

Impact



Growth

# Corporate Report

2025



Sustainability

## Our **STRATEGIC PRIORITIES**



financial sustainability

We will strike a balance between delivery of required services and supports and financial sustainability for Parkinson's NSW over the longer term.

Through advocacy and the use of formal submissions, bids, and grant applications, we will diversify streams of funding for Parkinson's NSW operations.

We will use best practice processes for planning, budgeting, tracking, and measuring the impact of investments in services and supports for the Parkinson's community.



service delivery

We are the peak body in New South Wales for the delivery of services and supports for people living with Parkinson's, care partners and their families.

We aim to increase capacity and maintain best practice standards of service delivery through taking consistent and innovative approaches.

We continue to enhance relationships with Support Groups and empower them to have a greater impact on the Parkinson's community.



advocacy &  
collaboration

We seek to partner with organisations to build and capitalise on the leadership position of Parkinson's NSW.

We collaborate to extend professional and decision-maker networks at local, state, national and international levels.

We work to mobilise communities while jointly seeking funding opportunities and developing increased services.

We build capacity through primary and allied health education, Support Groups, and development of state and national advocacy profiles.

# Our Vision

**A Parkinson's community empowered every step of the way.**

# Our Purpose

**We support, enable and advocate for and with people living with Parkinson's and their communities.**

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## Message from the CHAIR

The Board of Parkinson's NSW was faced with two key challenges in fiscal year **2024-2025** – navigating a slow economy while simultaneously setting strategies to boost revenue in order to fuel the organisation's growth, sustainability, and enhanced impact on our community.

The Australian economy delivered subdued results over the past year with a forecast growth in GDP of **1.3** percent – the weakest since the early 1990s aside from the COVID-19 period.

This was due to high global inflation, interest rates and slowing demand. Meanwhile inflation remained high while household spending decreased, and savings remained low.

Against this background, the Board opted for strategies which strengthened the financial position of Parkinson's NSW as a precaution against further economic headwinds, while at the same time investing in the resources necessary to deliver enhanced services.

In the absence of any significant ongoing government funding, we committed additional resources to fundraising operations – including donor acquisition, direct marketing with a shift away from hardcopy direct mail, and greater focus on raising our profile with trusts and foundations.

We also worked hard to expand our advocacy to the government and private sectors by both sharpening the focus of our executive team on these areas and supplementing internal resources with specialised outside providers with a track record of success in our sector. This approach delivered positive results which have been described in this corporate report.

In fiscal 2025 Parkinson's NSW Limited and controlled entities recorded total income of

**\$6,437,498** – an increase of **123%** over the **\$2,875,581** recorded in the prior financial year.

Expenses were down by **5%** from year to year, contributing to an operating profit of **\$2,632,248** for the year under review.

The controlled entities mentioned above are the Parkinson's NSW Trust and the Kevan Williams Trust.

With the generous cooperation of trustees Peter and Carol Wortley, Parkinson's NSW was granted stewardship of the Kevan Williams Trust in February of 2025. The Trust's investment assets were transferred directly into the Parkinson's NSW charity in a way that ensures long-term value, sustainability, and growth.

We also benefitted greatly from a visionary contribution made by David Lesnie who established the Lesnie Parkinson's Nurse Program – an initiative committed to sustaining and expanding the Parkinson's Specialist Nurse program across the state.

David's contribution is not only helping to safeguard existing nurse placements but is also seeding a transformative partnership between Parkinson's NSW and Neuroscience Research Australia (NeuRA).

I would like to extend the thanks of the board to the Parkinson's NSW management team and all employees. They have stepped up with enthusiasm to embrace the challenges presented over the past year, and they have enabled us to deliver a very positive set of operating results for **2024-2025**.

Thanks also to our Support Group volunteer leadership teams, and all group participants who show up regularly to encourage and support one another through their Parkinson's journey, whether as a person living with Parkinson's or a care partner.

In closing, my thanks also go to the volunteer Board Members of Parkinson's NSW for their dedication to steering the organisation through another challenging year. Your skills, dedication and life experiences contribute greatly to the vitality of Parkinson's NSW and the community it serves.

**Andy Esteban**

Acting Chair, Parkinson's NSW



## Message from the CEO

Sustainability is a key goal of the current Five-Year Plan for Parkinson's NSW. The Plan was jointly developed by the Board and management team of the organisation. Sustainability enables us to thrive, not just survive, and progressively deliver greater impact from services for our NSW Parkinson's community.

As you will learn in the Advocacy section of this report, we were unsuccessful in our formal budget submission proposing that the NSW Government co-invest with Parkinson's NSW and commit **\$1.13** million per year over a **3-year** funding cycle to grow essential services delivered by our organisation.

While such a grant would future-proof the organisation – and we will go to bat again in the coming fiscal year – we are still on the path to enhanced sustainability due to a strategic reorganisation, significant contributions from major benefactors, and carefully considered investments in areas likely to deliver higher yields from our fundraising efforts.

Also, as highlighted in the Chair's message, during the year under review we benefited from the transfer of the investment assets of the Kevan Williams Trust – which has maintained one of the longest-running philanthropic relationships in our organisation's history.

There was also one other visionary financial commitment to Parkinson's NSW this past year – the creation of the Lesnie Parkinson's Nurse Program by David Lesnie and his family. This initiative is committed to sustaining and expanding the Parkinson's Specialist Nurse program across the state.

Full details of both extraordinary contributions to the sustainability of Parkinson's NSW are provided in the Fundraising section of this report.

During the year under review, Parkinson's NSW Limited achieved a profit of **\$1,719,310** – a much more favourable result than the loss of **\$802,787** in the prior year.

In terms of expenses, spending on fundraising was down by **9%** thanks to a reorganisation and a reallocation of resources toward channels which produced a higher yield. Expenses were cut by pivoting away from a strong dependence on hardcopy direct mail and the accompanying postage, printing and packaging expenses.

In its place we made strategic and staffing changes which reoriented us towards more direct marketing strategies, supplemented by a campaign to raise our profile in the grants and foundations space.

At the same time we were able to increase spending on marketing and support groups by **5%** and our Parkinson's Specialist Nurse program by **11%**.

The Parkinson's NSW InfoLine went from strength to strength, including a reorganisation so the team now includes Counselling which was previously a separate department. The InfoLine team spent more than **1,947** hours supporting people who called. This represents a **49.9** percent increase in demand from year to year.

Demand also grew for the Parkinson's Specialist Nurse team. At the end of the fiscal year our nurses had a total of **2,896** patients on their books – an increase of **22** percent over the previous year.

We thank our supporters, partners and generous donors for their contributions to the mission of Parkinson's NSW. My heartfelt thanks also go to our dedicated and hardworking staff and volunteers.

**Mary Kay Walker**  
CEO, Parkinson's NSW

# Advocacy

## A voice for the NSW Parkinson's community

Over the past fiscal year Parkinson's NSW has undertaken ongoing advocacy campaigns addressing the Parkinson's community, political parties, government departments, agencies, and sector organisations.

### National Parkinson's Alliance

Our involvement in the work of the National Parkinson's Alliance (NPA) – which was launched in Canberra during the National Parkinson's Summit in March 2024 – continued over the past year through participation in the development of the National Parkinson's Action Plan (NPAP) which is being funded by a Federal Government grant of **\$800,000**.

