Issue 2 Winter 2025

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™
Together we can

In this issue:

CEO update

From A Walk in the Park to the collaborative energy of the Fight Parkinson's Research Symposium, our shared commitment to improving the lives of people living with Parkinson's was on full display throughout Parkinson's Awareness Month in April.

Close to 3,000 people participated across the country in this year's A Walk in the Park. We cheered from afar as community groups walked in Melbourne, regional Victoria, South Australia and New South Wales to help raise awareness.

From Federation Square to regional communities, the success of this year's walks highlighted the wide-reaching impact of Parkinson's and the incredible strength of those determined to make a difference. By walking together our powerful community of people living with Parkinson's, carers and supporters, are making progress. A Walk in the Park's profile and Parkinson's awareness continues to grow thanks to our amazing ambassadors and regional organisers who champion our community.

Whether you walked in the city or rallied support in your local area, you've shown that no one has to face Parkinson's alone. Thank you for driving progress and bringing our community together.

This April Fight Parkinson's once again welcomed an array of incredible researchers for our annual Parkinson's Research Symposium, warmly co-hosted at the Florey Institute.

The event successfully brought together researchers, clinicians, and the Parkinson's community to discuss recent developments and new research. Most excitingly the Symposium gave Fight Parkinson's the opportunity to announce the recipients of our new seed research funding grant.

Thanks to your generosity, two research teams have each received $30,000 to pursue innovative projects - one in clinical research and one in basic science. These promising studies are a direct result of your support and are key to driving progress in Parkinson's research. We look forward to sharing updates with you as these projects progress. You can read about their aims on page 4.

Fight Parkinson's, in partnership with the University of Tasmania, is proud to announce a major step forward in Parkinson's care research with an $815,000 investment to support the adaptation of the ParkinsonNet model to Australia.

Fight Parkinson's first introduced the best practice ParkinsonNet model to the Australian community in 2019, and has been a passionate advocate for its potential to improve care quality, coordination, and access. This new pilot is the result of years of advocacy and collaboration, and represents a transformative opportunity to reshape how Parkinson's is managed in Australia.

The National Parkinson's Action Plan (NPAP) project is now well underway. Over the coming months, we will be moving into a phase of community consultation to ensure the voices and experiences of people living with Parkinson's, their families, carers, and the wider sector are reflected in the development of the Plan. We are committed to making this process as inclusive as possible and will provide further updates about how you can participate, including opportunities to contribute feedback and ideas. Ongoing communication will be a key part of this next stage to ensure the Action Plan is shaped by the community it is intended to serve.

Fight Parkinson's CEO Emma Collin

In this edition of InMotion we reflect on your outstanding efforts to raise the awareness of Parkinson's within the broader community. We explore the next steps in bringing a ParkinsonNet model of care to Australia and provide further insights into the research projects your ongoing support has helped fund. Additionally, we look at the importance of building care teams that suit your needs and why networks of support are important to you living positively with Parkinson's.

Each day it is a privilege to be trusted with your stories and to share them with the Parkinson's community. Thank you to everyone who has spoken up to help raise awareness and support their fellow community members.

Emma Collin
CEO
Fight Parkinson's

News & highlights

The ParkinsonNet team Dr Marlena Klaic, Professor Jenny McGinley, Professor Michele Callisaya, and Mr Victor McConvey.

Revolutionary model of care ParkinsonNet to pilot in Australia

After six years of community advocacy and fundraising, a ParkinsonNet model of care will be implemented in Australia.

This April Fight Parkinson's was thrilled to announce a $815,000 contribution to a total $3.7 million of funding towards bringing a ParkinsonNet model of care to Australia. Its integration will begin with a pilot in Western Victoria and Tasmania, with the intention to deliver a National ParkinsonNet Centre in the next five years.

The pilot reflects the steadfastness of the Australian Parkinson's community in advocating for improved care now and in the future.

Funding for the project includes $2.88 million from the federal government's Medical Research Future Fund, awarded to Professor Michele Callisaya from the University of Tasmania.

ParkinsonNet is a multidisciplinary model of care developed in the Netherlands with proven success in Europe and the United States. Its implementation has shown improved health outcomes, reduced disability, lower hospitalisation rates and reduced healthcare costs.

In a bid to improve outcomes for the 219,000 Australians living with Parkinson's, the pilot will upskill health professionals and strengthen visible networks to create improved health care access.

ParkinsonNet will be a familiar and welcome concept for many Fight Parkinson's community members. The journey to bring the program to Australia began in 2019 when its founder Professor Bas Bloem travelled to Melbourne and it became clear the model aligned with the desires of the local Parkinson's community.

Implementation will take time, and bringing ParkinsonNet into the Australian context will present new challenges – among them, low population density and health professional shortages in the regions.

It is for this reason the approach will be staged, with the pilot program to run in Geelong, Barwon, and Tasmania before expanding nationally.

Many of the Fight Parkinson's community will already be familiar with the project lead, Professor Michele Callisaya who lives with Parkinson's herself.

Professor Callisaya is as determined as everyone in the Parkinson's community to ensure the implementation of a ParkinsonNet model of care in Australia is successful.

While a win for all Australians living with Parkinson's, the pilot will be of particular benefit to those living in regional areas who currently have reduced access to care.

The pilot will lead to a ready-to-implement roadmap and a National ParkinsonNet Centre, creating a legacy of improved care and support for all Australians living with Parkinson's.

Fight Parkinson's will lead training, mentoring, audit and feedback, and an online web-finder platform through the creation of the National ParkinsonNet Centre. The Centre will build a sustainable network of trained health professionals, ready to provide best-practice care to people living with Parkinson's across the country.

Fight Parkinson's will continue to keep you up to date throughout the pilot project.

Stay informed on Fight Parkinson's news and highlights in our new e-newsletter fightparkinsons.org.au/subscribe

News & highlights

Inaugural community-funded seed research grant recipients announced

With thanks to the fundraising efforts of the Parkinson's community, Fight Parkinson's announced the inaugural recipients of the Seed Research Grant Program at the Fight Parkinson's Research Symposium in April.

The generosity of the Fight Parkinson's community has enabled two researchers to receive grants of $30,000 to pursue promising new research towards early-stage ideas with potential for major breakthroughs. Two grants were awarded, one in clinical research and one in basic science.

Fight Parkinson's believes these projects are on the verge of major breakthroughs and reflect our unwavering commitment to foster innovation, break boundaries, and provide support for groundbreaking ideas that have the potential to be life changing for the Parkinson's community.

It is only through innovation that better therapies can be developed to ensure those living with Parkinson's live positively.

It was the opinion of the judging panel, which included both local and international professionals, that these two projects could mark a turning point for the 219,000 Australians living with Parkinson's.

Rewiring the brain: Tapping into natural regeneration

The basic science grant was awarded to Professor John Forsythe and his team at Monash University, where they are exploring the potential of the brain to regenerate stem cells affected by Parkinson's.

Working alongside Professor Mibel Aguilar, Professor David Finkelstein, and Dr Ketav Kulkarni, Professor Forsythe – an engineer - has likened the project to building bridges in the brain.

Unlocking the brain's regenerative potential: A novel therapy for Parkinson's disease explores the use of a gel to connect regenerative cells to Parkinson's affected areas of the brain.

The scientific community has recently discovered the brain retains the ability to create new stem cells up to the age of 80. Professor Forsythe and his team want to explore what this new information means for the potential for Parkinson's affected brains to self-heal.

"With deep brain stimulation technology, we know how to inject into the brain and how to do that very specifically," Professor Forsythe said.

"We intend to build a bridge between the hippocampus, which we now know is creating new stem cells, and encourage them to get to where they can differentiate into new neurons."

By directing these new stem cells to areas where dopaminergic neurons (dopamine-producing brain cells) have died, Professor Forsythe and his team hope the new stem cells will evolve into new dopaminergic neurons.

The team has had positive results in animal testing, observing behavioural improvement following the procedure.

If the science is successful, Professor Forsythe expects treatments using it could be done through a day procedure.

Professor Forsythe and his team will use the grant funding to continue to derisk their research with the aim to secure further investment in the program.

If successful, their findings could open the door to treatment strategies that not only manage symptoms but address the root cause of neurodegeneration.

