family, celebrate our present wellness, educate ourselves and NOT give PD centre stage in our lives.

We were aware of how easily PD can go down a dark scary road for our youngest family members. How do we include and educate the young ones in a positive, easy-to-comprehend manner. We wanted to instill caring and healthy outlooks.



As luck would have it, I found myself enjoying a delightful cartoon with a grandchild on a Saturday morning. It was one of the Winnie the Pooh Adventures—the episode where Eeyore loses his tail. On the Internet, Eeyore is often referred to as the character best representing clinical depression, but as we watched, I saw my grandchild's Papa portrayed on the screen and in the story line.

There Eeyore was;

... *expressionless*, with a face like Papa's—a face that doesn't and can't represent all of his emotions;

... *eyes drooping*—reflecting vision issues such as Papa's glaucoma;

... *ears lopped*—possibly muffling sound in the way that Papa experiences life without his hearing aids;

... *feet heavy in appearance*—like the invisible sensation creating mobility challenges for Papa;

... *slow and low speech*—sharing only words that were necessary, just like Papa's quiet speech;

... *confused mind*—unaware he had lost his tail and ultimately believing his found tail is new (Yup... that's Papa);

... *feeling unsure*—the day didn't feel quite right and he was unable to figure out why... there was Papa again;

... *expressing cautious optimism*—a trait often used by Papa as he navigates PD's own "100 Acre Wood";

... *blue from head to tail*—perfectly representing the sad feelings and/or depression that can sneak up on PD kinfolk;

... *surrounded by loved ones eager to help*—Eeyore's tribe had his back! And we have Papa's.

Eeyore was a wonderful tool to help explain Parkinson's symptoms and characteristics as well as PD's anomalies to my grandchildren (and others) utilizing visualization, imagination and encouraging questions.

Eeyore's positive mantras, "Things could be worse" and "Look on the bright side" were infused into the conversation as we each discussed our own steadfast journey into the mire that is Parkinson's.

Parkinson's behaviour is now referred to as an Eeyore-ism in our family. Whenever anyone makes the reference to Eeyore, the result is often a nod of understanding or a smile meaning "we've got this!"

Today my husband sports a Disney Varsity Jacket with an embroidered Eeyore on the back expressing (I imagine quite placidly) the following: "I'm so Excited I just can't sit still".

__Brenda Howse__ is carepartner to her husband Dale who was diagnosed in 2023. She lives in Tillsonburg where she facilitates PSSO's Support Group.

MY JOURNEY WITH PARKINSON'S

My journey with Parkinson's disease began similar to others'. Symptoms began years before a diagnosis. It started with symptoms of constipation, low vocal range and trouble swallowing. Each time a new symptom arose I would go to the doctor and the response I received the most was "This is just old age" or "Your body functions will change over time as you get older." That may be true for many people, but these symptoms affected my way of life and caused me to begin to withdraw. I was losing faith, and the scariest thing was the thoughts I had: "Am I dying?", "What will be the next thing to go?", "Perhaps I should accept this is just me getting older and move on." This was constant for over two years, then one year ago, my wife and I began to notice my right hand move and I could not stop it. I know that it was not the smartest idea, but my family and I looked to the Internet to try to find answers. Parkinson's disease came up and as I read the list of signs and symptoms in my head I thought "Tremors- Check. Constipation- Check. Trouble Swallowing- Check." It continued as we looked further into the disease.

At my next doctor's appointment they recommended a referral to a neurologist. I waited over six months, and after a 15-20 minute consultation, my neurologist told me that I did indeed have Parkinson's disease. He wrote a prescription and suggested contacting the healthline and Parkinson Society Southwestern Ontario. Hearing those words "You have Parkinson's disease" was a sigh of relief. I finally had an answer after many years of searching. However, then I began to think, "What will my next steps be?" I took the advice and contacted Parkinson Society Southwestern Ontario and I am so happy I did.