The NPA has engaged consultancy KPMG to support development of the plan.

The NPAP is a collaborative effort to address the diverse needs of people living with Parkinson's across the country. The NPAP will be a comprehensive document that aims to bring meaningful changes in critical areas, such as:

- Reducing stigma associated with Parkinson's
- Improving the education and capability of the health, disability, and aged care workforces
- Focusing on earlier detection and diagnosis
- Improving access to and coordination of treatments and supports
- Improving prevention for Parkinson's
- Collecting better data on Parkinson's prevalence
- Researching new or improved treatments and therapies
- Securing greater funding for Parkinson's research and translating current findings into practice

To help pave the way for the development of this NPAP, Parkinson's NSW promoted a survey and consultations by KPMG with people living with Parkinson's, their families, carers, support workers, clinicians, health care professionals, and researchers.

There were **36** in-person workshops and **18** virtual workshops conducted, along with **70** one-on-one phone interviews - all to gather information on the lived experience of Parkinson's.

The goal was to gather **3,000** responses for input into the planning process. It ultimately gathered responses from **5,029** people.

The National Parkinson's Action Plan will be documented and submitted to the Federal Government before the end of calendar 2025.

### State Government advocacy

Over fiscal 2024-2025, Mary Kay Walker, the CEO of Parkinson's NSW, led a two months-long, intensive advocacy campaign aiming to reach as many NSW Government decision-makers as possible.

Her campaign followed on the heels of a formal budget submission proposing that the NSW Government co-invest with Parkinson's NSW and commit **\$1.13** million per year over a **3**-year funding cycle to grow essential services delivered by our organisation.

The advocacy campaign involved **42** meetings with key officials in electoral offices and Parliament House, plus the gathering of letters of support from Members of Parliament to the Minister for Health, urging favorable consideration of the Parkinson's NSW proposal.

#### During this campaign, Mary Kay met with key government and shadow ministers and parliamentary advocates including:

- The Hon Rose Jackson MLC, Minister for Housing and Minister for Mental Health
- The Hon Jodie Harrison MP, Minister for Women and Minister for Seniors
- Dr Michael Holland MP, Member for Bega
- The Hon Damien Tudehope MLC, Shadow Treasurer
- Ms Kellie Sloane MP, Shadow Minister for Health
- Mr Geoff Provest MP, Shadow Minister for Seniors

#### Letters of support to the Minister for Health were also obtained from several Members including:

- Mr Philip Donato MP, Member for Orange
- Mr Justin Clancy MP, Member for Albury
- Ms Helen Dalton MP, Member for Murray
- Ms Maryanne Stuart MP, Member for Heathcote
- Ms Tanya Davies MP, Member for Badgerys Creek
- Ms Donna Davis MP, Member for Parramatta

Parkinson's NSW is a not-for-profit entity, not a government organisation. Funding for essential services to the Parkinson's community comes from hard-earned community fundraising, including support from individual donors, corporate partners, fundraising events, and people leaving gifts in their will (bequests).

While equivalent peak bodies for other degenerative neurological disease have been well supported to execute their missions, Parkinson's NSW has received modest funding from the NSW Government in recent years and currently has no significant ongoing funding in place.

It became unsustainable for our organisation to keep pace with growing demand without co-investment by the NSW Government – which is what was proposed in our formal 2026 Budget submission.

Despite these efforts, the organisation was unsuccessful in obtaining Government funding for the 2026 fiscal year. However, the organisation is now on a secure footing for the year ahead thanks to the generosity of donors such as the Kevan Williams Trust and the Lesnie Foundation.

Details of this support can be found on page pages 18 and 19 of this report.

## Research Support

During the year under review Parkinson's NSW support for research has included participant recruitment and formal endorsements of studies being undertaken by the University of NSW, University of Sydney, Neuroscience Research Australia, University of Queensland, Macquarie University, Monash University, and the University of South Australia.

This is in addition to the research being undertaken to develop the National Parkinson's Action Plan on page 6 of this report.

## National Parkinson's Alliance members:

- Parkinson's NSW
- Fight Parkinson's (Parkinson's VIC)
- Shake It Up Australia Foundation
- Parkinson's Tasmania
- Walter and Eliza Hall Institute of Medical Research (WEHI)
- Neuroscience Research Australia (NeuRA)
- Queensland University of Technology
- University of Tasmania
- Wings 4 Parkinson's
- Parkinson's WA, Parkinson's Qld and the Hospital Research Foundation Group incorporating Parkinson's SA, NT & ACT have been invited to join the NPA from 1 July 2025 ensuring the Alliance has truly national representation.



# Client Services Team

The Parkinson's NSW Client Services Team provides specialist support through the InfoLine (**1800 727 567**), NDIS Advocacy and – as of a reorganisation at the end of the fiscal year – Counselling.

The Parkinson's NSW Client Services Team brings together a wealth of expertise in nursing, pharmacy, advocacy, and social welfare. With decades of combined experience, the team provides specialist clinical guidance, practical in-home care solutions, skilled NDIS advocacy, and empathetic support informed by both professional and lived experience. The team ensures that people living with Parkinson's, their families, and carers can access sustainable, person-centred services that make a lasting impact.

Between July 2024 and June 2025, the team on the InfoLine supported people through **5,233** points of contact – the equivalent of **1,947** hours of direct assistance. This represents a **49.9** percent increase in demand from year to year.

Monthly points of contact varied from **298** in December 2024 up to a peak of **547** in March 2025.

Callers included people living with Parkinson's, carers, health professionals and the general public. The majority of enquiries were from people living with Parkinson's themselves.

The increase in call volume year-on-year highlights not only the increasing need for support services but also the expanding reach and effectiveness of the team's engagement strategies.

Sustained growth in demand requires strategic resource allocation and capacity building to maintain high-quality support and ensure the longevity of the team's impact.

## Types of Enquiries

The nature of enquiries to the InfoLine spans medical, emotional, and practical needs, showing the complexity of Parkinson's and the importance of holistic care.

- **Symptom Management and Treatments:** Callers frequently seek guidance on managing motor and non-motor symptoms, such as tremor, rigidity, hallucinations, and chronic pain. Enquiries often include understanding new therapies, preparing for neurologist appointments, and considering advanced options like Deep Brain Stimulation (DBS).

- **Carer Support:** Many carers contact the InfoLine for advice on coping with stress and balancing their wellbeing. The team connects them to the Parkinson's NSW counselling service, support groups and external programs such as Carer Gateway – helping carers build resilience and sustainable support networks.
- **Navigating Systems and Services:** People regularly need help understanding and accessing NDIS and My Aged Care services. The team supports callers with eligibility, application processes, and referrals to external advocates and aged care providers, ensuring timely and effective access to these critical systems.
- **Daily Living and Symptom-Specific Support:** Enquiries often focus on managing practical challenges like constipation, drooling, sleep issues, and dry eyes. The team provides tailored advice and connects callers with allied health professionals, including dietitians, physiotherapists, and speech therapists, to support daily living and independence.
- **Mental Health and Emotional Wellbeing:** Living with Parkinson's can bring feelings of anxiety, depression, or low mood. The team offers immediate emotional support and referrals to counselling and other mental health professionals, fostering long-term emotional wellbeing for both individuals and carers.



