Issue 2 Winter 2026

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™
Together we can

In this issue:

CEO update

Every single day, Fight Parkinson's strives to improve the quality of life for people living with Parkinson's, as well as the carers, friends, families, and healthcare professionals who walk alongside them in their journey. Reflecting on the past few months, especially April—Parkinson's Awareness Month—we cannot help but feel that there was a heightened sense of community, connection, and celebration in the air.

From acknowledging an abundance of significant dates that not only helped to increase awareness but allowed for the community to share their personal stories of lived experience, to the many major events that brought us all together, there was much to recognise, share, and commemorate.

As usual, April proved our busiest and most engaging month of the year—dedicated to promoting Parkinson's awareness through a united effort of an educational campaign, which took us back to the basics of Parkinson's knowledge, and the organisation of numerous community-based events. These were a reminder of Fight Parkinson's mission and inspiring contribution to our continued efforts towards freedom from Parkinson's.

In the same month, we marked 15 years of A Walk in the Park—the biggest community walk for Parkinson's in Australia. From Melbourne, to Geelong, and many more regional and remote areas in Victoria, thousands of you showed up to fundraise for Fight Parkinson's, show solidarity with people living with Parkinson's (including Young-Onset) and Atypical Parkinson's (including PSP, MSA, and CBS), and commemorate those whose journey is remembered with every step. Whether it was their very first Walk, fifth Walk in a row, or fourteenth Walk as a volunteer, we are honoured to share some personal stories from community members in this significant milestone year. Head over to page 5 to have a read.

With thanks to our corporate partners and sponsors, all the volunteers who gave their time and energy, and everyone who attended A Walk in the Park in their local community, we raised over $370,000.

We cannot thank you enough for your spirit of generosity, which will help to ensure that we can continue answering calls via the Fight Parkinson's Health Information Line, offering health education programs to the community, supporting peer support groups, as well as funding Parkinson's research and innovation programs and opportunities.

The Parkinson's Research Symposium also took place in April, hosting a day of collaboration, innovation, and connection for the Parkinson's community.

We took this opportunity to announce the Australian adaptation of 'Every Victory Counts' (see page 4), as well as the 2026 Seed Funding Grant recipients (page 11).

We remained focused during May—recognising Progressive Supranuclear Palsy (PSP) Awareness Month, sharing the research on 'encouraging an integrated palliative approach to Parkinson's care' from Professor Benzi Kluger, MD, MS, FAAN during Palliative Care Week, and launching our new online course about 'Sleep and Parkinson's', now available through our Community Learning Hub.

The World Parkinson Congress 2026 held in Phoenix Arizona provided an opportunity for Fight Parkinson's to join with colleagues, community, researchers, and clinicians from around the world. The triannual meeting

Fight Parkinson's CEO Emma Collin

was an opportunity to learn and share experiences. Fight Parkinson's presented on the National Parkinson's Action Plan (page 3), which launched in Canberra earlier this year, as well as at the Leadership Forum and Global Policy Forum. Along with Shake It Up foundation and Parkinson's NSW, we were pleased to host an event to connect all Australian's attending the meeting.

There were also invaluable moments to connect with influential authors like Steve Yellen (page 12) and our international friends from the ParkinsonNet global team network from countries including France, Norway, and Poland who are currently, or have already, implemented ParkinsonNet into their own healthcare systems.

This edition of InMotion invites the community to find opportunities for connection, hope, and understanding through a combination of personal stories, helpful tools and resources, and the recounting of events you may have missed.

Thank you to all those who contributed to the work of Fight Parkinson's over the past few months, whether it was through gifting a donation, sending us an inspiring message of thanks, or trusting us with your story of lived experience. We are truly honoured to be on this journey with you.

Emma Collin
CEO
Fight Parkinson's

Cover: Lawrie and Sam at A Walk in the Park 2026

News and highlights

The 2026 Parkinson's Research Symposium

With thanks to The Florey Institute, the annual Parkinson's Research Symposium returned to Melbourne in April.

For over 10 years, the symposium has become a forum for bringing together the Parkinson's community, researchers, and clinicians, as well as a trusted platform for showcasing high-quality Parkinson's research, strengthening collaboration across institutions, and supporting translation from discovery to real-world impact.

With close to 200 registrations to attend in-person, and over 520 online registrations, this year's event reached international status, as participants tuned in to watch from across the globe.

This year's Symposium focused on innovation in care and collaborative research, with an Agenda that included the following speakers:

- **Emma Collin, CEO of Fight Parkinson's** - Welcome and opening remarks
- **Peter van Wijngaarden, CEO of The Florey Institute** - Welcome from The Florey Institute
- **Professor David Finkelstein and Professor Kevin Barnham** - Prevention in Parkinson's: Environmental risk and emerging evidence
- **Professor Grant Dewson** - Collaborative research and strategic investment
- **Marty Rankin** - Fight Parkinson's A Walk in the Park Ambassador presentation
- **Polly Dawkins, Executive Director of the Davis Phinney Foundation** - International keynote address
- **Professor Jennifer McGinley and Dr Marlena Klaic** - Innovation in care – ParkinsonNet Australia
- **Professor John Forsythe and Professor Mibel Aguilar** - Update on 2025 Seed Funding Grant recipient's research project on neural repair in Parkinson's.