Improving outcomes for women through tailored exercise

Professor Meg Morris and her team from La Trobe University were awarded $30,000 towards clinical research.

Their project - *Improving Wellbeing in Women with Lived Experience of Parkinson's Disease Using Community-Based Gym Exercises* - will focus on the underrepresentation of women with lived experience of Parkinson's in clinical trials on exercise therapy.

Excitingly, this project not only focuses on women with lived experience but features an entirely female research team. Professor Morris will be supported by Dr Melissa Tang, Professor Michele Callisaya, Associate Professor Joanne Kemp, Claire Thwaites, and Lauren Mitchell.

Existing research shows exercise can help improve Parkinson's symptoms, but research has yet to explore which types and amounts of exercise are most effective for women.

This project seeks to increase equity of access to community fitness programs for women with Parkinson's by establishing a gym-based strength and fitness training program specifically designed for women living with the condition.

If successful, the pilot could improve women's health through better knowledge about the benefits and challenges of gym-based strength and fitness training, and by educating exercise trainers in how to modify gym programs to suit the diverse needs of all women with Parkinson's.

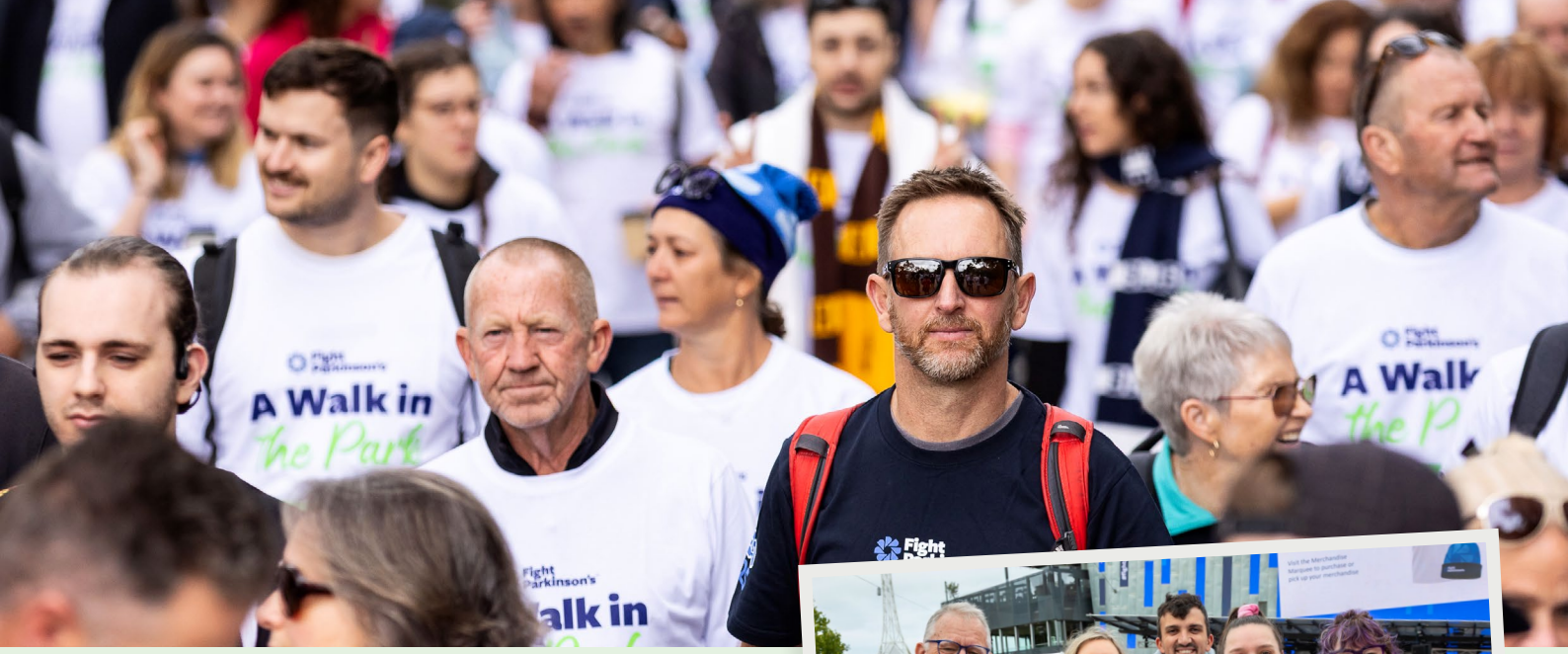
Trials will be run over eight weeks in both community gyms and rehabilitation facilities with the aim to provide clearer guidelines for exercise programs that can be used in a range of gym environments.

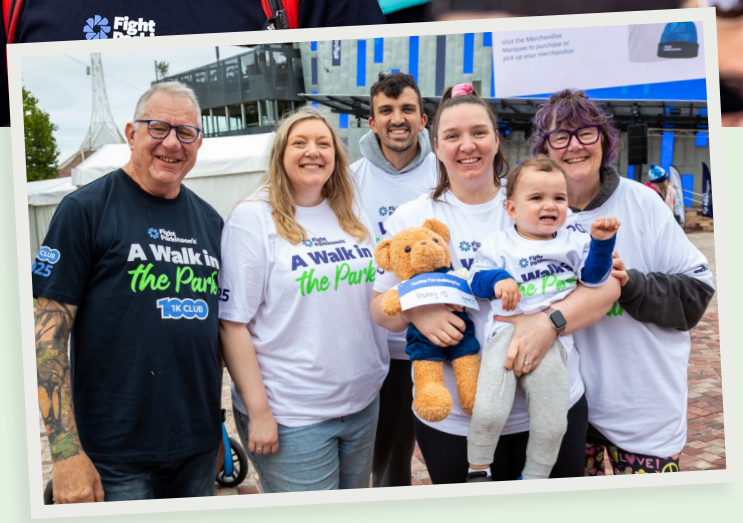
The exercise program will consider changes in upper and lower body strength, fluctuations in menstrual cycles, and fatigue in the women participating.

The team has committed to collect quantitative data and qualitative data to better understand what factors can improve women's access to gym facilities.

Fight Parkinson's looks forward to sharing the progress and outcomes of these projects with the Parkinson's community.

Claire Thwaites, Dr Melissa Tang and Professor Michele Callisaya accepted Fight Parkinson's inaugural clinical research seed grant.





A Walk in the Park

A Fight Parkinson's community event

A beautiful day, a united crowd, and a powerful sense of purpose – there is something so special about our Parkinson's community.

A Walk in the Park is one of our favourite days of the year, and once again, the Parkinson's community showed up in strength and spirit.

This year's event at Federation Square welcomed 2,000 members of the community from across Victoria. Meanwhile, an additional 12 regional walks took place, marking our biggest regional participation ever. In total, nearly 3,000 people united to take on the challenge, raise awareness, and show support.

The walk was once again held during Parkinson's Awareness Month, an apt time to raise awareness for the 219,000 people living with Parkinson's across Australia.

Living with Parkinson's can be difficult and A Walk in the Park provides a space for connection, positivity, and collective strength.

"We are stronger when we fight together. We can say more, do more, be more and achieve more. The way the Parkinson's community showed up for one another this April fills me with pride and hope," Emma Collin, Fight Parkinson's CEO said.

Emma was pleased to meet with community at several regional walks this year. She said the continued efforts from regional communities to raise awareness is to be admired.

Everyone had their own reason to walk and to see a sea of A Walk in the Park shirts across the state sent a powerful message of solidarity.

"When people walk together and support one another, it shows the commitment our Parkinson's community has to connecting with each other and helping to build local awareness," Emma said.

As each walk grows, so does the strength of our community and with it the awareness of Parkinson's and its far-reaching impact.

Entertainment galore

Thanks to The Devil Dogs the crowd were entertained throughout the day with some favourite rock classics. The Glee Club also graciously returned this year with an uplifting performance before the walk began and cheered on participants as they approached the finish line.

Ellen Smith was MC for the day and did a fantastic job at bringing up the energy and introducing the crowd to our fantastic ambassadors.

Tribute wall

The tribute wall provided a special space for quiet refection where walkers honoured and remembered those they were walking for. Each year as we look at the beautiful notes pinned to the wall, we reflect on the profound impact of Parkinson's. The wall is a powerful reminder of the community we fight to support.