## Connections to External Services

The InfoLine's impact extends well beyond information-sharing. Each call represents an opportunity to guide people toward sustainable, community-based support that enhances their quality of life.

- **External Health and Care**

**Services:** The team connects callers to Movement Disorder Neurologists, GPs, allied health professionals, and specialist pain and mental health services.

- **Government and Community**

**Programs:** The team helps people access My Aged Care, NDIS, Carer Gateway, respite services, and community-based disability and aged care supports.

- **Safety and Daily Living Solutions:**

The team provides information on trusted providers of assistive technology, personal alarms, adaptive clothing, and mobility aids, ensuring people can live safely and independently.

- **Education and Peer Networks:**

We link individuals to online and local support groups, educational webinars, and resources that promote long-term self-management and sustainable wellbeing.



## InfoLine Impact

- Points of contact have continued to rise, showing strong growth in both demand for and impact of the service. The substantial growth in enquiries reflects the growing trust and reliance on InfoLine services by people living with Parkinson's and their carers, affirming the team's role as a critical resource.
- Enquiries from carers also show significant increases, indicating growing awareness and support for caregiving needs.
- Although smaller in volume, enquiries from allied health professionals and others show some growth and a stable demand.
- Each enquiry received reflects the growing need for accessible, person-centred support and highlights the real-world impact of the InfoLine team as it guides people to sustainable solutions for living well with Parkinson's.
- A client feedback survey was started at the beginning of calendar 2025. To date responses have shown 100% satisfaction with the information and assistance provided by the InfoLine, and all respondents indicated that they would use the service again if required.

*"Your conversations were a leading light through potential dark times with my Parkinson's."*





# Advocacy

The Parkinson's NSW NDIS Advocacy service provides clients with tailored support and guidance to navigate the NDIS access process.

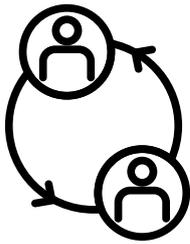
This includes helping to demystify requirements, gather the appropriate documentation, and prepare for meetings. The Parkinson's NSW advocate also supports clients in and resolving queries about accessing and planning NDIS support.

Eligibility for NDIS support requires a client to be under 65 years old and an Australian citizen or permanent resident. A diagnosis of Parkinson's means someone is eligible to apply. The NDIS will assess an application for access to see if a participant meets the eligibility criteria for disability, and/or early intervention. There are Parkinson's NSW clients approved in both categories.

This year the focus has moved away from the eligibility being dependent on diagnosis, to impairment. An impairment notice is now sent to each participant and only support relating to the impairments identified will be accessible.

Changes to legislation in October 2024, along with adjustments to NDIA processes and a slow to adapt system, resulted in clients facing delays of up to seven months for access applications.

This caused much distress and confusion for many clients and led to delays in necessary support. Encouragingly, processing times have since improved and applications are now typically resolved within one to three months.



## NDIS Advocacy by the numbers

**1,241** Points of contact recorded by phone, email and face-to-face

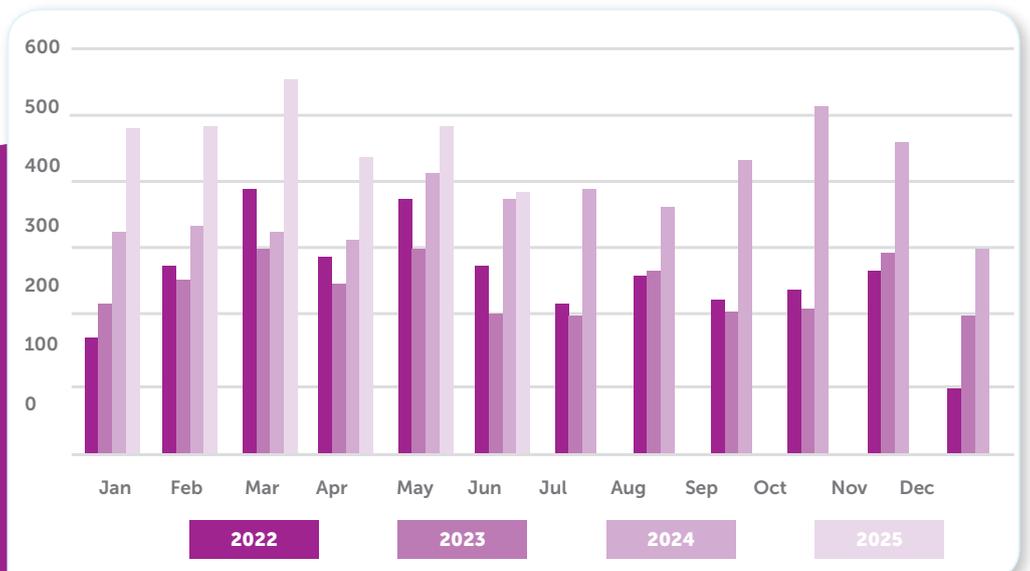
**934** Total advocacy clients supported

**114** New advocacy clients supported

**36** New approvals

InfoLine points of contact by month

2022 - 2025

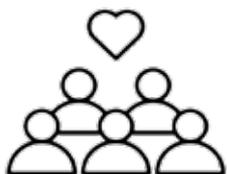


# Specialist Counselling Support

The Counselling team continued to operate with **1.5** Full Time Equivalent staff during the past fiscal year, but capacity was temporarily reduced for part of the year due to one counsellor taking maternity leave.

During the year under review, the Counselling team supported **229** clients and conducted **931** individual client sessions. Despite the temporary drop in available resources, the number of individual client counselling sessions handled in 2024-2025 was just **5** percent lower than the previous year. At **230**, the number of group counselling sessions was unchanged from year to year.

Face-to-face counselling sessions were delivered at Parkinson's NSW headquarters in North Ryde, War Memorial Hospital and Wolper Jewish Hospital. To maximise accessibility and convenience, counselling sessions were also made available via telephone and teleconferencing.



**229** Clients

**931** Individual client sessions

**230** Group sessions

# Issues addressed in counselling

**Anxiety and Depression** – Supporting both people living with Parkinson's and their carers

**Negativity Bias** – Helping rewire thought patterns through positive affirmations and strategies to foster neuroplasticity.

**Carer Identity Loss** – Assisting carers who experience a profound sense of loss and disorientation after the death of the person they cared for.

**Vicarious Anxiety and Depression** – Supporting carers affected by the emotional and mental health challenges of the person they care for, including when it leads them to develop similar symptoms or emotional distress.

**Suicidal ideation** – Providing guidance and support for carers managing a loved one's suicidal thoughts, including planning safe interventions.

**Delusional Behaviour, Paranoia, and Hallucinations** – Offering emotional support and practical safety planning for carers managing challenging or aggressive behaviours in a loved one with Parkinson's.