When I called and spoke to the staff, I instantly felt relieved and that they genuinely cared about me and my family. Within two weeks I received a welcome package in the mail, and I attended a support group in my city. I love attending the support group because I am able to talk with others who are experiencing the same disease, and I have learned a lot from their first-hand experience. There are great speakers that come into the group who bring a wealth of professional knowledge, and I do not feel like a burden if I have a question. My favourite aspect of the organization, being newly diagnosed within the past few months, is the resources available to me. I like how everything is in easy terms and I can follow along to see progression in research.

Upon beginning my search for resources and finding an answer, I felt lost, powerless, frustrated at my body and the world. My wife, family and I struggled to understand what the next stages were. However, with the amazing team and supports at PSSO, I am confident that I will continue to live my best life.

__Preston Kimmerly's__ Parkinson's journey began with years of unexplained symptoms. After finally receiving a diagnosis, Preston turned to Parkinson Society Southwestern Ontario (PSSO) for support.

Through PSSO, he found invaluable resources, a welcoming support group and the confidence to navigate life with Parkinson's. With the support of his wife and family, Preston is committed to living his best life and encouraging others to seek the help they need.

NEWLY DIAGNOSED:

SHARING THE FIRST STEPS OF YOUR JOURNEY

Being newly diagnosed with Parkinson's disease can feel overwhelming, but you're not alone. ***Newly Diagnosed*** is a space where those who are beginning their Parkinson's journey can share their personal experiences, challenges and triumphs.

By sharing your story, you can inspire and support others who may be navigating similar emotions and uncertainties. Your voice matters, and your journey could offer comfort and connection to someone else starting out.

If you'd like to be featured in the next issue of The Parkinson's Update, contact Kevin Blondin, Marketing & Communications Specialist at Parkinson Society Southwestern Ontario, at **kevin.blondin@psso.ca.** Your story can be a light for others!

TRANSFORMING PARKINSON'S DIAGNOSIS:

A Canadian Perspective on a-Synuclein Biomarkers

In the ongoing effort to diagnose Parkinson's disease (PD) earlier and more accurately, researchers have developed an approach to isolate a biomarker (molecules observed in blood or tissues, often in elevated amounts) associated with the disease. This innovative work was funded by the Michael J. Fox Foundation, on behalf of the Parkinson's Progression Markers Initiative, and was recently published in the prestigious journal The Lancet Neurology.

This study is a remarkable advance to the diagnostic and consequent therapeutic aspects of Parkinson's research and introduces the potential for similar approaches to be used for other neurodegenerative diseases, including Lewy-body dementia and multiple system atrophy (MSA).

The PD biomarker of interest is α-Synuclein, a protein which, when misfolded, forms aggregates known as Lewy bodies in the cytoplasm of cells. They are a known cytotoxin, and are commonly observed in individuals with PD. As Lewy bodies accumulate and spread, they contribute to neuronal death in the brain, resulting in characteristic early-stage symptoms such as tremors, stiffness in the extremities and loss of balance, as well as late-stage symptoms like impaired speech and cognition, as well as loss of motor control.

Currently, Parkinson's diagnoses are heavily reliant on observable physical symptoms. This is not the most reliable method however, and carries the risk of misdiagnosis, as numerous neurological conditions, such as MSA, have a similar early presentation but follow different clinical courses than PD.

Fortunately, research described in this article has led to a novel diagnostic tool, the α-synuclein seeding amplification assay (αSyn-SAA). Using this method, cerebrospinal fluid (CSF) samples can be screened for abnormal presentations of α-Synuclein, thus adding a precise biomolecular method of diagnosis to the current one that relies on physical observations.

Its effectiveness has been shown in individuals already diagnosed with Parkinson's, as well as those at risk, with up to 93% accuracy. It has been able to detect 98% of α-Synuclein-related diseases, with high specificity and sensitivity. It is important to note that αSyn-SAA only identifies the presence of α-Synuclein and cannot definitively confirm which α-Synuclein-related disease an individual might have. However, there is constant movement to build on the groundwork αSyn-SAA has provided. This includes quantifying the process by measuring the concentration of malformed α-Synuclein protein in an individual's CSF with the hope to carry out diagnosis using less invasive tests, e.g., screening for α-Synuclein via blood test or nasal swabs instead of CSF collection.