In addition to these insightful presentations, CEO of Fight Parkinson's, Emma Collin, also announced the upcoming Australian edition of 'Every Victory Counts' – Australia's first evidence-based, single-source guide for people living with Parkinson's, in collaboration with the Davis Phinney Foundation. Read more about 'Every Victory Counts' on page 4.

The 2026 Seed Research Grants were also announced at this year's Symposium. Details of these research projects can be found on page 11.

"Chris and I wish to express our gratitude and thanks for yesterday's symposium at The Florey. To be present with fellow community members, carers, professional medical researchers, and medical scientists was an absolute privilege. We are so grateful to all who strive to improve the quality of life for our Parkinson's community, and we are convinced that the next generations are in good hands." *– Liz and Chris McNeill*

Along with everyone who attended (both in-person and online) the Parkinson's Research Symposium 2026, Fight Parkinson's would also like to thank each of the esteemed speakers who presented this year.

National Parkinson's Action Plan

On 24 March 2026, Australia's first National Parkinson's Action Plan (NPAP) was launched in Canberra, providing actions to improve awareness, care, support, and research for people affected by Parkinson's across the country.

The NPAP represents years of advocacy and collaboration across the Parkinson's community and sector, led by the National Parkinson's Alliance (NPA) of which Fight Parkinson's is a founding member.

Most importantly, it reflects the voices and experiences of more than 200,000 people living with Parkinson's, their families, and carers.

The community and cross-sector collaboration underpinning the plan has been significant. A comprehensive literature review of national and global peer-reviewed research informed an extensive consultation process, supported through a national survey and face-to-face workshops.

In Victoria, 1,354 community members contributed to the survey, with seven face-to-face workshops and two online sessions delivered, ensuring participation from both metropolitan and regional communities, including dedicated engagement with people living with PSP, MSA, or CBS.

The consultation between June and August 2025 was followed by in-depth interviews with people living with Parkinson's and caregivers, as well as extensive sector engagement through workshops with researchers, clinicians, and state and federal government policy-makers.

We extend our sincere thanks to all members of the community who contributed to this foundational work.

News and highlights

Every Victory Counts – Australian Edition

In collaboration with the Davis Phinney Foundation, Fight Parkinson's is pleased to announce that an Australian adaptation of 'Every Victory Counts' will soon be made available, free of charge, both physically and digitally.

'Every Victory Counts' is a practical guide to living well with Parkinson's. Originally developed in the United States by the Davis Phinney Foundation, it has evolved over a 15-year period across seven editions.

The manual explores the many aspects of life with Parkinson's, bringing together expert insight and lived experience to help readers better understand Parkinson's and the many ways it may affect their lives. It includes topics like exercise, emotional health, building your healthcare team, and more.

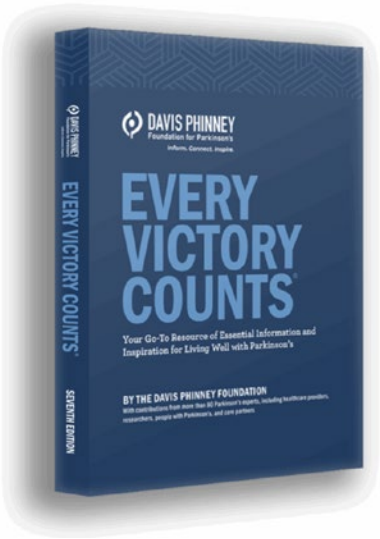
We hear consistently from our community that the Parkinson's journey can feel overwhelming. Many people tell us they don't know where to begin, that information is fragmented or difficult to navigate, and that they are searching for guidance they can trust and reflects the realities of living with Parkinson's.

This project is a direct response to what our community has told us they need. It has been designed to empower people living with Parkinson's, their families, carers, and healthcare professionals with trusted information, practical strategies, and tools to help people live well.

Fight Parkinson's is committed to ensuring this resource is freely available to Australians. We believe everyone deserves fair and equitable access to trusted Parkinson's information and support, regardless of where they live or their personal circumstances.

What makes the Australian edition especially valuable is that it brings together international expertise, national and local clinical knowledge, and the lived experiences of Australians living with Parkinson's. It is a resource shaped not only by evidence, but by community.

To stay up to date with the latest news from Fight Parkinson's and register your interest in receiving updates about 'Every Victory Counts', scan the QR code or visit fightparkinsons.org.au/every-victory-counts



The APVMA chemical review on Paraquat

Following its chemical review of the herbicide, Paraquat, the Australian Pesticides and Veterinary Medicines Authority (APVMA) has announced its final decision that Paraquat products will remain registered for use in Australia, subject to new restrictions and additional safety controls.