*When I was diagnosed with Parkinson's, my neurologist was inaccessible for months at a time and my GP and regular therapist confessed they were no experts when it came to Parkinson's. The monthly support group led by Parkinson's NSW Counsellor Shushann became my lifeline, providing vital knowledge and guidance in those early dark and lonely days.*

*"As my Parkinson's progressed, issues arose that could not be dealt with in the group. The counselling sessions proved a godsend. No matter what I throw at her, Shushann has always been able to reassure me and shift my anxieties."*

*"Because of the disease's complexity, there was so much to learn and negotiate on different levels – physical, emotional, mental. Shushann's holistic approach addressed all these levels with strategies that were practical and achievable and never overwhelming. Her sessions are always reassuring and inclusive. Shushann is brilliant at encouraging respectful communication."*

# Nurses' Casebook

## Nurse Lauren

A 61-year-old man recently diagnosed with Parkinson's was referred to me for education and support. He had been seen by a neurologist but initially decided that he did not want to commence levodopa therapy.

I attended a home visit and spent time explaining the nature of Parkinson's. Also on that visit I performed a full nursing assessment.

We discussed the risks versus benefits of levodopa therapy, and I recommended that he start the therapy because there was no benefit to be gained from delay. He has since commenced levodopa therapy.

I have also recommended Parkinson's-specific exercise classes nearby and he is commencing these soon. Speech therapy is also now in progress.

He has been referred to Parkinson's NSW for counselling services to assist him in coming to terms with his diagnosis. Now that he feels supported, he can contact me about any symptoms going forward.

He sent me an email shortly after we first met. It said: 'Many thanks Lauren, I found today enormously beneficial!' Sometimes it's just the simplest things that can make so much difference for people.' He really felt so alone previously but now knows that I am only a phone call away.

*"The local Parkinsons Specialist Nurse Lauren is fabulous and should be cloned. She does an outstanding job."*

## Nurse Jemma

I had a patient and his carer who were both overwhelmed with the burden of Parkinson's disease. They stated they were burnt out and desperate for help and support.

The patient presented with symptoms of freezing of gait, confusion, and increased tremor. Carer burden was significant. They didn't have any family present; it is just the two of them. They had limited care services in place and stated they felt alone, isolated, and desperate as well as feeling like no one was there for them.

I set up a home visit where I went to see them and suggested some strategies such as recommending support groups. We were able to get an increase in their care package which allowed a carer to

come and assist with activities of daily living and outings. This allowed the patient's wife to attend to her care needs which reduced her feelings of burnout. We also discussed structured exercise groups to give the patient something to look forward to and have social interaction rather than feeling isolated at home.

I then established a schedule where I would make phone calls every three weeks to provide support and give them the opportunity to ask any questions they may have.

As a result both the patient and carer became more settled and reported they were able to get back to enjoying life without feeling Parkinson's disease was in complete control of their lives.

The carer said, "I now feel like someone has my back."

*"Parkinsons nurse was excellent – very professional & informative. NDIS Advocacy was also very helpful."*

## Nurse Rebecca

A 73-year-old lady with 12-year history of Parkinson's was referred to the Parkinson's Nursing Service by her private neurologist, requesting a review and advice around management.

The patient is very active in the community, running social groups, spending time with grandchildren and enjoying arts and crafts (crocheting and knitting). However, she experiences significant motor fluctuations, limiting her participation in the activities that she enjoys so much and is affecting her quality of life.

A nursing assessment was conducted, establishing the need to optimise her medication by improving movement and reducing side effects. It was suggested she would be a suitable candidate for device assisted therapy. A referral to see a Movement Disorder Neurologist in the Ballina Movement Disorder Clinic was recommended.

The patient was seen in clinic and is now on the waitlist to commence device assisted therapy.

The patient is in the work-up phase and pre-assessments are being completed by the nurse. These include a Levodopa Challenge\*. Ongoing support and follow up continues.

*\*An assessment of a levodopa dose cycle, assessing patients' movements in an ON state and in an OFF state, and the transitional stage as medications wear ON. Assessment takes approximately four hours and is recorded via video and written documentation.*

# Parkinson's Specialist Nurses

There was no change in the number of Parkinson's Specialist Nurses during the 2024-2025 fiscal year. Four nurses remain based in Coffs Harbour, Port Macquarie, the Tweed region, and Goulburn.

These roles were jointly funded by Parkinson's NSW and the respective Local Health Districts – Mid North Coast, Northern NSW, and Southern NSW.

At the end of the fiscal year, our nurses had a total of **2,896** patients on their books, an increase of **22** percent over the previous year.

There was also a growth of **16** percent year-to-year in telehealth consultations – a reflection of new telehealth programs established in Coffs Harbour and the Tweed region in the prior fiscal year.

A significant increase was recorded in the number of Device Assisted Therapies supported which grew by **53** percent over the prior fiscal year. The major contributor to this growth was increased support for Deep Brain Stimulation (DBS) patients.

## What do Parkinson's Specialist Nurses do?

- New Patient Assessment – Can take **1-2** hours with patient (not including report writing)
- Follow Up Review – **30** minutes to **1** hour
- Levodopa Challenge/Apomorphine Assessment – **4 to 5** hours (not including report writing)
- Patient Education – **1** hour
- Phone calls – anywhere from **15** minutes to **1** hour each
- Carer Support/Education – **1** hour per session
- Bowel Assessment Reviews – **1**-hour sessions, multiple times in a month
- Phone calls about patients from doctors, pharmacists, partners, family members, friends, and Support Group Leaders



# Fundraising

Due to a lack of ongoing government funding, Parkinson's NSW is completely dependent on various forms of fundraising to enable its essential services for the NSW Parkinson's community. Without your participation in our appeals, community events and advocacy none of what is presented in this report would have occurred.

*We thank you and the community we serve thanks you.*

The Parkinson's NSW fundraising team includes a Donor Development Manager, a Direct Marketing Officer, a Community and Fundraising Events Officer, and a Grants Manager. The total resources of this team amount to **2.8** Full Time Equivalent employees.

During the 2024-2025 fiscal year, **5,373** unique donors made charitable contributions to support the work of Parkinson's NSW. They included individuals, companies and foundations.

Of these contributions **913** regular givers accounted for **8,642** transactions totaling **\$265,004**

The total raised from charitable giving in the year under review was **\$5,353,166**.

**Multiple bequests amounted to \$1,971,858.**

## We acknowledge the generosity of:

- Estate of the Late Julianna Vizi
- Estate of the Late Marilyn Edith Daniel
- Estate of the Late Aileen Dawn Adams
- Estate of the Late Richard Laurence Taylor
- Estate of the Late Peter Lloyd Binnie
- Estate of the Late John McMahon
- Estate of the Late Heather Lynette Mitchell

## We also acknowledge the contributions of the following generous donors:

- Keven Williams Trust
- Lesnie Foundation
- Norman Family
- Key Foundation
- Judy Grant
- Reg Richardson
- Bernard Royle
- Warren Lesnie
- Nicholas Korner
- Siu-Hee Cheng
- Adam Liberman
- Ian Morrison
- Trevor & Kimberly Allison
- John Bell
- Isobel Boccalatte
- Ann Crowley
- Andrew Foti
- Edwin Ho
- Marianne Lesnie
- Shane Magennis
- Brendan Mcallery
- Ian Morrison
- Jennifer Thurstun
- Pat Turner
- Bruce Wilson
- Louise Christie
- AbbVie Pty Ltd
- Penrith Anglican College
- PD Warrior
- Eureka Insulation
- Accent Benchtops
- Port of Newcastle Operations Pty Limited
- Order of the Eastern Star - Holroyd Chapter No. 20



## Community Fundraising

Community fundraising initiatives raised more than **\$110,985** during the 2024-2025 fiscal year.