This work has caught the attention of prominent researchers investigating the role of protein misfolding in neurodegenerative diseases at Western University. Dr. Martin Duennwald received his PhD at the University of Cologne, Germany, and completed his postdoctoral training at the Massachusetts Institute of Technology (MIT). He points out that because present-day diagnosis of PD involves an assessment of symptoms and Parkinson's is most common among the elderly, it can become challenging to distinguish between Parkinson's symptoms and natural aging. "Spinal taps are painful, time-consuming, and require highly specialized healthcare providers," says Dr. Martin Duennwald. "The prospect of identifying an effective biomarker from blood is very exciting." Furthermore, when a patient is finally assessed and diagnosed, it is often too late for effective intervention because at the time of diagnosis, "70-80% of targeted neurons are already destroyed."

Dr. Duennwald has emphasized that the ability of αSyn-SAA to increase general screening of patients could raise the number of cases caught prior to severe neurodegeneration and aid in earlier evaluation for those at risk due to family history. Therefore, treatments including drugs like Levodopa (L-DOPA), or procedures like deep brain stimulation (DBS) can begin earlier, slowing down the overall development of symptoms rather than just managing them.

Earlier diagnosis also creates opportunities for surgical interventions, a form of treatment that is commonly denied to the "elderly [who] can be excluded from the surgery due to risk factors" that come with late-stage PD combined with age.

We can also see advancements in understanding the neurodegenerative disease and combating its effects. "With a reliable biomarker, we can accelerate clinical trials." Dr. Duennwald explains. "Usually, we test treatments on those with late PD, [and] finding patients earlier in the disease progression can mean more valuable research."

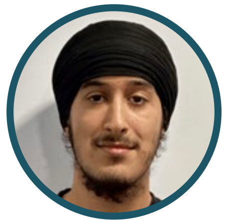
One concern for Canadian patients is waiting for access to these new technologies, and the outlook is hopeful. "As of late, Canada has been faster in adopting FDA-approved diagnostics." Canadian research alone is limiting, and we often rely on international collaboration. Dr. Duennwald believes that "if the data is convincing, this new technology can get approved very rapidly. Canadian patients can see this assay in their hospitals in a couple years rather than a decade."

Due to the vast potential the current assay possesses, Dr. Duennwald emphasizes the importance of this technology's innovation and the data supporting its efficacy. "Only systematic research will give us the answers." He also notes the possible challenges with the assay development. "What if α-Synuclein is not sufficiently present in blood?"

However, he is still optimistic for the future optimization of the αSyn-SAA, as this breakthrough guides further innovation in new technologies. Ultimately, he envisions an "affordable, quick, easy testing system" in the future of Parkinson's management.

__Stephanie Di Guglielmo__ is a fourth-year student completing an honours degree of Physiology and Microbiology-Immunology at Western University. Her work in basic medical research labs has fostered interest in the pathophysiology, prodrome and early diagnosis of disease, particularly in relation to neurodegenerative conditions.

__Cadence Lankin__ is a passionate advocate for both her local community and medical research. As the president of Students Fight Parkinson's, she dedicates herself to raising awareness and funds for Parkinson's disease research, with a focus on making a tangible impact in the lives of those affected.



__Karmjit Singh__ is a medical sciences student at Western University, driven by his passion for medical research. His interest in healthcare is deeply personal, emerging after relatives were diagnosed with multiple system atrophy (MSA) and Parkinson's disease.

RESEARCH CELEBRATION RECAP

On October 28, 2024, we held our Annual Research Celebration, at The Ivey Spencer Leadership Centre in London, acknowledging those in our Graduate Student Scholarship Program. It was a fantastic evening of networking and learning, including presentations from our researchers, and hosted by Reta Ismail from CTV News.