Walk ambassadors

Every year members of the Fight Parkinson's community bravely share their stories to help increase awareness. In 2025 an incredible nine community members shared their stories of living with Parkinson's and the effect it has had on their lives.

Sharing such deeply personal experiences is never easy but when our community raise their voices, it makes a powerful impact beyond our existing reach.

This year's ambassadors Peter Brown, Kylie Christian, Geoff Constable, Isa and Alan Adams, Sean Anderson, Georgy and Annie Hicks, Tom Jambrich, Jeannette Branch, and Sean Atkinson courageously stepped up as advocates for the Parkinson's community.

Ambassadors are essential to help raise awareness to the broader community, they provide real and raw insight into the challenges of living with and caring for someone with Parkinson's. This year they spoke to their local communities, shared their stories through social media, and were even called upon to speak to media far and wide.

Top fundraisers

A Walk in the Park is not only a time for the community to come together, it is a vital fundraiser supporting Fight Parkinson's services. Without the generosity of you and those you helped engage, Fight Parkinson's could not continue to support the 219,000 people in Australia living with Parkinson's and their families.

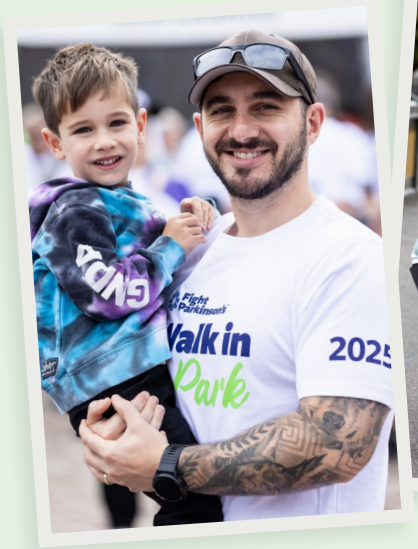
This year you raised over $377,000, well eclipsing our goal of $358,000. We extend our appreciation to everyone who contributed to this year's fundraising efforts. Fight Parkinson's would like to acknowledge the top individual and team fundraisers for 2025 for their outstanding contributions.

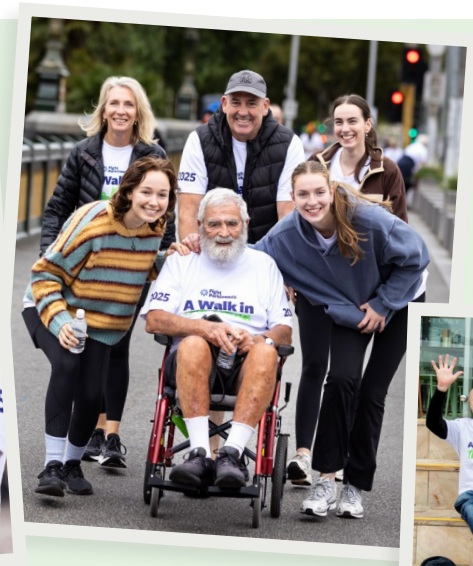
Top individuals

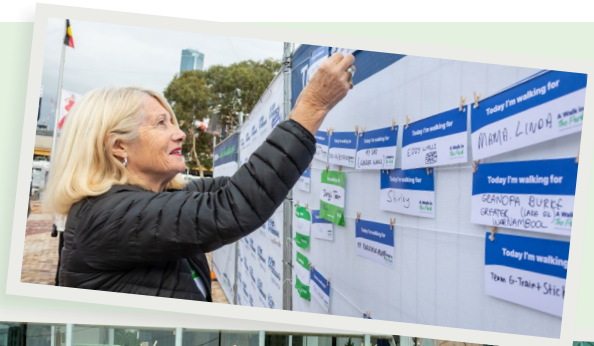
Isa Adams	$17,000
Sean Anderson	$8,509
David Smith	$7,497
Frank Halim	$6,000
Peter Brown	$5,488

Top teams

Hyxy's Team	$16,396
Young@Park Walkers	$14,765
Team Bassi	$12,883
Team Isa	$11,785
Team G-Train and Sticko	$11,191







Raising voices and raising funds

When David was diagnosed with Young Onset Parkinson's he didn't tell many people in his life. He didn't want people to start seeing him as his diagnosis instead of himself, so he kept quiet and worked hard to mask his visible symptoms.

It took David a long time to find the confidence to share his diagnosis with his community. But with time and a greater understanding of what Parkinson's looks like for him, he found his voice.

Now, he speaks freely about the reality of living with Parkinson's and how it's changed his and his family's life.

"Back then I just told family and close friends, I hadn't told work or anything like that," David said.

"It was about seven or eight years before I told people at work about it, some people said 'oh yeah, we knew' and others said they had no idea.

"I tried to hide it, I would move my mouse to my left hand and things like that, I just wasn't ready to tell everyone about it."

As he found the confidence to share his diagnosis more broadly, the support from his loved ones was essential.

They have stood by him every step of the way helping make the journey to acceptance easier. Recent life-changing deep brain stimulation (DBS) surgery has improved his symptoms, and David isn't wasting a second of time.

"They've been amazing, completely amazing," David said

"We got to a point where it's not about Dad having Parkinson's, and we just get on with it.

"Now that I am "well" again after having DBS, I'm looking forward to doing whatever I can with the family as well.

"People ask how long does this work, and we don't know exactly how long it will last for, but we'll make the most of it while we can."

Over a decade since he was diagnosed, David is now a proud spokesperson for the Parkinson's community and one of the A Walk in the Park 2025 top fundraisers.

He didn't get there alone though, his fundraising efforts were thanks to the support of his friends and family, with close to 40 of them joining him at Federation Square.

Walking together at the front of the pack, David was proud to have such a strong support network around him.

"The first couple of times we walked, we stuck at the back of the pack, but this time I got everyone up the front," he said.

"It was fantastic to have that support. There are some who happily donate or walk and there are some that do both, anyone who can help me out that's fantastic.

"Having those 40 people, a combination of family and friends was amazing. We had a drink afterwards and had a catch up."

For David, A Walk in the Park is an important opportunity to connect with the broader Parkinson's community. It's a chance to celebrate the strength and resilience of people living with Parkinson's while also acknowledging the difficulties they face.

As the event continues to grow, David hopes to continue supporting Fight Parkinson's and raising awareness in years to come.

If he helps even just one person learn more about Parkinson's and its far-reaching impact, David said his job is done.

By joining the movement to show the strength of the Parkinson's community, David hopes more positive change will be on the horizon.

"I come back each year so we can keep raising money and so we can help more people out," he said.

"It's probably a bit selfish, but it's something I can do that could help me, so I think, let's get involved and help."

A Walk in the Park

A Fight Parkinson's community event

First time walker, life-long supporter

Parkinson's first impacted Marie's life more than 30 years ago when her mother was diagnosed. After her mother passed away in 1999, Marie didn't expect the condition to impact her life again. But 25 years later, when a friend was diagnosed, Marie was reminded how important being a community member for loved ones is.

When Marie heard about A Walk in the Park just a week before the event, she signed up and joined thousands of other supporters at Federation Square.

It was a special way to spend a morning, even by herself.

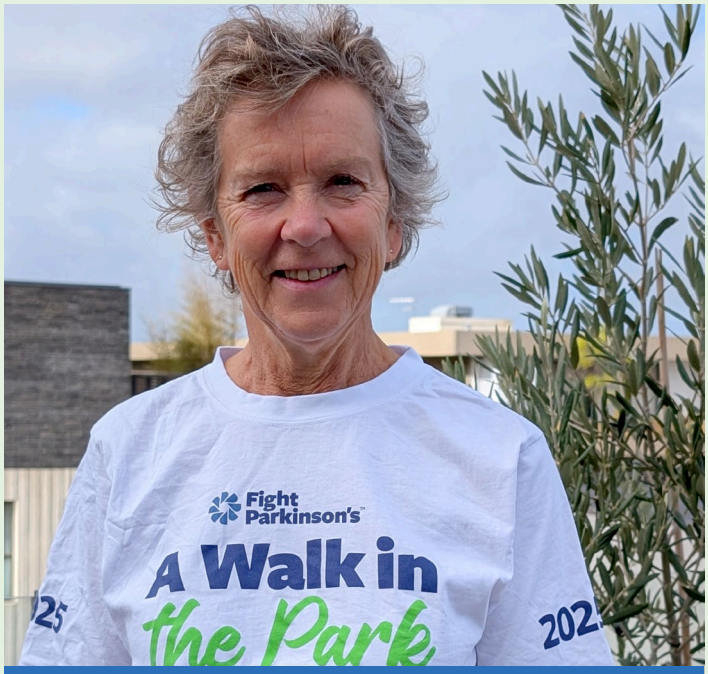
"It was quite moving," Marie said.