The organisation's two signature annual events continued to be the Great Parkinson's Tea Party and Step Up for Parkinson's. The Tea Party raised **\$8,980** over a two-month campaign while Step Up raised **\$79,189**. A new ambassador program was a highlight of the Step Up campaign during which videos and social media posts from Australian cricketer **Ellyse Perry**, world champion cyclist **Amanda Spratt** and news presenter **Mark Ferguson** were widely shared.

**Significant ongoing fundraisers over the past year included:**

**Dean Laws and the Dean Team** held the fourth annual Parkinson's Marathon Walk raising **\$12,047**.

**Michael Costello** – who is living with Parkinson's – hosted his third high tea in his retirement community, sold his artwork, and held a raffle to raise **\$4,715**.

**David Welsh** – who is also living with Parkinson's – has been fundraising through a stall at his local Bunnings, raising more than **\$2,467**. He also teamed up with Len Pascoe to hold a Johnny Cash and Roy Orbison tribute concert and together they raised **\$1,400**.

**Pump for Parkinson's:** The Coffs Harbour Parkinson's community is well supported by two local businesses – the Bailey Centre Liberty Service Station and PK Express Transport. Every year they donate a set amount per litre of fuel

sold in a specified 24-hour period. This year raised **\$5,000** to support the Parkinson's Coff's Harbour Nurses Fund.

**Coffs Harbour Parkinson's Support Group** held raffles and community events to raise awareness and funds for Parkinson's NSW programs.

**Goulburn Parkinson's Support Group** held its popular annual Shakin' Cocktail Party raising funds to support of the local Parkinson's Specialist Nurse. This year it raised **\$6,522** towards supporting the local Parkinson's Specialist Nurse.

**Bossley Parkside Care Community** annual raffle raised more than **\$1,500**.

**Among other community fundraising initiatives, golf days proved popular:**

- Eureka Insulation raised **\$10,265**
- Club Jamberoo (Doug Smith and Paul Rodgers) **\$1,100**
- Northbridge Golf Club Ladies **\$1,928**

The Order of the Eastern Star - Holroyd Chapter No. 20, celebrated their centenary, presenting CEO Mary Kay Walker with a gift of **\$5,000**.

Penrith Anglican College raised **\$5,500** for Parkinson's NSW, a Jashn 4 tribute concert raised **\$2,200**, and Wollongbar Christian Church High Tea resulted in **\$3,000**.

Donations were also received from participants in third party events including the Mudgee Classic **\$1,600**, Cole Classic **\$246**, Sydney Half Marathon **\$1,228**, City2Surf **\$18,598**, and Sydney Marathon **\$881**.

*At the heart of this initiative lies the Lesnie family's belief in lasting impact. Their gift reflects more than financial support -- it reflects leadership, compassion, and a clear call to action.*



## Direct Marketing

The Direct Marketing fundraising function shifted its focus to electronic delivery of appeals and messaging during the year under review. This was in response to a change in donor preferences as well as the need to reduce mailing expenses.

Parkinson's NSW also changed to a new telemarketing vendor in the past year and they have assisted in acquiring new donors.

Direct Marketing ran four appeals over the fiscal year. These entailed postal and email direct appeals, supported by digital marketing in newsletters and social media.

To be financially prudent we utilised reporting and segmentation of our donor database to reduce the number of donors who receive postal appeals and sent a large proportion to donors via email instead. We also took this opportunity to provide information on our services and donor impact information to maximise return on investment.

- The **Spring appeal** featured Parkinson's NSW InfoLine specialist staff and their experiences of supporting this service. This had the additional benefit of creating engagement and understanding of services.
- The **Christmas appeal** featured Dani who was diagnosed with early onset Parkinson's. Here we also provided an impact statement showing how donors make a difference.
- The **Autumn appeal** featured Wendy – a Parkinson's NSW Support Group leader – and shared her experience as someone who has been diagnosed with Parkinson's for a number of years. It also included a survey which was well received.
- The **Tax time appeal** featured Jeni who was only recently diagnosed and her experiences as she sought Parkinson's NSW services – particularly the Newly Diagnosed seminar and our InfoLine. This was supported with profiles on two of our staff members responsible for those services and we also provided a leaflet that people could keep which lists the various ways they may be able to seek assistance.

Our **regular giving programs** were also successful. They were sourced from existing donors who expressed an interest during our appeals, surveys, or communications, and through telemarketing.

**913** individuals who pledged regular giving made **8,642** unique donations totalling more than **\$265,004**.

A survey of **250** supporters of Parkinson's NSW fundraising efforts found that of those who have experienced the organisation's services, more than **72%** said the experience exceeded or greatly exceeded their expectations.

The survey also found that doctors, health professionals, family and friends are the main ways people find out about Parkinson's NSW. Further, **102** of the respondents said they have Parkinson's and **115** know or knew someone living with the disease.

When asked to rank their preferences for desired methods of communication, respondents ranked email first, closely followed by post. The least preferred option for donor communication was via phone.

Parkinson's NSW is also registered on various workplace and reward giving platforms such as Benevity and Good2Give. Our thanks go to participating companies such as **American Express, GiftHub, Macquarie, Salesforce, QBE, Microsoft**, and **Suncorp** for providing donation platforms for their employees and customers. Thanks also to Salesforce and Suncorp for matching donations.

## Trusts and Foundations

We gratefully acknowledge the grants received through various state and national trusts, foundations, clubs and councils which help to sustain programs and services and offer opportunities for new initiatives.

**During the past fiscal year these included:**

- The NSW Department of Communities and Justice, Carers Investment Grant Program 2025-2027 – Providing funding for Parkinson's NSW to deliver 20 free seminars across rural NSW to identify and support the carers of people with Parkinson's disease. This initiative will empower these 'hidden' carers, ultimately enhancing their long-term physical and mental health.
- Disability Advocacy Futures Program, Special Purposes & Projects and Sector Development Grants 2025 – Enabling the establishment of two Parkinson's Support Groups in key Culturally and Linguistically Diverse communities within the South Western Local Health District. This initiative addresses service gaps for individuals living with Parkinson's disease in these communities.
- Collendina 5 Foundation – Ongoing support which enables us to deliver our services throughout NSW.

- JLDJS Foundation – Ongoing support for research initiatives by Parkinson’s NSW.
- James Frizelle Foundation – The Foundation provided vital funding to support our Parkinson’s Specialist Nurse in the Northern Rivers Region.
- Community Underwriting – Continued support for our seminars aimed at individuals newly diagnosed with Parkinson’s disease.
- HV McKay Charitable Trust – The Trust provided crucial funding for support group leaders from rural NSW to attend the Parkinson’s Symposium in Sydney.
- Goulburn City Council – Support for a Parkinson’s Education Seminar in Goulburn.
- James N. Kirby Foundation – The Foundation provided specialised Parkinson’s seating and furniture for our counselling room, enhancing client comfort and the benefits they receive.
- Maitland City Council – Funding to support art therapy classes for people with Parkinson’s in aged care.
- Bathurst RSL Club Ltd (Bathurst ClubGRANTS) – Funding to support a Parkinson’s Education Seminar in Bathurst.
- Bathurst Panthers (Bathurst ClubGRANTS) – Funding to support a Parkinson’s Education Seminar in Bathurst.
- Club Forster and Sporties Tuncurry, through ClubGrants, provided funding for the Forster Tuncurry Support Group leaders to attend the Parkinson’s Symposium in Sydney.