While Paraquat will not be banned, the regulator has introduced a range of new restrictions, designed to reduce exposure risks for users during agricultural use, including:

- An 80% reduction in the maximum application rate per hectare
- A ban on backpack sprayers
- Requirements for enclosed mixing and loading systems
- Stronger personal protective equipment requirements for users
- A two-year transition period for existing product stock.

In 2024, Fight Parkinson's supported a ban on Paraquat in Australia based on the available scientific evidence and concerns about the potential role of environmental risk factors in Parkinson's.

Fight Parkinson's is now carefully reviewing the detailed scientific assessments and expert reports relied upon by the APVMA in reaching its decision. We will continue to engage with researchers, clinicians, policymakers, and the Parkinson's community to better understand the implications of this outcome and continue to advocate for the community.

While the APVMA's decision is not the outcome Fight Parkinson's and many in our community hoped for, it should not be interpreted as evidence that there is no association between Paraquat exposure and Parkinson's, nor that concerns raised by researchers around the world have been resolved.

Importantly, while there was evidence of association and increased risk, there was not definitive proof that Paraquat causes Parkinson's in an individual.

Fight Parkinson's will continue to monitor emerging evidence, support research, and advocate for policies that prioritise prevention, community health, and better outcomes for all Australians affected by Parkinson's.

We thank the people in our community who have shared their experiences, contributed submissions, and helped raise awareness of this important issue. Your voices continue to play a vital role in advancing understanding of Parkinson's and the factors that may contribute to it.

A Walk in the Park

A Fight Parkinson's community event

15 years of commemoration, celebration, and community

During Parkinson's Awareness Month, thousands of you participated in scheduled A Walk in the Parks across Victoria—from central Melbourne to some of our most regional and remote areas—highlighting lived experience, amplifying voices, and building momentum for a future where every person living with, or caring for someone with Parkinson's can access the support, connection, and opportunities they deserve.

This year marked an incredible milestone as we celebrated 15 years of walking together. We are so grateful to everyone who joined us—people living with Parkinson's (including Young Onset) and Atypical Parkinson's (including PSP, MSA, and CBS), the families and carers who walk beside them, and those whose journeys we remember with every step.

Together, we celebrated not only the strength of this community but also the impact of Australia's largest walk for Parkinson's.

For 15 years, you have continued to show your unwavering spirit and support—increasing awareness of the fastest-growing neurological condition in the world, standing in solidarity with your fellow community members, and raising much-needed funds for the Parkinson's community.

A Walk in the Park would not be the incredible success that it is each and every year without you, so thank you for your fundraising efforts, your participation, and your support.

THANK YOU!

Thank you to our 2026 A Walk in the Park Ambassadors, whom championed this year's Walk and we were proud to feature across our social media in the lead up to this milestone event.

• Isa Adams • Sean Anderson •
• Sean Atkinson • Kate Cowen • John Eren •
• Rod Hadfield • Shane Jacobson •
• Georgy McIntyre • Marty Rankin •

Top fundraisers

Fight Parkinson's would not be able to offer and contribute all that we do, without the generosity of the community. While we do receive some government funding, we rely heavily on our fundraisers, donors, and corporate sponsors to continue improving the quality of life for people living with Parkinson's, and their carers and loved ones, across Victoria.

In addition to keeping our health information line up and running, your support also allows us to continue offering tailored education sessions, online learning courses, access to peer support groups, and research programs and opportunities. A very big thank you to everyone who fundraised for A Walk in the Park this year, especially our $1K Club members and the top fundraising individuals and teams listed below.

	Top individuals		Top teams
1	Sean Anderson Raised: **$11,000**	1	Young@Park walkers Raised: **$21,458**
2	Peter Brown Raised: **$8,412**	2	Team G-Train And Sticko Raised: **$14,242**
3	Isa Adams Raised: **$6,498**	3	Hyxy's Team Raised: **$11,675**
4	David and Amy Smith Raised: **$5,639**	4	David and Amy Smith Raised: **$7,706**
5	Karyn Spilberg Raised: **$4,512**	5	Bassi Workwear Raised: **$7,597**

Sharing stories of community and connection

A Walk to remember Rob

For the past five years, Janis, her husband, Stephen, and their family have been participating in A Walk in the Park, to honour the memory of Janis' brother, Robert (Rob)—who was diagnosed with Young Onset Parkinson's in 2013 and passed away in 2020 at the age of 68.

After their mother suffered a stroke and spent time recovering in rehab, Janis said that her bond with Rob grew from his dedication to caring for the family.

"We were very close, and I still miss him dearly," said Janis.

Though Janis now knows many individuals who live with Parkinson's, it's only after becoming a monthly donor to Fight Parkinson's, and reading 'InMotion', that Janis and her family began to learn more about Parkinson's.

For Rob, his Parkinson's symptoms included some tremors in one of his arms and a decline in his usual capacity to recall important dates and events. But these are not the traits that his family choose to commemorate him by. Rob was described as having a "very inquiring mind", who was a "serious but caring" person, a highly accredited police officer, author, food-reviewer and writer, loving brother and father of two.