"When I turned up it really kind of hit me, you turn up and you see all the people at different stages, I did get a bit teary when I first walked into Federation Square, but it was a great event, I really enjoyed it."

One of the big takeaways for Marie was how positive the day was, with family and friends supporting loved ones and plenty of smiles about.

It was a great reminder of how important it is to be a supporter for your loved ones at every stage of life.

Reflecting on her mother's experience with Parkinson's, Marie said she didn't understand much about the condition at the time. With her mum keeping quiet about how Parkinson's was impacting her daily life, and Marie living hours away, she wasn't aware of the full extent of its impact.



Marie decided to walk last minute and is already looking forward to 2026.

Marie said supporting loved ones and being willing and open to meeting their needs is important. She is hopeful those diagnosed can find the support in their communities to be by them in the good and the bad days.

Marie hopes that by raising awareness of Parkinson's, others stepping into support roles can gain a better understanding of their loved one's experiences.

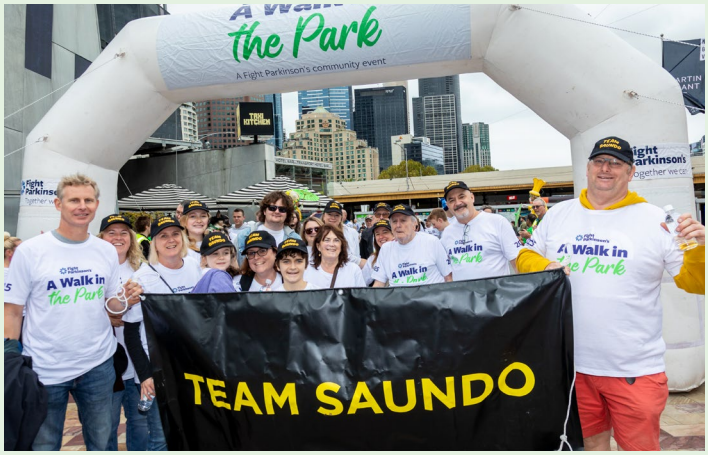
Hearing from the A Walk in the Park ambassadors on the Federation Square stage was also an important opportunity for her to learn more.

With one walk under her belt, Marie is already thinking to the 2026 walk, with plans of bringing down more friends and fundraising.

She is hopeful that others who may have walked alone or stumbled upon the event by chance will also be inspired to return next year.

"I was really glad I went, and I think next year I might encourage some friends to go, get a little team together maybe, and definitely do some fundraising," she said.

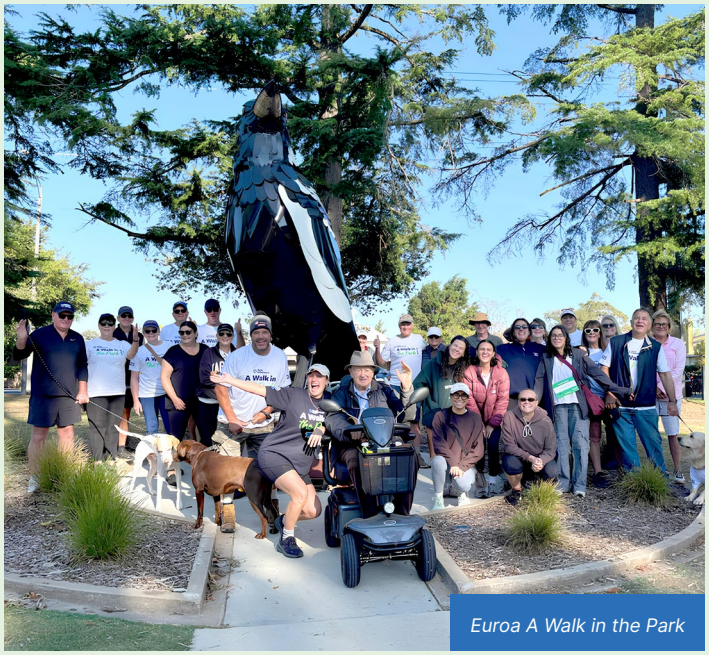
"I can only see it getting bigger, slowly people like me might get some more people involved and things grow from there."



Latrobe Valley A Walk in the Park


Horsham A Walk in the Park


Moorabbin A Walk in the Park


Euroa A Walk in the Park

From little things, big things grow

A Walk in the Park has become a mainstay for many regional Fight Parkinson's Peer Support Groups and it is always exciting when a new walk is established.

Regional walks are a testament to your dedication to raising awareness right across Victoria.

This March the Fight Parkinson's Latrobe Valley Peer Support Group celebrated their first A Walk in the Park.

The group formed three years ago and welcomes people from as far as Sale to their monthly meetings. With a consistently strong turnout of 20 people, organising their own A Walk in the Park felt like a natural next step for the group.

The first big question was "where do we walk?" but some forward-thinking from two of the walk organisers Wendy and Barry Mathieson led them to looking at local Parkrun circuits.

With the hard work of designing a route already done for them, the pair trialled several before settling on a track that was flat and wide – perfect to ensure all their members could participate. Morwell Wetlands was chosen also for its high traffic exposure and regular use by the public, to bring eyes to the impact of Parkinson's.

For their first A Walk in the Park, the group were focused on raising awareness of Parkinson's and its symptoms. On the day, one of the organising committee members Fran Dodd kindly set up an information booth for walkers and the public, and common symptoms were signposted along the route.

Local exercise therapist Kathleen Millett helped get the group warmed up before the walk with a Parkinson's-focused stretching session before the group took off. Fight Parkinson's CEO Emma Collin enjoyed the chance to meet with more members of the community.

Wendy hoped using these placards to raise awareness of common symptoms might trigger someone in the public to seek help for loved ones with changed behaviours.

"I had it in my head a granddaughter might see the signs and think 'oh yes my pop's voice is getting a lot softer' and she might look into that. The signs were reminders of those early symptoms that you might not link to Parkinson's, soft voice, hanging arms, things like that that people don't put together," she said.

Small but mighty, the group had several media interviews for both local newspapers and radio to get the word out – sharing the realities of Parkinson's with the broader Latrobe Valley community.

Wendy and Barry said they couldn't be happier with the group's first event. Though the morning was a bit chilly, the walk was well received by the community and a strong example that across communities of all sizes, Parkinson's has an impact and so does coming together.

The Latrobe Valley Peer Support Group is already looking forward to planning their next A Walk in the Park event, bigger and better, for 2026.

Coming together in various communities across the state amplified the strength in numbers of the Parkinson's community. These collective efforts contributed to significant funds raised, helping Fight Parkinson's to continue to deliver information, education, and support programs that empower people living with Parkinson's.

A big thank you to the Latrobe Valley Walk organisers, including Fran and Garry Dodd, Wendy and Barry Mathieson, Barb MacDonald, Neil Fitzclarence and Jennie Wood, together with Latrobe City Council. We would like to extend our thanks to all the Fight Parkinson's Peer Support Group members, volunteers and attendees who make regional walks possible.

More regional walks are planned for later this year. To find a walk near you, visit awalkinthepark.org.au/regionalwalks. Every walk contributes to improved outcomes for the Parkinson's community. If you would like to host A Walk in a Park in your local area Fight Parkinson's can provide support year-round. To register your interest, please email the Fundraising Team at fundraising@fightparkinsons.org.au.

Managing symptoms

Communication and Parkinson's

Communication goes beyond expressing basic wants and needs. It allows us to build connections, express our personalities, and share how we feel.

For people living with Parkinson's, changes in speech and communication can be challenging. It's important to watch for communication changes and take proactive steps to reduce their impact.