- Dick & Pip Smith Foundation
- BR & JR Trust
- Skipper Jacobs Charitable Trust

## Services enabled by fundraising

- **1800 InfoLine** service staffed by nurses, a former community pharmacist and a social worker. The InfoLine acts as the first point of contact, advice and service linkage for people living with Parkinson’s, caregivers and family members.
- Comprehensive Parkinson’s education for consumers made available free of charge or at heavily subsidised rates.
- Operations of a network of **74** in-person, online and teleconferencing based support groups – **78** percent of which are in high-need regional and rural areas of the state.
- Community-based Parkinson’s Specialist Nurses.
- Specialist counselling services for people living with Parkinson’s, families and caregivers.
- NDIS advocacy



Charity Golf Classic



## The Lesnie Legacy: A Family's Gift to Transform Parkinson's Care

When it comes to supporting the Parkinson's community in New South Wales, few contributions are as visionary and heartfelt as the one made by David Lesnie with the support of his family.

David's longstanding dedication to community service and philanthropy has taken on a bold new chapter with the establishment of the Lesnie Parkinson's Nurse Program, an initiative committed to sustaining and expanding the Parkinson's Specialist Nurse program across the state.

*This isn't just a generous act - it's a catalyst for change.*

Parkinson's Specialist Nurses are among the most effective frontline supports for people living with Parkinson's, especially in regional and rural areas where access to neurological care is limited. They provide critical clinical care, emotional support, and coordination of services – yet the sustainability of this program is under threat, with government funding uncertain beyond the current budget cycle and always at the whim of health sector funding.

*David Lesnie saw the challenge and chose to lead.*

**With the backing of his family, David is not only helping to safeguard existing nurse placements but is also seeding a transformative partnership between Parkinson's NSW and Neuroscience Research Australia (NeuRA). Together, this collaboration aims to:**

- Expand nurse placements into high-need areas
- Build a long-term funding model less vulnerable to government volatility
- Strengthen clinical research into nurse-led interventions
- Provide the evidence needed to influence future health policy
- Raise national and international recognition of the impact of this work

At the heart of this initiative lies the Lesnie family's belief in lasting impact. Their gift reflects more than financial support—it reflects leadership, compassion, and a clear call to action.

You can contribute to the Lesnie Parkinson's Nurse Program and be part of a movement to ensure that every person living with Parkinson's in NSW has access to the care they deserve.

Together, we can turn one family's vision into a legacy of support and transformation.

To learn more or contribute to the **Lesnie Parkinson's Nurse Program** please contact Gary Cowlshaw, Donor Development Manager.



*"We are deeply grateful for the Lesnie family's commitment, and we invite others to follow their lead."*





We are deeply grateful for this opportunity to carry the Keven Williams legacy forward," said CEO Mary-Kay Walker. "It's a privilege to be entrusted with these assets, and we recognise the decades of care, diligence and intent that have gone into preserving and growing them."

## A Lasting Legacy The Keven Williams Trust's support of Parkinson's NSW

For more than **40** years, the **Keven Williams Trust** (KWT) has been a quiet but steadfast supporter of Parkinson's NSW. Established in the early 1980s by the estate of Keven Williams, the Trust has channeled consistent support to Parkinson's services across the state since 1985 – marking one of the longest-running philanthropic relationships in our organisation's history.

In February 2025, that legacy took an inspiring new step forward.

With the generous cooperation of Peter and Carol Wortley, Parkinson's NSW has been granted stewardship of the Keven Williams Trust. The Trust's investment assets – held and managed for decades through Tanguu Holdings – are being transferred directly into the charity in a way that ensures long-term value, sustainability, and growth.

This moment represents far more than a financial transaction. It honours the original intent of the Trust: to make a lasting, meaningful difference in the lives of people living with Parkinson's. And it entrusts Parkinson's NSW with the privilege of carrying that mission into the future.

The structure of the transfer reflects the thoughtful approach shared by both parties. Rather than triggering unnecessary costs or administrative complexity, the assets are being handed over in specie – a direct transfer of shares. This prudent decision ensures that the principal remains intact and able to grow, supporting future services and innovation across the organisation.

Parkinson's NSW is committed to ensuring that the name and spirit of **Keven Williams** is honoured in an appropriate and lasting way.

**From all of us at Parkinson's NSW:**

*Thank you to Peter,  
Carol, and most of  
all, to the memory of  
Keven Williams. Your  
generosity will endure.*

# Support Groups

During fiscal 2024-2025 there were **74** face-to-face Parkinson's NSW support groups operating in New South Wales. They engaged with more than **2,500** participants and included **15** groups for carers.

Two groups in Coastal Waters and Yamba closed during the year while three new groups opened in Woolgoolga (Woopi), North Ryde, and Murwillumbah.

In addition to face-to-face meetings there were a number of virtual groups meeting via Zoom teleconferencing over the year. These included:

- **Carers Chat** which recorded significant growth in the number of people registering, from **20** to **50**. This group is only for carers/spouses of someone living with Parkinson's. Parkinson's NSW counsellors facilitate these monthly meetings.

- **DBS and Assisted Therapies** – Quarterly meetings for those considering or who have DBS or an advanced therapy (Apomorphine, Duodopa). These sessions are facilitated by a health professional, recorded and shared only with people who register for the meetings.
- **Let's Talk Parkinson's** which consistently attracts registrations of **150** to **200** participants and meets every two months. It covers topics presented by health and allied health professionals. These meetings are recorded and added to the Living Well with Parkinson's library on the Parkinson's NSW YouTube channel.
- **Support Group Leadership Teams** – **10** meetings over the course of the year.
- **Young Onset** – Two meetings were held for people living with a diagnosis of early onset Parkinson's and their care partners.

*Feedback from attendees revealed that the two days were "worthwhile," "uplifting," "wonderful," "interesting and informative," and a lot was gained from participating.*



## 2025 Support Group Leaders Conference

On **2** and **3** April – at the start of Parkinson’s Awareness Month – Parkinson’s NSW Support Group Leaders travelled to the Sydney Masonic Centre for the first Leaders Conference since 2019, followed by a Research Symposium.

There were almost **70** leaders and committee members in attendance, most of them having travelled from regional and rural areas.

### Speakers at the Leaders Conference included:

- Diana Piper from the Centre for Volunteering, on the rewards and challenges of being a volunteer.
- Leadership and management professional Greg Zimbulis who spoke on ‘simple, easy to apply leadership actions to make things happen.’
- John Back, Communications Manager and Stacey Foster, Support Group Coordinator of Parkinson’s NSW who presented their Support Group Education Framework which focuses on the day-to-day operations of Support Groups.

- Mary Kay Walker, CEO of Parkinson’s NSW, who gave an update on the organisation’s most recent advocacy and community engagement efforts.

There were many opportunities for Support Group Leaders to discuss topics with each other at their tables and then come together as one group at the end.