We had three research presentations from students awarded the Scholarship in 2024, including: Cannabidiol (CBD) an Nrf2- Protecting Cells in Parkinson's Disease by Juan Jurado Coronel, PhD Student in Neuroscience; MRI Imaging in Freezing of Gait in Parkinson's Disease by Mojtaba Sharafkhah, PhD Student in Neuroscience; and Investigating Parkin Oxidation by Viveka Pimenta, PhD Student in Neuroscience. Unfortunately, Nate Rothery, PhD Student in Neuroscience, was unable to present his project: Developing a prognostic model for Freezing of Gait in Parkinson's Disease. All the presentations were compelling, and these projects are very exciting as they are providing hope for the future for those affected by PD. We were also very fortunate to hear from Gary Pullam, one of our board members, on his own experience with PD. His presentation was very personal and genuine, all the while highlighting the importance of the research that is being done.

Our Graduate Student Scholarships are awarded annually, in the amount of $25,000 per research project. This continued investment is something PSSO is very proud of. We look forward to awarding these scholarships again in 2025 and help provide hope for the future.

VOLUNTEER TESTIMONIAL:

SHEREE VOLLMER

When I retired in 2020 after a fulfilling career in Patient Food Services at the London Health Sciences Centre, I looked forward to exploring volunteer opportunities. Like many, my plans were put on hold by the pandemic. Life took a different turn in June 2023 when my partner, Paul, was diagnosed with Parkinson's.

We connected with Parkinson Society Southwestern Ontario (PSSO) and began attending monthly support group meetings. That's when I saw just how much PSSO relies on volunteers to support its vital programs and events. I started volunteering a year ago and quickly gained a deeper appreciation for everything the organization offers to those living with Parkinson's.

Being part of events like the Annual Parkinson Golf Classic and the Walk for Parkinson's have been especially rewarding. Seeing the dedication and teamwork from staff and volunteers to ensure the success of these events are truly inspiring.

I also enjoy spending a couple of days each week at the office, helping with tasks like answering phones, assembling information packages, and preparing mailings. It's a great feeling to know that my time is helping to make a difference. Volunteering with PSSO is not only fulfilling but also a meaningful way to contribute to an important cause.

> **“Volunteers are critical to what we do, whether it be hosting fundraising events, support groups or providing information to new clients and Sheree is simply the best. Every week Sheree comes in with her upbeat attitude and is always willing to pitch in with whatever needs to get done. On a personal note, Sheree really made me feel welcome when I started here at PSSO in September. She has been a pleasure to work with and I look forward to working with her going forward.”**
>
> — *Kyle Campbell,*
> *Events & Volunteer Specialist*

CELEBRATING OUR HEROES

Volunteers are the heart of Parkinson Society Southwestern Ontario, and Volunteer Spotlight is our way of honoring those who go above and beyond to make a difference. This section highlights the incredible stories of dedication, compassion, and impact from the volunteers who inspire us every day.

Are you a volunteer with a story to share? Or do you know an extraordinary volunteer who deserves to be celebrated? Let us shine a light on their remarkable contributions!

Above, we feature a testimonial from one of our exceptional volunteers, alongside stories of four individuals whose efforts have truly made a difference.

To share your story or nominate an outstanding volunteer for the next issue of The Parkinson's Update, contact Kevin Blondin, Marketing & Communications Specialist, at **kevin.blondin@psso.ca**. Let's celebrate the difference you make!

ADRIENNE ROUTLY-HOULE

A number of Stratford Support Group members got together for lunch at the Best Western Arden Park to celebrate the holidays on December 13.

PSSO Support Groups across our regions are facilitated by volunteers who monthly give of their time to be with our friends who are living with Parkinson's and their carepartners. The Stratford Support Group has been very fortunate to have had Adrienne's leadership over the past 18 months. Her quiet, kind, caring and compassionate facilitation of conversations within the Parkinson's community that meet at Chartwell Anne Hathaway has greatly contributed to the group's success. Adrienne has worked diligently in arranging guest speakers to present various topics to the group's attendees. We have all benefited from the knowledge shared by nutritionists, dieticians, speech-language pathologists, and other healthcare professionals who have spent time with us. We are extremely grateful for Adrienne's leadership and dedication to the group and wish her every success as her Business Development role at Chartwell expands. We will miss her presence in the group but fully expect that she'll poke her head through the doorway and say hi on her visits to Stratford!