How Parkinson's affects communication

Communication is multifaceted and includes speaking, writing, and body language. People living with Parkinson's may experience changes to how they speak, the words they use, how their face and voice show emotion, and their handwriting.

While not everyone with Parkinson's will experience communication difficulties, many do. Changes you may notice include:

- Quiet or hoarse voice
- Slurred speech
- Changes to rate of speech
- Reduced intonation
- Difficulty in expressing thoughts and ideas
- Needing more time to process information
- Difficulty paying attention
- Reduced facial expressions and body language
- Small, spidery handwriting
- Increased effort and fatigue when communicating

Helpful tips for improving communication

- Stay relaxed
- Speak louder and slower
- Maintain good posture
- Take a deep breath before speaking and take top up breaths in long sentences
- Emphasise key words
- Use gestures
- Reduce background noise
- Seek advice from a speech pathologist for tailored strategies

Tips for maintaining communication skills

Speech and communication skills require ongoing practice.

- Stay socially active - join a social or singing group, Fight Parkinson's runs free Online Singing sessions fortnightly
- Maintain existing social activities and be creative to keep doing the things you enjoy, for example if evening fatigue is hard, meet for brunch instead of dinner
- Practice techniques learned in speech therapy
- Discuss new or changing challenges with your loved ones and health team

Inform yourself, inform your team

Parkinson's affects everyone differently, sharing your experiences with your health team helps them provide the best support.

Speaking openly with your speech pathologist about changes in your communication will put them in the best position to give the advice that is most helpful for you. Consider sharing feedback from your friends and family about your communication as well as any changes you have noticed yourself.

It's important to keep practicing your new strategies at home and to remember that some days will feel easier than others. On the harder days, it is key those around you know how to support you in making sure you're not left out of the conversation.

Tips for communicating with someone living with Parkinson's

Below are some tips you can share with your family, friends, and carers so that they can better communicate with you

- Be patient
- Allow extra time for responses
- Face the person you're speaking with
- Use simple language where appropriate
- Check you have the listeners attention before you begin
- Take care not to misinterpret reduced facial expressions as disinterest
- Be honest when you haven't understood something
- Remind the speaker of their strategies
- Be careful not to speak across them instead of to them
- Openly discuss communication challenges

The Fight Parkinson's multi-disciplinary health team includes a speech pathologist.

Speak with us to explore the benefits of adding a speech pathologist to your health team. The Fight Parkinson's team can also help you in finding peer support and singing groups that suit you. Call the Fight Parkinson's Free Health Line Service at 1800 644 189.

Positive living

Building your multidisciplinary health team

Throughout your Parkinson's journey, you'll likely work with a wide range of health professionals. Building a multidisciplinary team, made up of experts from different areas of healthcare who understand your needs and make you feel supported, can help you live well with Parkinson's.

A multidisciplinary model of care is widely regarded as the best approach for Parkinson's. These teams bring together health professionals from a variety of medical disciplines to provide coordinated, comprehensive care. The integration of a ParkinsonNet model of care into Australia will further support the development and management of these multidisciplinary teams.

While no two health teams will look the same, many people with Parkinson's benefit from working with certain professionals.

Neurologist

Parkinson's is a neurological condition and as such the most appropriate person to manage your care is a neurologist.

Typically, your GP will have referred you to a neurologist to confirm your diagnosis, however it is important to remember to find a neurologist that suits your needs. Within the neurology speciality, there are doctors who have specialised interests in Parkinson's who may be better placed to help manage your care.

Fight Parkinson's can provide advice and support on finding a neurologist to suit your needs.

Physiotherapist

Engaging with a physiotherapist early in your Parkinson's journey can help keep you mobile as Parkinson's affects your physical movement. They can be useful at all stages of the condition. If you already see a physiotherapist they may be able to continue to treat you, however there are also clinicians that specialise in movement disorders.

When you see a physiotherapist they can:

- Recommend exercises to improve muscle strength and flexibility
- Help you maintain your fitness
- Work with you to improve balance and prevent falls
- Help with pain relief

Speech pathologist

Despite their name, speech pathologists can help with all forms of communication, including facial expressions, body language, speech and fluency. They can also assist with swallowing problems. A speech pathologist will work with you to make communication easier. Their work can be both reactive and proactive, helping you to maintain your communication skills.

When you see a speech pathologist they can:

- Suggest exercises and techniques to strengthen your voice
- Help you with swallowing problems
- Suggest communication aids if talking has become very difficult for you

Occupational therapist

Occupational therapists are health professionals who can help people with Parkinson's stay independent for longer and carry on doing the activities that are important in their lives. They do this by giving advice on how to manage a wide range of everyday tasks, life and work skills, and hobbies. They can also recommend ways to make the home and workplace safer and easier to cope with.

When you see an occupational therapist they can:

- Suggest easier ways to do tasks that are difficult for you
- Recommend changes to make your home safer, such as handrails
- Recommend mobility equipment or aids
- Help you keep up hobbies and leisure interests
- Help you find ways to continue working

Parkinson's nurse

A Parkinson's nurse has specialist experience, knowledge and skills in the field of Parkinson's. They work closely with neurologists to ensure effective medical management of symptoms related to Parkinson's. A Parkinson's nurse can assist with a range of symptoms such as continence and organising your medication. Sometimes you may also hear a Parkinson's nurse called a movement disorder nurse. There are limited numbers of Parkinsons nurses available, they may be available within a specialised movement disorder service.

Pharmacist

Having a regular pharmacist can help remove some of the stress of filling prescriptions for your Parkinson's medications. Pharmacists can be important sources of information to help manage your medications and provide information on medication which may interact with your Parkinson's drug therapies or may worsen your Parkinson's symptoms.

Psychologist or accredited social worker

Psychologists are mental health specialists that can support you through emotional and psychological difficulties a Parkinson's diagnosis can bring. A large portion of people living with Parkinson's will experience anxiety, depression and stress.

A psychologist can:

- Help you to deal with your emotional reaction to diagnosis
- Undertake assessments, and suggest strategies to manage memory and cognitive difficulties
- Teach strategies to manage anxiety and stress
- Talk with you and develop strategies to overcome depression
- Suggest strategies to help you cope with the ongoing challenges of Parkinson's

Finding the right health team for you

Mandy was diagnosed with Parkinson's in 2020 and is an advocate for building a tailored health team.

Shortly after her diagnosis Mandy began working with a multidisciplinary health team to help manage her symptoms. Building strong relationships with those professionals she engages with has helped her continue to live positively. Over the years she has adjusted her health team and amended her appointment schedule to best suit her goals.

"Everybody's journey is different and having a team that suits you and your needs is incredibly important," Mandy said.

"What works for me might not work for somebody else so having your own personalised team it just makes life so much easier."

Mandy is also an advocate for opening communication lines between her specialists and keeping her health team informed of what complementary therapies she is accessing. By sharing this information her team has been able to offer helpful referrals and support.

She also stresses the importance of listening to your body and respecting when it needs a break.

"You don't think of speech as being exhausting but learning to talk louder and over my symptoms is exhausting and doing an hour of that is mentally exhausting," Mandy said.

"Having Parkinson's can really knock you down, so keeping your mental health and knowing when you need a mental health break from all appointments to say have a coffee with a friend rather than have an appointment is really important. I don't do it very often but when I need to, I do have a break."