They shared their own experience with leadership so far, wrote a vision statement for their Support Groups, and learned about building a leadership team, succession planning, managing leadership burnout, and Support Group administration – including communications, financial management, annual plans, event management, and risk management.

Feedback from attendees at the Support Group Leaders Conference and Research Symposium revealed that the two days were “worthwhile,” “uplifting,” “wonderful,” “interesting and informative,” and a lot was gained from participating.



"The friendship and comradery of our group members with Parkinson's says it all. They look forward to the guest speakers and to see their fellow members again, with laughs and stories from over the month since the last meeting."



Eastern suburbs Community Heroes presentation

## Parkinson's Awareness Month

Support groups participated in Parkinson's Awareness Month in April 2025 as well as the annual Community Heroes initiative.

Each year, support groups are invited to nominate an individual or organisation in their local community that has provided significant or meaningful support to their group. When Parkinson's NSW receives those nominations, it creates certificates for the Heroes and passes them onto the Support Group to present at a special time of their choosing.

**During Awareness Month, several of support groups held events in the community:**

- Temora, Tumbarumba, Forster-Tuncurry, Albury, Armidale, and Southern Highland Support Groups all ran information tables at their local shopping centres.
- Coffs Harbour Support Group leader, Graham Saxby, presented to the Chamber of Commerce on how businesses can support the Parkinson's community in Coffs Harbour.
- Port Macquarie Support Group ran a raffle as well as an information session at the local library, which was attended by Parkinson's Specialist Nurse, Jody Lloyd, Parkinson's NSW CEO, Mary Kay Walker, Member for Port Macquarie, Rob Dwyer, and Kate Meredith from the Mid North Coast Local Health District.

## National Volunteer Week activities

With the permission of Support Group Leaders, Parkinson's NSW nominated them for Volunteer Team of the Year at the NSW Volunteer of the Year Awards, run by The Centre for Volunteering.

## Support Group Fundraising

Goulburn Support Group held its annual Shakin' Cocktail Party to fund the local Parkinson's Specialist Nurse. **\$6,522** was raised by the event.

Coffs Harbour and Narrabri Support Groups conducted regular raffles and attended community events to raise money for their local Parkinson's nurse and to build awareness for Parkinson's NSW.

## Impact of support groups

*"The opportunity to hear from our specialist nurse at support group meetings is invaluable. It is also rewarding to be able to learn from others in the support group as well as offer assistance in all manner of ways."*

*"Support groups offer a place of acceptance and unity, a place to help learn about Parkinson's and resources that are locally available. It's also a place to learn about living with the condition – the good, the bad, the ugly and the funny, in a way that no doctor can."*

*"Our support group bridges the gap between the Neurologist and the home via education, support, and friendship. It is a safe space to voice concerns and seek possible solutions."*

*"The Central Coast Parkinson's Support Group is like a big family. I have watched the group grow into a place where we can all be ourselves, share our concerns and wins that we have had. Parkinson's is a disease that is very confronting, but it is the ongoing support of others who give up their time to share the knowledge and give us hope that we can keep going."*

*"I find the support group meeting a chance to talk with people with Parkinson's also time to have a cup of tea and take a break – even though small – from day-to-day realities of living with Parkinson's."*

*"I've been coming to this group for a while, and I have made a best friend. That's huge for me because for many years I felt isolated and lonely. Now my best friend and I go to exercise class together three times a week as well as to the support group each month."*

*"The best outcome for us is when support group members develop deep and sincere supportive relationships with others that extend beyond our monthly meetings."*

*"The Chinatown Support Group has become a vital bridge for Chinese Australians to connect, learn, and laugh together – no matter where they live in Sydney."*

## Reflections on Support Groups

By Stacey Foster, Support Group Coordinator

Parkinson's NSW support groups have their own structure that works for them. Generally, meetings range from group discussions to educational sessions by guest speakers, and a chance to socialise. Some groups like to add extra activities such as exercise and dance classes, art workshops, or choirs.

Support groups are run by and for people who have Parkinson's in common. Often walking through the door is the hardest part but given the space to talk freely in an environment of trust, people leave with genuine friendships.

Two of the support groups that were established this year were born out of community members identifying a gap in the support network in their respective communities.

One group was established by a woman living with Parkinson's. With assistance of the local Parkinson's Specialist Nurse, she advertised the first meeting in January. With only five people indicating they would

attend, she wasn't expecting much.

When more people kept arriving and more chairs had to be found and almost 40 people attended that first meeting, it was clear they were also feeling that gap in their support network. Each meeting since has seen the same number of people attending, seeking out connection, socialisation, and education.

The second support group was established by a professional supporting people to live independently in their homes. With an increase in clients who were living with Parkinson's and the closest support group in Tweed Heads, she contacted Parkinson's NSW and asked, "What's the process for starting a new support group?"

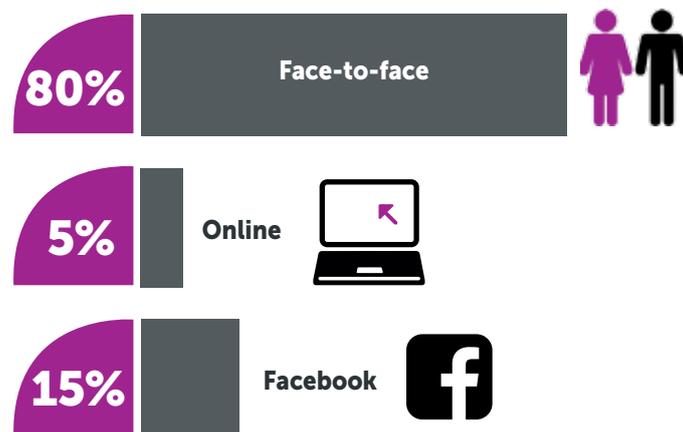
In the lead-up to the first meeting, she had seven people interested in attending. On the day, almost 40 showed up. The support group is coming up to its first anniversary and each month they have 30 – 35 people attending. They are well supported by the leader as well as the Parkinson's specialist nurse, an exercise physiologist, and a mobility equipment supplier with a personal connection to Parkinson's.

Recently, this support group created a vision statement with part of it stating: "To build a warm, welcoming community where no one faces Parkinson's alone – a place of support, shared learning, socialising, and genuine connection."

## Face-to-face Support Groups by Location



## Modes of Support Groups



# Marketing, Digital & Community Engagement

The Parkinson's NSW Marketing, Digital & Community Engagement team continued to expand the organisation's reach and impact throughout the 2024-2025 fiscal year. The team's function includes newsletters (print and digital), social media, website content, fundraising communications, and community engagement campaigns – all designed to keep the community informed, connected, and inspired.

## This year delivered more growth in our digital presence:

- **2.8** million digital touchpoints – a **38%** increase on last year
- **10%** growth in eNews readership
- **199,000** minutes of video content viewed – a **31%** increase year-on-year

Popular video content included practical wellbeing advice, lived experience stories and campaign highlights.

The Parkinson's NSW website continued to attract a global audience with visitors from Ireland, Malaysia, the United States, United Kingdom, Canada, and Germany.