ERIN MCCREADY

Erin McCready played a crucial role in Walk for Parkinson's, from the beginning stages of our planning to the day of the event. She single-handedly found local businesses to donate our pizza and snack donations, our raffle prizes, and more! Her passion for supporting people with Parkinson's led her to take the time out of her busy schedule to help make our event a success. We are extremely grateful for her support for Walk for Parkinson's Brantford!

DOROTHY FYFE

In 2008, when her husband Mike was first diagnosed with Parkinson's, Dorothy reached out to PSSO for help. They were connected with a long-time volunteer, John, and made to feel very welcomed in the support group in Sarnia. They had many questions answered, received great advice and especially met many new friends. Opportunities arose to help out with social activities. PSSO Walk for Parkinson's is a lot of fun while raising funds to help support, educate and give money to research. Her work in Life Enrichment at a local long-term care home gave her the skills needed to assist and then lead a Chair Exercise Group, starting back in 2015. Volunteers are always needed to keep programs going and to continue a strong Support Group. The group changes over the years, but is needed more than ever as Parkinson's continues to multiply. Volunteering is a way to ensure others are able to benefit from what you have learned. More than that, it gives you people to walk with on the journey.

JUNE AND RON CORRIVEAU

June and Ron are long-time members of the Goderich Support Group and have participated in the Walk for Parkinson's since 2014. They are devoted volunteers at the Goderich Walk and work tirelessly to help organize and run the event each year. From putting up lawn-signs and sourcing refreshments and entertainment, to helping with set-up, registration and parking, they have been an essential part of making the Goderich Walk a success each year. They are passionate about volunteering with PSSO to raise awareness about Parkinson's disease and learn from people in the Parkinson's community. Thank you June and Ron!

CHARITABLE GIVING

It is important to understand different charitable giving vehicles and the tax implications. When we talk to clients, we recommend they consider these points:

1. Donate publicly traded securities. It is always better to donate appreciated publicly traded securities instead of cash. You will receive a donation receipt for the market value, and you will eliminate the capital gains tax. If you still want to own the security, you may repurchase it with other money immediately. The adjusted cost base will reflect the new market value.

2. Consider a planned gift. Leave a bequest in your will, or consider maximizing your legacy with the purchase of life insurance. Depending on how it is structured, you may receive a donation receipt for the annual premiums. If you have an insurance policy that is no longer required to fulfill your estate, business, or other needs, you may want to consider donating it to a registered charity. You will receive a tax receipt for the appraised value of the policy.

3. Consider a donor-advised fund. Donor-advised funds (DAFs) are the fastest growing charitable vehicle in Canada. A donation receipt is issued upfront, while establishing a long-term legacy of giving. A DAF allows you to donate now and decide later. It's been a busy year with talk about markets, interest rates, cost of living crisis and increased need from charities. We find clients need clarity around a couple of items from the Federal Budget's impact on charitable giving.

ALTERNATIVE MINIMUM TAX:

When Budget 2024 was released, it included an adjustment to previously proposed changes on the Alternative Minimum Tax (AMT) in relation to the charitable tax credit. It now allows individuals to claim 80% of the charitable donation tax credit when calculating AMT. Additionally, tax payers now must include 30% of capital gains on donated shares to registered charities in income for AMT purposes, which was increased from nil under the previous rules.

Individuals subject to AMT and considering a gift of securities should consult with their tax advisor to understand the impact on their personal situation.

INCREASES IN CAPITAL GAINS RATE:

Proposed in the 2024 budget was an increase to the capital gains inclusion rate from 50% to 66.67% for individuals on capital gains in a year that exceeded 250,000. The capital gains rate for corporations will increase to 66.67% on all capital gains.

These changes apply to capital gains realized after 24 June 2024. If a client has publicly-traded securities held personally and in a corporation, consult with a tax advisor to determine the optimum giving strategy.

Canada has some of the most generous tax incentives when it comes to charitable giving, and while we know the tax receipt isn't the number one reason Canadians give, it's important to take the time to understand your client's charitable goals and total financial situation to assess what options are available, and to recommend a course of action.