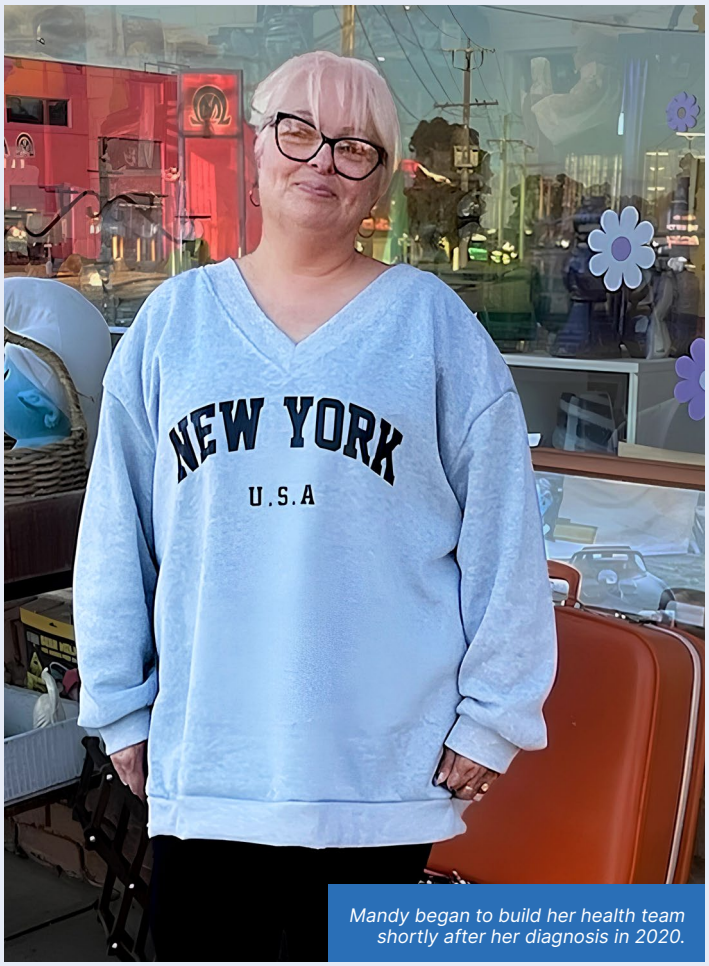
Your team, your way

There is no one-size-fits-all approach when it comes to building your health team. Take the time to find the right providers for you. The professionals listed above are just some of the many you might work with.

Positive living also extends beyond your health team. Your team could also include complementary therapy providers as well you family, friends and carers. These support networks are just as valuable in helping you live well with Parkinson's.

You can access health care professionals using your private health insurance (extras) or by speaking with your GP about a chronic disease treatment plan which will provide up to five visits in a calendar year with a Medicare registered health care professionals. A mental health treatment plan will give you up to 10 visits with a psychologist or accredited social worker, your GP can assist with this.

Contact the Fight Parkinson's health team on 1800 644 189 for more information about the health services and professionals located near you and for guidance on setting up your own multidisciplinary health team.



Mandy began to build her health team shortly after her diagnosis in 2020.

Research

Parkinson's Research Symposium

Fight Parkinson's annual Parkinson's Research Symposium brought together more than 300 community members with leading scientists and clinicians from Australia and abroad.

This annual event grows each year as more community members join us in person and virtually. The eagerness within the Parkinson's community to remain informed on the latest advancements in Parkinson's treatment and research continues to showcase its value.

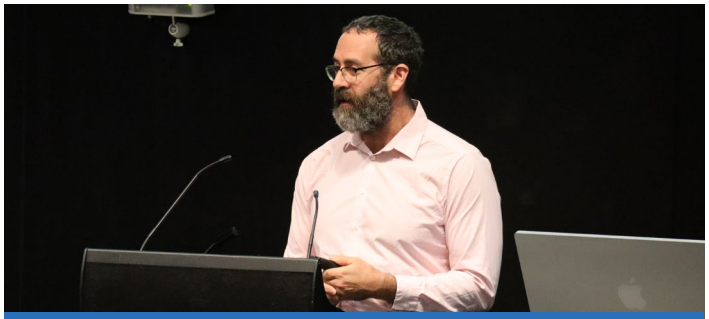
Industry experts from near and far

We were honoured to welcome Dr Benzi Kluger from the University of Rochester Medical Center, New York whose keynote presentation *Until a cure is found, Advancing the care agenda* delivered a thought-provoking approach to Parkinson's care.

Dr Kluger discussed the benefits of person-centred care and taking a holistic approach to the management of Parkinson's. He emphasised the importance of prioritising individuals wants over clinical possibilities.

After building his career in progressive neurological conditions, Dr Kluger discussed a life-long approach to managing Parkinson's from the time of diagnosis. This involves impeccable symptom management, multidisciplinary care, and includes psychological and spiritual care. His presentation started conversations among attendees during and beyond the session.

Professor Michele Callisaya has become well-known within the Parkinson's community. Her presentation echoed Dr Kluger's calls for person-centric care and investigated the implementation of a ParkinsonNet model of care in Australia. Her presentation coincided with the significant announcement that in collaboration with Fight Parkinson's, she and her team at the University of Tasmania have secured funding to bring a ParkinsonNet pilot to Tasmania and Western Victoria. You can read more about the ParkinsonNet pilot on page 3.



Dr Benzie Kluger opened the day with a raw conversation on person-centric care in his presentation Until a cure is found, Advancing the care agenda.

Addressing changing science and social barriers

Dr Arthur Thevathasan wrapped up the morning's session, providing a welcomed update to new treatments for Parkinson's. He spoke to developments in deep brain stimulation and guidance on selecting the right treatment plan for each individual.

Participants then heard from Professor David Finkelstein and Dr Melissa Tang about how biomarkers are developing the clinical understanding of Parkinson's. The duo highlighted how biomarker identification could accelerate future Parkinson's research and the future of individualised care.

Fight Parkinson's own Victor McConvey joined Sheenagh Bottrell and Dr Kishore Kumar to discuss the scientific and societal differences experienced by those with Young Onset Parkinson's. Dr Kumar provided insights into why it is useful for scientists to identify an age cut off when looking to expand research, while Mr McConvey and Ms Bottrell discussed the complexities of early diagnosis.

Inaugural Seed Research Grant Program recipients

Thanks to community support Fight Parkinson's announced the recipients of two $30,000 research grants.

Professor Finkelstein announced the grant recipients before inviting them to present briefly on their projects.

Professor John Forsythe and his team, Professor Mibel Aguilar, Professor David Finkelstein, and Dr Ketav Kulkarni were awarded the basic science grant for their project *Unlocking the brain's regenerative potential: A novel therapy for Parkinson's disease*. Professor Meg Morris and her team Dr Melissa Tang, Professor Michele Callisaya, Associate Professor Joanne Kemp, Claire Thwaites, and Lauren Mitchell were the awarded the clinical research grant for their project *Improving Wellbeing in Women with Lived Experience of Parkinson's Disease Using Community-Based Gym Exercises*.

Both projects were met positively by community members in attendance. A detailed review of the successful grant applications, made possible thanks to the generosity of the Fight Parkinson's community, can be found on page 4.

Live from the Netherlands

There was no better way to wrap up the day of learning than hearing from Ingrid Sturkenboom, occupational therapist and ParkinsonNet's trainer.

Ingrid joined remotely from the Netherlands to speak directly about the ParkinsonNet model. Her presentation was especially valuable following the announcement of Australia's own ParkinsonNet pilot earlier in the day.

Ingrid helped the community understand the model and how it could benefit individual health outcomes in Australia.

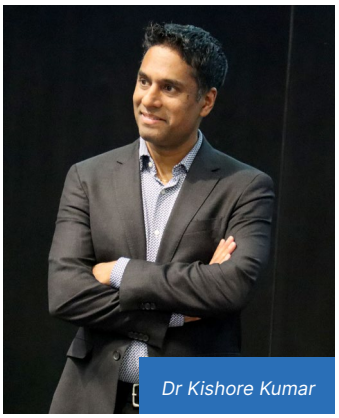
Fight Parkinson's is thankful to everyone who attended or tuned into the 2025 Research Symposium. This annual event is an important opportunity for our community to come together with researchers and clinicians to build collective knowledge.

The Symposium is a tangible example of Fight Parkinson's commitment to advancing research and improving lives. We hope the speakers offered valuable insights and new hope for upcoming scientific developments.

Atypical Parkinson's Seminar

The Atypical Parkison's Seminar is a bi-annual part of Fight Parkinson's education calendar supporting those with Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Syndrome (CBS). The seminar was run for both community members and health professionals in early June, we look forward to sharing more about the event's success with you in the Spring 2025 edition of InMotion.