Janis and her family at A Walk in the Park 2026 in Melbourne

On their fifth Walk together, Janis stated that in addition to honouring Rob, it's witnessing the connection between other families that keeps them coming back to A Walk in the Park each year.

14 years of loyalty: Lynda's volunteer journey

Inspired by her mum who lived with Parkinson's for 27 years and passed away in 2016, Lynda has attended 14 of the past 15 A Walk in the Park events in Melbourne, volunteering at 12 of them.

"Mum was an inspiration," reflected Lynda, "And even though she never went to the Walk, we as a family felt we needed to go to that first year in support and I have never looked back."

From packing merchandise for delivery to participants, handing out snacks at the finish line, assisting at the registration tent, to marshalling participants along the course, Lynda has stepped into every volunteer role at A Walk in the Park. One year, she volunteered to push a participant in her wheelchair through the course, so that her family could enjoy the Walk together.

Contemplating her favourite aspect of volunteering at A Walk in the Park, Lynda stated that it was witnessing families of all generations walking together.

"I always get emotional watching others," said Lynda, "Especially as we cheer them over the line and when I put my bib on the tribute wall at the end of the day."

Fight Parkinson's is deeply grateful for Lynda's continued support outside of her regular duties and the selfless spirit she brings to A Walk in the Park, year after year.

"This year, I knew a few people walking from other areas of my life too, which is great because this one cause can bring so many people together."

Lynda and her dogs, Sarge (above) and Jessie (below), at A Walk in the Park over the years

Emily walks with purpose

Emily has been volunteering at A Walk in the Park in Geelong for the past five years, which she was inspired to do when her father was diagnosed with Parkinson's in late 2019.

"Seeing his strength and how he approaches life motivates me to do what I can to help support Fight Parkinson's," said Emily.

Although the news of her father's diagnosis resulted in "a big learning curve" for their family, Emily stated that Fight Parkinson's "became a really helpful hub to learn more" about Parkinson's—not just for herself, but for her parents, who also contacted our organisation for information and support.

"Events like A Walk in the Park are so important for bringing people together who live with similar experiences and supporting the amazing work that Fight Parkinson's does. I've seen first-hand how Fight Parkinson's not only supports people living with Parkinson's, like my dad, but also the people around them."

From connecting with other volunteers, giving back to the community, to sharing the day with her parents, Emily finds many rewarding aspects of the Walk each year, which she says feels "more like a celebration."

"It's such a special day where you can see the impact that Fight Parkinson's has on the community," said Emily, "And what that support means for those living with Parkinson's and their families."

Emily, her partner, and their puppy, Stanley

Lawrie's birthday in the park

You may remember Lawrie whose story we shared during MSA Awareness Month back in March. A passionate football player and sports fan during the 60s, Lawrie now leans into his other interests, like collecting memorabilia of The Beatles, and cruising the world with his wife of 53 years, Sam.

A Walk the Park 2026 in Melbourne was Lawrie and Sam's very first Walk. And it was a particularly special day, as it also happened to align with Lawrie's birthday. The staff at Fight Parkinson's were excited to surprise Lawrie with a birthday cupcake after he and Sam crossed the finish line and were delighted to hear about their positive experience on the day.

"The greatest thing about the Walk for us both was the experience of meeting most of the staff from Fight Parkinson's," said Lawrie, "The event was full of life and excitement amongst the community of carers, and the children and grandchildren of people that live with Parkinson's and Atypical Parkinson's... Both Sam and I look forward again to next year's Walk to join in on this very special day."

Lawrie with his birthday cupcake at A Walk in the Park in Melbourne

THANK YOU

Corporate partners and sponsors:

• Country Care Group • Kieser Australia • St John of God Frankston Rehabilitation Hospital •

To our community supporters for generously providing gifts and fundraising incentives. All of the generous, passionate, and thoughtful individuals who volunteered their time and energy to help ensure that everyone was safe, informed, and supported throughout the day. And of course, to all those who walked, fundraised, or showed support for Fight Parkinson's.

Managing symptoms

Staying well in winter

Now that winter has well and truly arrived, it's vital for people who live with Parkinson's to take extra precautions, especially vaccinations, to avoid any potential changes to their Parkinson's symptoms.

According to The Australian Department of Health, Disability and Ageing, people aged 65 years and over are at a higher risk of severe illness from respiratory viruses like influenza, COVID-19, and respiratory syncytial virus (RSV). But there are ways to protect yourself and your loved ones from becoming unwell during the winter season. The most effective method is to ensure you are up to date with your vaccinations.

Influenza, COVID, and RSV vaccines are safe and do not interact with Parkinson's medications. Your Parkinson's symptoms may become more noticeable for a day or so following a vaccine, however this is only temporary.

Simple tips to help stay well

- Stay well hydrated
- Wash and sanitise your hands regularly
- Avoid touching your eyes, nose, and mouth with unwashed hands.

Stay up to date with your vaccinations

All vaccines available in Australia are tested thoroughly to make sure they are safe and work well. Vaccination is the best way to reduce your risk of severe illness this winter, and each vaccine can be given at the same appointment or at a separate visit.