Jo-Anne Ryan | *Vice President | Philanthropic Advisory Services | TD Wealth | Private Giving Foundation*

IN MEMORIAM

We offer our sympathy to the families whose loved ones have passed away between July 1, 2024 and December 31, 2024.

Alton "Al" Nicholson
Edsel Durocher
Donald Mead
James Wagstaffe
Christopher King
Cyriel Cogghe
Edward Regan
Craig Heinbuch
Nancy Palmeri
Daisy Hodgetts
Jim Etherington
Reg Warner
Robert "Bob" McKay
Marie Skinn
Aaron Showalter
Henry Rastel
John Polanic
Maria Marra
Peter Fitzgerald
Colomba Snyders
Ernie Toth
Doris Williams
Grant Spragg
Frances Newman
Irene Maribeth "Marty" Stevenson
Delores McLeod
Paulette Parent
Tina "Martina" Donkersgoed
Donald Dumais
Patricia White
Nancy Ray
Heather Alexander
William "Bill" Bertram
Ruthann MacLeod
Sharon Lannon
Marryl Ebanks
Sharon Shapiro
James "Jim" Dawe
Ken Amos
Kaye Ducharme
Robert "Bob" Lee
Robert Foulds
Margaret Chalmers
John Geminari
Allan Richards
Omer & Marilyn Hageniers
William Fisher
Ron Edwards
Perry Wallace
Tom Hern
Ross Hicks
Grace Roth
"Dorothy" Evelyn Evers
Jerry Dadurka
Rosalia Madonia
George Vermeersch
Emery Silverthorn
Dave Stephens
Patsy Morrison
Jane Simpson
Thomas "Tom" Thompson
Carol Bernier
Ryan "Bud" Pelletier
Joan Hamilton
Edward Pollesel
Margaret MacDonald
Robert "Bob" Campbell
Michael "Mike" Roszell
Peter "PJ" Johnson
Walter Ahrens
Gerald "Jerry" LaPointe
Irvin Wand
Elizabeth "Betty" Neill
Gordon Kathen

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.

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WE WANT TO HEAR FROM YOU!

Do you have a personal journey or insight about living with Parkinson's disease or supporting someone who does? Or perhaps you'd like to share your thoughts or provide feedback on our work?

Your stories and perspectives can inspire hope, provide encouragement, and help us better serve the Parkinson's community. If you'd like to be featured in the next issue of ***The Parkinson's Update*** or simply want to share your input, we'd love to hear from you!

Contact Kevin Blondin, Marketing & Communications Specialist at Parkinson Society Southwestern Ontario, at **kevin.blondin@psso.ca** to learn more. Your story could make a meaningful difference!

UNSEEN STRENGTH:

MORE THAN YOU CAN SEE

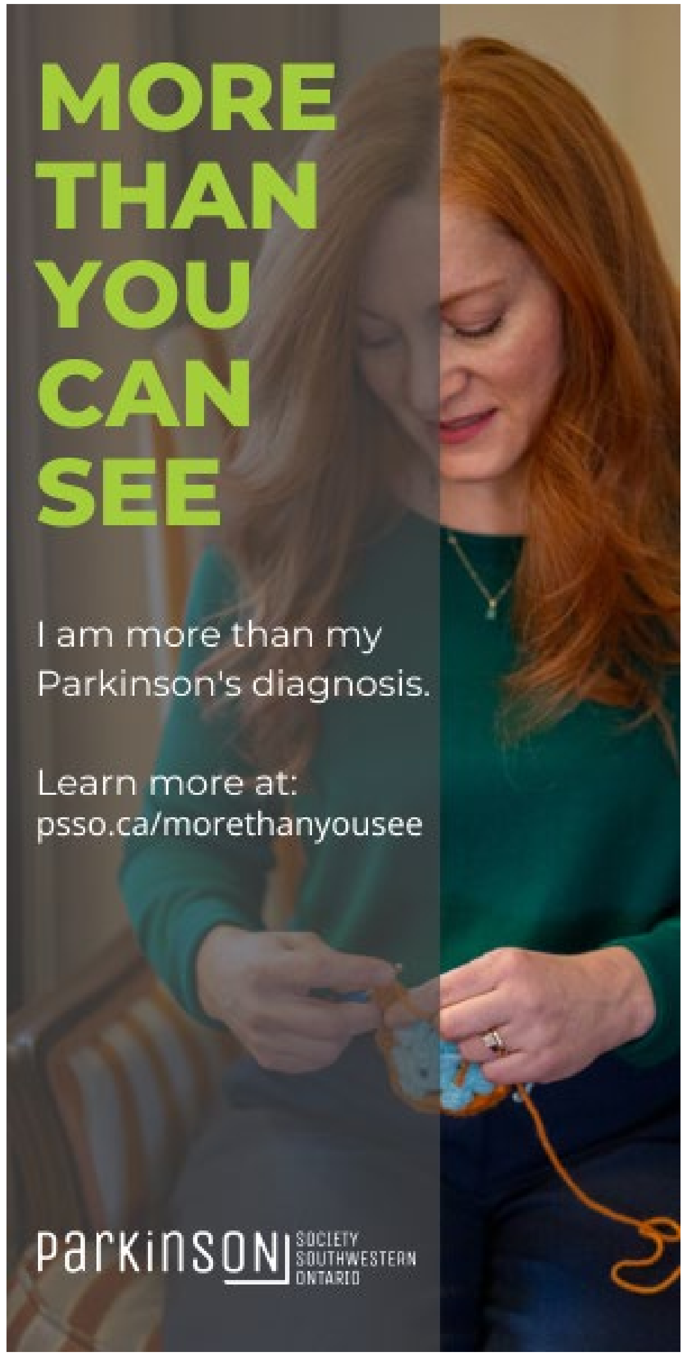
Parkinson's is more than a tremor. It's more than just a disease. It's ***More Than You Can See***.

This April, during Parkinson's Awareness Month, we will once again launch our More Than You Can See campaign, sharing four powerful stories from within our community. These stories aim to educate and raise awareness about the unseen aspects of Parkinson's disease—highlighting non-motor symptoms like depression, anxiety, apathy, sleeplessness, and more.

This year, our theme focuses on mental health, celebrating the strength and resilience of individuals who are overcoming these hidden challenges every day.

From April 10 to 16, join us in marking Parkinson's Awareness Week, with Parkinson's Awareness Day falling on Friday, April 11. On April 10, we're raising flags across our four regions in southwestern Ontario (pending approvals) to amplify the voices of our community and bring greater understanding to this disease.

We invite you to engage with us and share your story to help your community see that Parkinson's is truly ***More Than You Can See***.



WHO WILL YOU WALK FOR?

SAVE THE DATE
SEPTEMBER 6 & 7

Stay tuned for more details at **walkforpd.ca**

JOIN US FOR FOUR REGIONAL CONFERENCES THROUGHOUT THIS APRIL!

LIVING WELL

WITH **Parkinson's**

2025

APRIL 4

TILLSONBURG

Lion's Auditorium
Tillsonburg
Community Centre

10:00am - 3:00pm

Naturopathic Approach to Mental Health in Parkinson's
Dr. Reina Persaud, ND

Non-motor PD Symptoms and their Mental Health Connections
Dr. Deepa Dash

APRIL 9

BRANTFORD

TownePlace Suites
by Marriott Brantford
and Conference Centre

10:00am - 2:30pm

Depression, Anxiety & PD
Dr. Meteusz Zurowski

Nutrition Strategies for Brain Health and Vitality
Sandra Venneri,
Registered Dietician

APRIL 14

CHATHAM

John D. Bradley Convention Centre

10:00am - 3:00pm

Coping Mechanisms and Adjustments to your Life with Parkinson's Disease
Andrea Wathy
and Allison Eaton

Navigating Life with 2 diagnoses: Parkinson's Disease and Dementia
Dr. Kristopher Romero

APRIL 23

WALKERTON

Best Western Plus
Walkerton Hotel &
Conference Centre

10:00am - 3:00pm

A Parkinson's Physiotherapy Pitstop
Deepha Romuwalt, PT

Introduction to the Translational Initiative to De-risk Neurotherapeutics
Dr. Ravi Menon, PhD

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