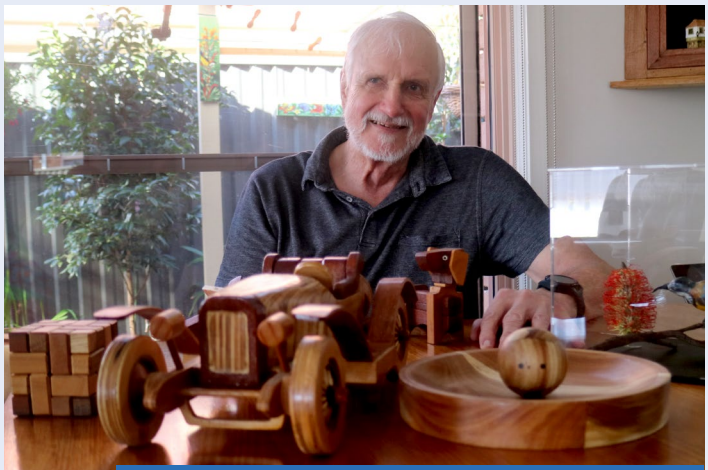
Sheenagh Bottrell



Dr Kishore Kumar

If you missed any of this year's Parkinson's Research Symposium presentations keep an eye out on Fight Parkinson's social media to see how recordings of each session are available.

Personal Story



Leigh shows off some of the things he's made since diagnosis.

Retiring on your own terms

Leigh didn't want to spend his retirement sitting in an armchair, so he hasn't let his Parkinson's diagnosis disrupt his plans.

Christmas is meant to be a time of joy and festivity, even more so when it's the first after you've hit retirement age but for Leigh, Christmas Eve 2013 wasn't the day he had hoped for.

After several months of worsening symptoms and concerns that a previous diagnosis of essential tremors was incorrect, 24 December 2013 was the day Leigh was told he had Parkinson's.

His diagnosis wasn't unexpected, he had begun to do his own research and felt his symptoms aligned with those of Parkinson's, but that didn't make hearing it any easier.

"It takes a little while to come to terms, and that wasn't a good time of year to be doing that," Leigh said.

"So maybe it took me a little bit longer than most people would but I eventually got to the stage where I was able to confront it.

"I thought, it's a diagnosis, it's not a sentence."

Now, 13 years later, Leigh is proud to reflect on his journey so far.

He's continued to do the things that bring him joy and has learnt to have patience and trust in his body.

Leigh's diagnosis wasn't quite how he'd planned to begin his retirement but after a career as a printer, it was time to leave the factory. With plenty of free time, Leigh wanted to continue working with his hands as an artisan.

Alongside his wife Linda there was one thing they knew they weren't doing in retirement - sitting in a corner with a cardigan around their shoulders.

Once an artisan, always an artisan

There aren't many things Leigh can't do. He has always been a talented woodworker, metalworker, and painter. Combining his skills across various works of art has allowed Leigh to continue creating even when his Parkinson's symptoms are more pronounced.

Leigh said it took a lot of conscious and consistent effort to get to the point where he could freely work on whatever he feels like. It wasn't always an easy journey though and reflecting on the past can be difficult.

"I couldn't use a screwdriver," Leigh said.

"It seems stupid to think that somebody would get upset about something simple like using a screwdriver, but I kept at it and eventually I got to the stage where I could use a screwdriver again.

"As well as not being able to use a screwdriver, I could barely hang a towel over a towel rail, now I barely think anything of it. It's taken quite a while to come to that stage, months, but if you keep doing it, you get there."

Working with his body and not against it, Leigh has also taken up new skills since his diagnosis.

In times when his symptoms are more pronounced, working with wood could be difficult, so he began working with leather.

More stable and with consistent movements, working the new material helped him open the door to return to some of his former works.

"You've got markers so you can mark the leather and run the punch down the little groove so the stitches stay straight, so that was a good choice and one of the first things I realised I could do," Leigh said.

"Then I started to do more woodwork after that, and I found that was a lot easier because I had already done woodwork before and I had a memory bank to draw on.

"I think once your mind realises you can still draw on that memory bank, things become easier. They did for me anyway."

Keeping true to himself and his lifestyle

Once diagnosed, Leigh took a while to process what having Parkinson's would mean for him. It undoubtedly changed his expectations for his retirement, but once he was able to accept that he had the condition, he said life has continued well.

Leigh has always preferred quiet company, so he wasn't keen on forcing himself to attend group sessions or events that he knew weren't his style. Instead, he continued to engage socially in things he enjoyed, such as at the local men's shed and in the workshop in the retirement village, he and his wife live in.

It was through these connections he met a painter, who asked Leigh to be the model for a local art show in which the portrait of him won first prize.

"I don't think big groups suit me, they might suit some people," Leigh said.

"You figure out a way to get what you want to do done, that's what it comes down to."

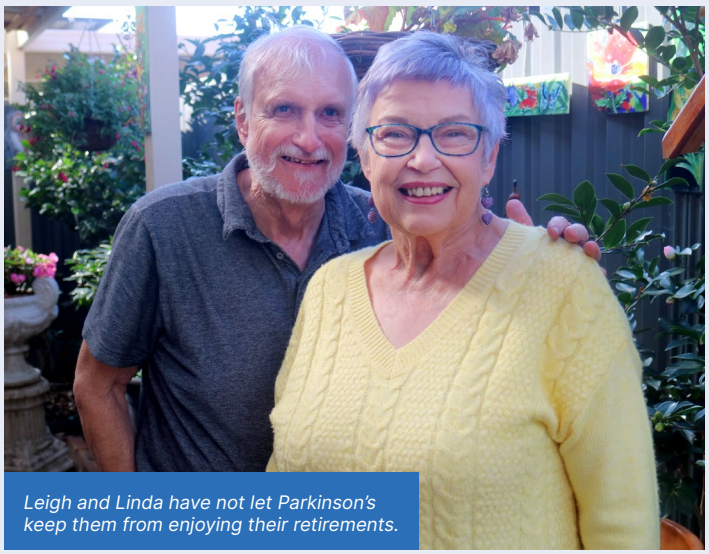
Persistence throughout diagnosis

Leigh's Parkinson's was initially misdiagnosed as essential tremors, but when medication was having little impact on his symptoms, with the support of his GP he was referred to his neurologist.

He said it's very important to have the confidence to find and build a health team and health program that suits individual needs. Parkinson's was not in his life plans, but Leigh hasn't let it take those plans away.

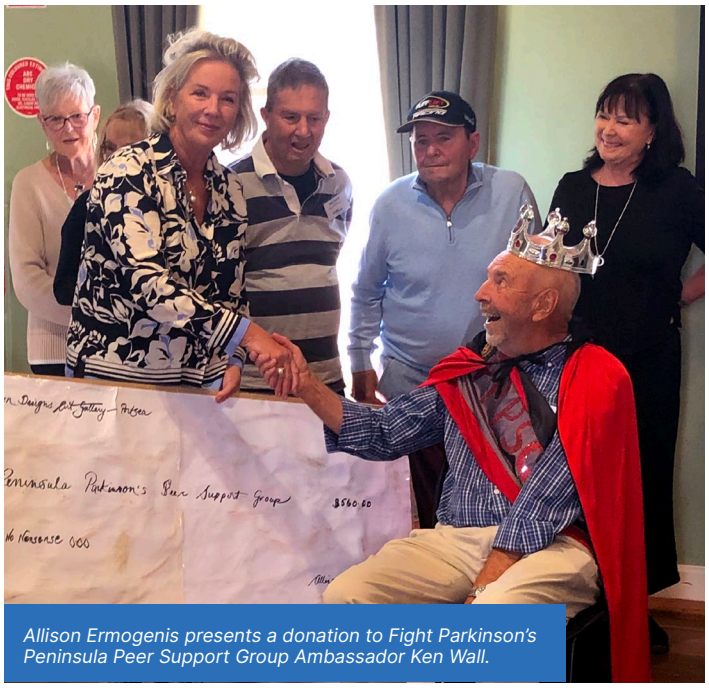
"You don't sit in that corner. Definitely don't sit in the corner," he said.

"The worst thing you can possibly do is go and sit in a chair, sit in a corner and do nothing. You have to try."



Leigh and Linda have not let Parkinson's keep them from enjoying their retirements.

Support for You



Allison Ermogenis presents a donation to Fight Parkinson's Peninsula Peer Support Group Ambassador Ken Wall.

Fight Parkinson's Peninsula Peer Support Group crowns new ambassador

Contributed by Pat Lawson-Black

Just two years since the Fight Parkinson's Peninsula Peer Support Group was founded, it has seen exponential growth. This April the group celebrated World Parkinson's Awareness Month.