Influenza, also known as the flu:

- Because influenza viruses change each year, annual vaccination is recommended
- The flu vaccine is best given ahead of the winter season
- Influenza vaccinations are free under the National Immunisation Program for people aged 65 and over, who hold or are eligible for a Medicare card
- Call your GP or local pharmacy to ask if they offer this vaccine.

COVID-19 boosters:

- If it's been 6 months or more since your last COVID booster, speak with your health care provider about getting an updated dose for continued protection against variants
- People aged 65 to 74 years are recommended to get a free COVID-19 vaccination every 12 months
- People 75 years and over are recommended a free dose every 6 months
- COVID-19 vaccines are provided free by the Australian government, regardless of your Medicare or visa status.

Respiratory Syncytial Virus, also known as RSV:

- RSV is a common contagious virus that infects the airways and lungs, which spreads through droplets when an infected person talks, coughs, or sneezes
- If you are 75 years or over, and hold or are eligible for a Medicare card, you can get a free RSV vaccine under the National Immunisation Program
- Currently, a single dose of the RSV vaccine is recommended for all persons.

Should you contract COVID-19, people living with Parkinson's may be eligible for subsidised anti-viral medication. The vaccines and anti-viral medications are safe to take when you have Parkinson's and with medication used to treat Parkinson's symptoms.

If English is not your first language, you can ask for an interpreter when speaking with a healthcare professional. You can also bring a family member, friend, or carer to support you.

Please reach out to the Fight Parkinson's Health Information Line on 1800 931 031 for any questions or if you need support.

Support for you

20 years of Painting with Parkinson's: Mixing colour and compassion to create a community

Creating art uses other pathways in the brain that we don't necessarily use in day-to-day life, making it a great experience for people who live with Parkinson's.

During a walk through the gardens of Berwick 20 years ago, Anne was inspired to form a support group. This Victoria-wide support group initially began as "a place for people struggling with infertility", but evolved over time to eventually become the Fight Parkinson's Berwick Painting with Parkinson's Support Group. It was founded and lovingly grown by Anne Atkin—previous art teacher, published author, Parkinson's ambassador, and recipient of the 2020 Medal of the Order of Australia for her support and contributions to the Parkinson's community.

Though she stepped down from leading the support group in 2021, Anne continues to advocate for the Parkinson's community and was still more than happy to speak about the history of Painting with Parkinson's.

"I wanted to give people who have never had a chance to experience creativity a chance to come and have a go," she said. "Art helps to soothe the central nervous system."

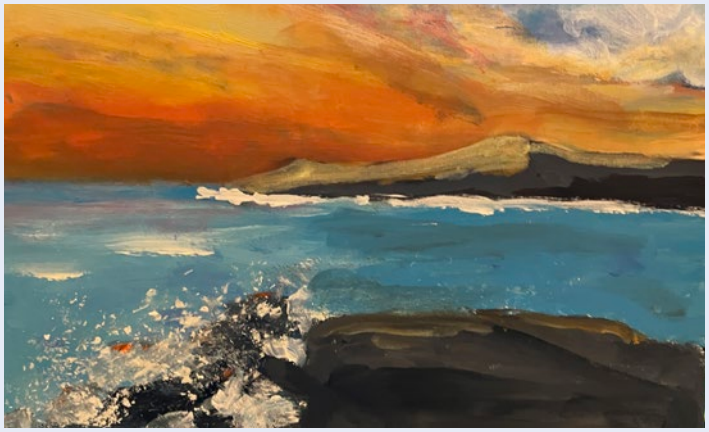
Although creativity was the main focus of the support group, Anne—who was diagnosed with Parkinson's herself at the age of 55—began to implement other strategies which she found offered her sustained relief from her own symptoms.

This included a combination of:

- Humour
- Mindfulness
- Positive thinking
- Socialisation
- Visualisation
- Wellness

All in a safe and supportive setting.

Anne says that what she observed through Painting with Parkinson's, is that the people she witnessed painting in her support group seemed to experience some ease in their tremor. But this wasn't the only positive relief that she observed. Referring to the group as "a package-deal of things that can help us feel we are taking some control back in life", she said that every activity was focused on striving to retrain the brain.



"The social aspect of Painting with Parkinson's also helped with my own depression," said Anne, "We found that people's moods would come up after a few weeks, like they are no longer as depressed as they used to be. I think it gives a sense of value to the individual."

Participants of Painting with Parkinson's groups across Australia attest to the activity's value in improving self-esteem, overcoming loneliness and isolation, and a way to provide personalised therapy.

Anne also shared that the support group provided people with Parkinson's an amazing opportunity to explore their sense of colour and creativity. Playing games was also something that she began to implement into the sessions as a way to spark joy.

Remembering back over her 15 years of running the Fight Parkinson's Berwick Painting with Parkinson's Support Group, Anne said that everyone benefits in one way or another from being creative.