The group started with seven participants meeting in a Mornington coffee shop - and now has almost 200. They recently got together at the Mt Martha Community House for a very special occasion. To mark World Parkinson's Month the group unanimously voted for a new group ambassador, Mt Martha resident Ken Wall.

"Ken is the driving force behind the many successes of our group," said treasurer Phillip Hancorne.

"A man whose international business career was curtailed by Parkinson's, Ken has thrown his energy and expertise into providing Peninsula dwellers living with Parkinson's this amazing resource and support system."

Group participants enjoy celebrating occasions, and they take a light-hearted approach to formality. The appointment of 'Ambassador Ken' was performance art extraordinaire.

He was draped in a monogrammed silk sash, covered with a scarlet cape festooned with golden angel wings, and crowned with a mock silver crown studded with plastic rubies and sapphires - all while the audience happily recorded the events.

The new ambassador's first job was to accept a donation, a princely sum, from talented artist Allison Ermogenis, who runs the Aegean Designs Art Gallery in Portsea.

"This is our biggest donation to date" Phillip Hancorne said.

"In fact, it is our only donation to date."

The audience applauded as a giant cheque was presented. "There's always a BBC – a bloody big cheque," said one attendee.

In recent months the group has also created a website, appointed a meeter and greeter and photographer, opened an online conversation site, started a podcast platform in conjunction with local radio RPP FM, helped organise a weekly Dancing with Parkinson's group, and held an in-house 'Planning for the Future' open forum.

Ken Wall is crowned Fight Parkinson's Peninsula Peer Support Group Ambassador by treasurer Phillip Hancorne.

Fundraising

A masquerade with a mission

Any excuse to dress up is a good one, but when attendees know their ticket cost is going towards a great cause, a night out is even sweeter.

Niki Matziaris has spent much of her career, and more recently home life, caring for people living with Parkinson's.

With a 35-year long career in the community sector she worked with many clients with Parkinson's before her late sister was diagnosed with the condition six years ago.

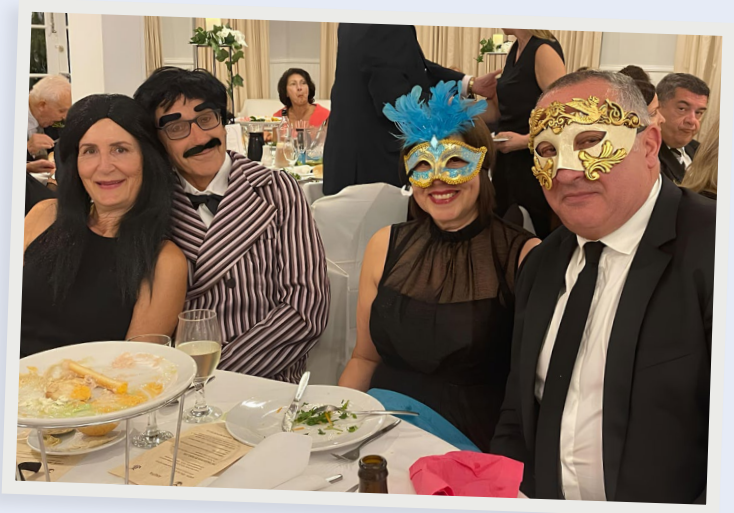
Her growing understanding of Parkinson's combined with her knowledge that government funding cannot always meet community needs, led Niki to want to do something to support the Fight Parkinson's community.

"Due to my work and personal experiences, I became very sensitive towards the people suffering from neurological diseases and knew that the government funding does not meet the need of people with these conditions. When the opportunity of the annual fundraising event came up, I proposed at the Australasian Hellenic Educational Progressive Association (AHEPA) Nafsika Unit meeting that we fundraise for Fight Parkinson's," Niki said.

And just like that she had a masquerade ball to plan.

Combining the fundraising opportunity with an evening event was the perfect opportunity to spread awareness and have plenty of fun while doing so.

Niki said it simply was not possible to capture the joy from the night in photos.



Dr Dionysios Velakoulis, a neuropsychiatrist at the Royal Melbourne Hospital, gave a presentation to the masked attendees, broadening their understanding of Parkinson's, its far-reaching impact and highlighting exciting new research being undertaken.

"Dr Velakoulis provided a compelling insight into the current research on Parkinson's and its profound impact on both patients and their loved ones. As of today, there is still no known cure, making our collective efforts to fund continued research all the more crucial," Niki said.

Not only was the event well attended by the AHEPA Victoria community, but there was a fantastic adherence to the dress code.

Niki said the enthusiasm from the community to dress to impress, learn more about the condition and support Fight Parkinson's was astounding.

"I was in awe of the wonderful adherence to the masquerade dress code—everyone looked absolutely stunning," Niki said.

Niki hadn't expected just how strongly the community would rally behind the event and as it began to take shape, she noticed the community's support growing stronger each day.

Sponsorships, raffle tickets, and an auction helped boost the events fundraising potential beyond what Niki had anticipated.

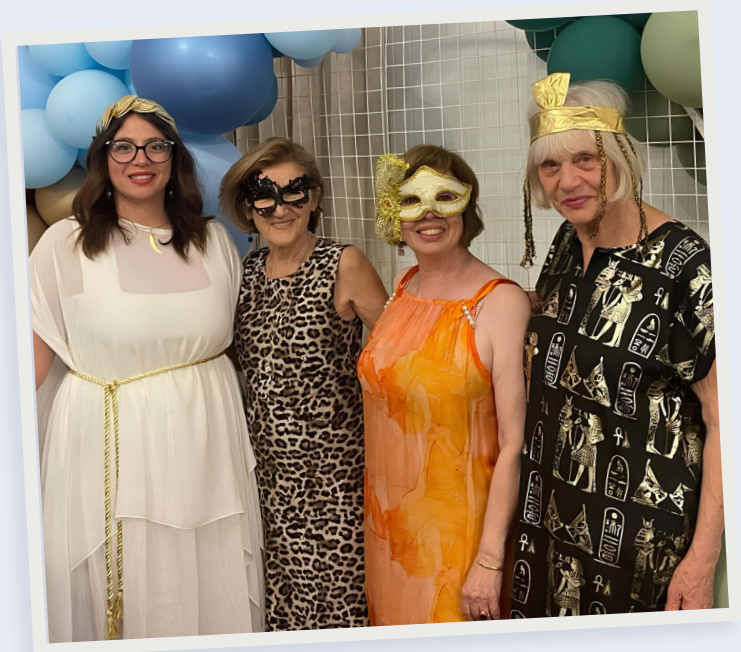
"I felt very moved with the support and the willingness to assist as much as they could in supporting this cause. Even the owners of reception they felt so moved and donated the GST and a bottle of wine for the raffles," she said.

Together the AHEPA Unit Nafsika raised $7,000 for Fight Parkinson's to help ensure that no one is left to face their Parkinson's journey alone.

Gathering at the beautiful Normanby House in Thornbury, the festivities lasted late into the night.

"We ended the night in high spirits, dancing and celebrating well past midnight, knowing that we had not only created beautiful memories but also contributed to an important cause."

Fight Parkinson's relies on the community's generosity to fund our information, education and support services. That's why we are so grateful when people in the community support us by holding their own fundraising events. If you're hosting an event, let us know by contacting fundraising@fightparkinsons.org.au or calling us on (03) 8809 0400.



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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.

Travel Grants open

World Parkinson Congress 2026

Travel grants are now open to attend the 2026 World Parkinson Congress.

Grants are open to people living with Parkinson's who are:

- **engaged in their Parkinson's community and willing to educate and engage on return home**
- **able to contribute to overall expenses**

Grants are available up to $1,300USD

Next year's Congress is being held in Phoenix, Arizona, USA from 24 May to 27 May, 2026.

Applications open 1 August and must be submitted by 12 October.

Learn more at www.wpc2026.org

Community Callout

Be a positive voice

Fight Parkinson's online Positive Life Sessions offer practical tips and valuable insights from our health team and community members. Previous sessions have covered topics such as telehealth, medication management, emotional well-being, sleep, sex and staying active.

If you would like to be a voice in our Positive Life Sessions and inspire others to live positively and confidently with Parkinson's, contact us today.