"We had a man in a wheelchair, who couldn't speak, or move on his own. His family brought him along. I put a paint brush in his hand, and he eventually got the idea and the strength to hold a brush, dip it in paint, and have a go. We framed the paintings and the family hung them in his home."

She also mentioned a gentleman whose work went on to be included in several exhibitions and expressed his gratitude for Anne and Painting with Parkinson's, saying, 'You put a brush in my hand, and now I'm an artist.'

When asked what she would say to someone who was thinking about joining a Fight Parkinson's Painting with Parkinson's Support Group, but might be feeling apprehensive or nervous about doing so, Anne replied with the Painting with Parkinson's creed: All people are valued.

"If you don't want to have a go, that's fine. Come and sit and have cake or tea or coffee with us and just enjoy. And when you're ready, you let us know."

If you are interested in joining your local Fight Parkinson's Painting with Parkinson's Support Group—or another Peer Support Group—please contact the Fight Parkinson's Health Information Line.

Phone
Health information line: Free call 1800 931 031*
**A free translation service is available on this line.*

Email
info@fightparkinsons.org.au

Research

2026 Seed Research Grants

Following a successful inaugural program in 2025, Fight Parkinson's was proud to announce the winners of this year's Seed Research Grants at the Parkinson's Research Symposium.

The Seed Research Grant Program is designed to nurture research projects, by providing researchers with the resources to explore new hypotheses and experimental ideas. Fight Parkinson's aim to accelerate the development of discoveries that may lead to transformative solutions for individuals living with Parkinson's.

Congratulations to the successful applications for the 2026 cycle of our Seed Research Grants:

Basic Science Seed Grant

Research Lead: Assoc/Prof Christine Nguyen: BOptom, PhD, CertOcTher, Head of Ocular Biomarker Laboratory, Department of Optometry and Vision Sciences | Faculty of Medicine, Dentistry and Health Science, The University of Melbourne

Research Team & Roles:

- Dr Da Zhao (ECR): Tissue neuroprotection expertise/ Retinal function expertise
- Dr Pei Ying Lee (ECR): Clinician-scientist optometrist/ Eyescan OCT expertise
- Prof Pete Williams: Vitamin B3 NAM expert/Translational neuroscientist
- Prof David Finkelstein: Parkinson's biologist/Consumer advocacy

Project Name: The Eye as a Window to Nicotinamide Neuroprotection in Parkinson's

Project Details: Imagine a future where a screening eye test at your local "Specsavers" could assess your risk of developing Parkinson's and your prognosis could be improved by taking a safe and inexpensive vitamin. A surge in Parkinson's is impending with rates set to double by 2040. Neuroprotective treatments in Parkinson's have failed to date because they have been trialled too late, after many neurons have been lost.

Our solution is to shift diagnosis to the prodromal phase using the eye, an accessible outpouching of the brain and treat early metabolic dysfunction before irreversible cell loss. This leverages recent advances in the field of retinal biomarkers in Parkinson's to link them to metabolism—a key early mechanism in Parkinson's—while demonstrating the potential of nicotinamide (NAM, the amide form of vitamin B3) as a neuroprotective treatment in an animal model as proof-of-principle.

Clinical Seed Grant

Research Lead: Dr Sarah Davies: Lecturer in Occupational Therapy, School of Health, University of the Sunshine Coast (UniSC)

Research Team & Roles:

- Associate Professor Florin Oprescu: Chief Investigator, UniSC, Public Health and Methodology
- Dr Elizabeth Proud: Chief Investigator UniMelb, Physiotherapist and Victorian Site Coordinator
- Robyn Higgins: Associate Investigator and Lived Experience Representative QLD
- Sheenagh Bottrell: Associate Investigator and Lived Experience Representative VIC
- Christine Fosberry: Student Investigators UniSC, Occupational Therapy Student
- Jenna Walker: Student Investigators UniSC, Occupational Therapy Student
- Santika Miller: Student Investigators UniSC, Occupational Therapy Student

Project Name: Mapping Real-World Stigma to Support Victorians with Parkinson's

Project Details: Many Victorians living with Parkinson's experience daily stigma, where symptoms like tremor or slowness are misread as intoxication or incompetence. This is more than social discomfort; it is a barrier to health and wellbeing. Existing survey methods, which rely on respondents recalling details of their experience hours to months after the event, fail to capture the specific contexts or "hot spots" where this stigma happens. This project addresses that gap by mapping these moments in real-time to create more targeted, actionable solutions.

We will utilise the Smartphone Ecological Momentary Assessment (SEMA3, University of Melbourne) app to capture stigma experiences in real-time. By moving beyond "after-the-fact" questionnaires, participants report stigma moments exactly as they occur, providing high-resolution data on environmental and social triggers.

Fight Parkinson's is thrilled to announce the winners of the 2026 Fight Parkinson's Seed Research Grants.

Personal story

Discovering the human endeavour

Steve's powerful perspective on living with Young Onset Parkinson's

An analytical-thinker, Parkinson's advocate, and prominent champion for self-efficacy—these are just a few of the complimentary terms that we would use to describe Steve, who is also a father and husband, someone who lives with Young Onset Parkinson's, and author of 'Living Parkinson's'.

After receiving his diagnosis, it took two days for Steve to 'Google' the life expectancy of someone who lives with Young-Onset Parkinson's, and two years to begin to proactively address his diagnosis, which he received in 2019 at the age of 55. As someone who was already focused on staying in shape and eating healthy pre-diagnosis, he continued living life as usual, that is until his doctor suggested it was time to consider taking Parkinson's medication.

"I think it was almost a defence mechanism that I kind of compartmentalised my diagnosis," said Steve, "But that's when I really decided that I was going to break this whole problem down and figure out what to do."

Leaning into his analytical background, Steve began researching Parkinson's more seriously and taking part in numerous Parkinson's research studies to further his understanding of the disease and connect with medical professionals. He then went on to attend Parkinson's Policy Forums in Washington, D.C. and collaborate with other advocates across the United States of America.

Steve also began to push the limitations of his body, training for and completing numerous physically challenging competitions, including 10 Spartan Races, 7 Sprint Triathlons, and more. Reflecting on his achievements and where his internal drive comes from, Steve first acknowledged that everyone's capabilities and limits are different when it comes to living with Parkinson's, maintaining that 'Your goals, are YOUR goals.'

But searching introspectively, Steve boiled his self-motivation down to a concept called 'self-efficacy', which refers to an individual's belief in their capacity to execute behaviours necessary to produce specific performance outcomes. It's the confidence in one's ability to influence control over one's environment.

"If you break it down and simplify it, it's really a person's belief to take control of their situation," said Steve, "And I think I've had quite a lot of that naturally."

One method that Steve suggests to help enhance your self-efficacy, is to focus on short-term goals and accomplishments.

"Instead of thinking about exercising for the next 10 years, I'm thinking about my next Spartan Race or my next triathlon. And then when I finish it, I get this dose of energy to go and do the next one."

Steve also mentioned that he applies this concept to all areas of his life, not only to his physical well-being.

"I've always been the kind of person that if I saw this 20-year track, it's hard for me to feel motivated, but when I see the finish line, I can sprint for it, rest, get up, and try again the next day. And I look at my advocacy work in the same way. Like when I was trying to get different senators to commit to sponsoring a bill—when I got one, I thought oh man, I am ready to do more. It was like throwing another log on the fire."

Steve and his son, Zack, at the Parkinson's Policy Forum

Recounting the moment he had completed last year's Spartan Race, Steve said that he was covered in rain and mud, struggling to change his clothes, when his wife asked if he felt any regrets. Though it took him an extra hour to cross the finish line, Steve found the joy in sourcing his motivation, challenging his mind and body, and digging deep for his resilience—stating that he couldn't wait to do the next one.

"To me, what self-efficacy is really about, is setting goals that let you push yourself just hard enough to feel good once you finish... What I do, or what anybody else does, has absolutely nothing whatsoever to do with what YOU do... If walking a lap around the track without assistance or running a 5km is your goal and you can do it safely, that's really what matters. It's just setting the right goal for yourself."

Determined to face his Young Onset Parkinson's with action, curiosity, and intention, Steve began publishing newsletters called 'Team Yellen' as a way to keep his friends and loved ones informed and updated. This is when a friend of Steve's—also a professional author—reached out and asked if he had ever considered writing a book. Many discussions later, Steve realised that the problem-solver in him had already methodically broken down his approach to living well with Parkinson's into seven core strategies:

1. Building the **attitude** that fuels resilience
2. Gaining the **knowledge** to make informed decisions
3. Assembling a strong **support** team
4. Using **exercise** as a tool in the fight to slow progression
5. Strengthening overall **wellness**
6. Elevating your voice through **advocacy**
7. Advancing science by participating in **research**

These strategies make up the main pillars of the practical guide that Steve published in February of 2026 titled, 'Living Parkinson's'.

Grounded in solid research and real-life experience, 'Living Parkinson's' is not just a book filled with personal stories, expert insights, and practical tools that can be adapted to create a plan for living well with Parkinson's, it is an insightful reflection of Steve's tenacity and his humanity for his fellow community members living with Parkinson's.

The book was not written as a 'one-size-fits-all' prescription, but rather it's a collection of tools and approaches, mixed with personal reports of lived experience, that Steve hopes will inspire readers to take control, find purpose, and face Parkinson's head-on.

"Whether you've just been diagnosed or you're 10 years into your journey, I hope you'll find several of the 'What you can do today' action items in the book that you can immediately use to improve your journey. That was my goal in writing 'Living Parkinson's'."

Fight Parkinson's would like to thank Steve for his generosity of time given to speaking with our team here in Australia. We'd also like to acknowledge all of his continued Parkinson's advocacy work and congratulate him on the successful publication of his book.

Visit www.livingparkinsons.com to learn more about Steve and his book, 'Living Parkinson's'.

Steve during a Spartan Race in 2023

Ask the Expert

Strength through community: A seed research grant update

At the 2025 Parkinson's Research Symposium, Emeritus Professor Meg Morris and her all-women team from La Trobe University were awarded $30,000 towards clinical research on community gym exercises for women living with Parkinson's. Upon completing Phase 1 of their clinical trial, Professor Morris offers an update on the team's research.

Professor Morris and team—including Neurologist Dr Melissa Tang, Professor Jo Kemp, Professor Michele Callisaya, Ms Claire Thwaites, Professor Jennifer McGinley, Ms Lauren Mitchell, Ms Rachel Mouer, and Ms Linda Magennis—were inspired to embark on this project after many years of conducting research on exercise and physical activity for Parkinson's.

"What we realised was that women were under-represented in clinical trials of exercise therapy for Parkinson's and the results for women were not always separated out. Therapies are often designed based on research results, so the lack of reporting in relation to sex and gender was impacting tailoring of therapies according to the specific needs of women," said Professor Morris.

Phase 1 of their project was conducted with the team at Box Hill Aqualink and centres on exercise therapy to help women live well with Parkinson's. It aimed to evaluate the safety, acceptability, and benefits of community-based gym exercise programs for women who live with Parkinson's. This trial was designed with meaningful insights from a consumer panel of women led by Professor Michele Callisaya from the University of Tasmania.

The exercise programs were individualised according to motor and non-motor symptoms of Parkinson's. Delivered by community-gym based exercise trainers who have received education on Parkinson's and ongoing support from physiotherapists, the programs aimed to improve movement control, strength, fitness, and bone health.

Women living with Parkinson's aged 70 years and younger, with mild to moderate symptoms, were offered 16, one-hour sessions of gym-based exercise for eight consecutive weeks. They came into the gym and were supervised to do strength training, flexibility, mobility, and relaxation exercises including use of bikes, rowers, and weights machines.

Lisa Silvari is one of the personal trainers from Aqualink who was trained by the team to ensure safe and effective exercise delivery to the participating women.

"As a personal trainer, being able to work alongside professionals from La Trobe University on the Parkinson's Trial has created a valuable opportunity to enhance my skills and broaden my understanding of Parkinson's through practical application. Through this process, I have observed that progressive strength training represents an effective adjunct intervention for mitigating motor decline and supporting functional capacity in Young Onset Parkinson's," said Lisa.

What this Phase 1 clinical trial has shown is that women can benefit from exercising in a community gym when they are supervised by trained staff who understand how to modify and progress exercises according to the needs of each woman.

Professor Morris stated, "What I hope to see in the future is that community gym exercises are readily available for women living with Parkinson's and designed to meet their needs".

Fundraising

Peter champions the Fight Parkinson's 2026 Tax Appeal

At just 50 years old, Peter was diagnosed with Young Onset Parkinson's. Today, he is an advocate for Fight Parkinson's and the hero of our Tax Appeal for 2026.

From assistance finding a specialised speech pathologist, guidance navigating the complexities of the NDIS application, connection with a Fight Parkinson's Peer Support Group, to continued support as he experiences new symptoms—Peter has contacted the Fight Parkinson's Health Information Line on numerous occasions throughout his health journey with Parkinson's.

And he hopes that the information line will be available long into the future, not just for himself, or his wife, but for other Australian's living with, or caring for someone who is living with Parkinson's.

No one should face Parkinson's alone. With your support, they won't have to. Your gift will give someone the expert care, knowledge, and guidance they need to face Parkinson's with confidence today, and in the years ahead.

Scan the QR code or visit fightparkinsons.org.au/donate to donate to Fight Parkinson's today.

Cut out this useful card and keep it with you...

Some people may not understand what Parkinson's is. This card provides an explanation that you are living with Parkinson's and may be experiencing symptoms.

By cutting it out and keeping it in your purse or wallet, you can provide essential information to others that you are living with Parkinson's and may need their patience or assistance.

I have Parkinson's

Please be patient and give me time to move or communicate. I may:

- be slow, unstable or unable to move
- have a tremor or uncontrolled movement
- speak quietly or slur my words

Stressful situations can worsen my symptoms

About Fight Parkinson's

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About InMotion

***InMotion* is an information service of Fight Parkinson's.**

Fight Parkinson's is the operating name of Parkinson's Victoria Ltd.

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Publisher: Fight Parkinson's

Print post approved: 100011035

Frequency: *InMotion* is published four times a year and distributed to members of Fight Parkinson's.

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Editorial policy:
While submissions for inclusion in *InMotion* are welcome, the final decision rests with the editor. All submissions are subject to the publisher's editorial guidelines and may be edited for space or clarity.

Community Callout

Share your story

InMotion magazine features real-life stories and experiences from people living with or caring for someone with Parkinson's, (including Young Onset) and Atypical Parkinson's (including PSP, MSA, and CBS).

Every story shared reminds others facing similar experiences that they are not alone.

If you have a story to share, we want to hear from you.

Email us at marketing@fightparkinsons.org.au

Cut out card

See reverse for details.

My name is:

Fight Parkinson's
Together we can

_____

With my consent or in an emergency, please call:

Name: _____
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