**2.8** million digital touchpoints  
**199,000** minutes of video viewed  
**10%** growth in eNews readership

## Step Up for Parkinson's

The fourth annual Step Up for Parkinson's campaign in May 2025 continued to grow as the signature community fundraising event for Parkinson's NSW.

- **162** participants and **21** teams joined in across NSW and beyond
- Activities included walking, cycling, Pilates, yoga, running, and personal challenges
- The campaign has now raised more than **\$348,400** since its inception.

**A highlight was the Virtual Wall of Inspiration, where participants shared who or what motivated them. From stepping up for a parent, spouse, or friend to honouring their own Parkinson's journey, every story was personal and powerful:**



*"I'm stepping up for my beautiful husband Troy. Young onset Parkinson's was a plot twist that we were unprepared for. We have however found our silver lining and decided to just live the best way we can for as long as we can. Life still gets to be good." - Kate*

*"I am stepping up for myself with fantastic support from my hubby." - Wendy*

*"I'm a caregiver, not by choice but by love. I have a best friend named Steve." - Stephen*

*"I'm stepping up for Parkinson's for my pop." - Hayley*

*"I'm stepping up for my dad Col. Dad was diagnosed with Parkinson's 20 years ago and has fought hard through all the ups and downs."*

*"I am inspired to step up for Parkinson's for the marvellous group of 'Gentle Folk' I have been privileged to meet since my diagnosis almost 19 years ago." - Di*

Step Up has become an event for families, carers, and supporters to have conversations, honour loved ones and raise awareness and funds in their own circles.



## The Great Parkinson's Tea Party

Returning in **October 2024** after its successful launch in the previous year, the Great Parkinson's Tea Party brought people together across NSW.

From High Teas and Garden Parties to birthday themed gatherings, hosts added their own flair while raising funds and awareness.

Events were held in metro, regional and rural communities including Newcastle, Albury, Grafton, Southern Highlands, and Wollongong.

Over its two years, the Tea Party has raised more than **\$28,500** – proving that a cup of tea can go a long way in supporting people with Parkinson's.

## Parkinson's Awareness Month – April 2025

April was a time of connection and action, with World **Parkinson's Day (April 11)** at its heart and a wide range of community led activities across NSW and beyond.

Support Groups hosted stalls, forums, art exhibitions, raffles, and open days, while a refreshed online hub offered downloadable factsheets, infographics, and social media resources. More than **345** people accessed our free Introduction to Parkinson's online learning module, with **10%** completing it during April.

Our Parkinson's awareness campaign reached **1.2** million people across social channels – a **10.6%** increase on last year – and sparked conversations sharing their own stories and connecting with others.

Beyond the numbers, the campaign challenged misconceptions, highlighted resilience, and reminded people that they are not alone.



## The Parkinson's Marathon Walk

The Parkinson's Marathon Walk, organised by the Dean Team, returned for its third year on **28 July 2024** at Artarmon Reserve. Forty-four fundraisers took part, raising an impressive **\$12,047** to support our work.

The Marathon Walk has become a much-loved part of the community calendar. People from across NSW come together to exercise, share stories, and enjoy the camaraderie of walking side by side.

The event not only raises vital funds, but also creates a visible show of strength, resilience, and hope – reminding participants and the wider community that no one walks the Parkinson's journey alone.



## Community events

Beyond our signature campaigns, dedicated supporters took part in running, swimming, cycling and endurance events across NSW – including the Mudgee Classic, Sun Run, Cole Classic, Beach2Beach, Stadium Stomp, True Grit, City2Surf and the Sydney Half Marathon. Together, these community-led efforts raised more than **\$16,300** for Parkinson's NSW.



## Volunteer Week

Each year in May, National Volunteer Week recognises the important roles that volunteers play in communities across Australia.

At Parkinson's NSW, we particularly recognise and say thank you to all our Support Group leaders, teams and committees who volunteer their time to run our **74** Support Groups across NSW.

Being a leader or part of the leadership team of a Support Group is a commitment, and it often comes with sacrifice. We understand that beyond your leadership role you are juggling many different aspects of your life – whether you are a person living with Parkinson's, a carer, a family member, or a health professional.

In addition, our volunteers often 'fall into' the leadership role or are expected by participants of the group to step up and volunteer.



a: Dani McCarthy Stepping Up for Parkinson's b: Kerry Thompson hosted a Tea Party c: Robert Dwyer Member for Port Macquarie with Mary Kay Walker, CEO of Parkinson's NSW d: Parkinson's Community Hero presentation in Kiama e:& f: Parkinson's Marathon Walk participants g: Jamberoo Golf Day h: Volunteer week.



Launch of Education Module 3

# Education and Quality Assurance

## Online Parkinson’s Education Modules

In the past fiscal year, **267** health professionals completed Parkinson’s NSW Education Modules **1** and **2**. Module **1** is Introduction to Parkinson’s and Module **2** is Best Practices for Parkinson’s.

There was a consistent increase in participation, reflecting a growing awareness of the importance of understanding Parkinson’s symptoms and effective medication management. The continued uptake demonstrates the value health professionals place on evidence-based learning to enhance their care of people living with Parkinson’s.

Also, during the past year Parkinson’s NSW launched online Education Module **3** which is Optimising Exercise Programs for People with Parkinson’s. Module **3** was officially launched on **29 May 2025**.

It was developed in collaboration with leading subject matter experts and is tailored specifically for exercise professionals. It provides comprehensive, evidence-based guidance on supporting people with mild to moderate Parkinson’s symptoms through safe and effective physical activity.

**By completing this module, exercise professionals will be equipped to:**

- Understand the role of exercise in managing Parkinson’s symptoms
- Design and deliver safe, balanced, and personalised exercise programs
- Align programs with each person’s goals, functional impairments, and motivational factors

This initiative reflects the continued commitment of Parkinson’s NSW to promoting quality care and enhancing the quality of life for people living with Parkinson’s.

## Acknowledgement of Education Advisory Committee & Cognition Evolve

We extend our sincere thanks to the dedicated sub-group of the Education Advisory Committee for generously sharing their time and expertise in developing Module 3.

- Associate Professor Natalie Allen
- Professor Emeritus Colleen Canning
- Andrew Han, Physiotherapist
- Nathanael Lum, Exercise Physiologist

We also gratefully acknowledge the valuable contributions of our Education Manager and the team at Cognition Evolve whose collaboration was instrumental in the successful design and development of this module.

## 2025 Parkinson’s Research Symposium

The second annual Parkinson’s Research Symposium was held on **3 May 2025** at the Masonic Centre in Sydney. It attracted more than **200** attendees – an increase of **100** participants from the previous year. The event was supported by AbbVie and Medtronic.

It brought together scientists, clinicians, and health professionals from across Australia to explore the latest developments in Parkinson’s research, and how emerging evidence is shaping current care and treatment approaches.

**We were privileged to welcome a line-up of respected presenters, including:**

- Professor Carolyn Sue
- Dr Melissa McConaghy
- Colleen Kerr – Speech Pathologist
- Dr James Peters
- Associate Professor Richard Gordon

- Professor Glenda Halliday
- Dr Paulo Silva Pelicioni
- Rachael Mackinnon – Clinical Nurse Consultant

A highlight of the day was the panel discussion – The person with Parkinson's at the centre of research: How much have we advanced and how much we still need to do?

**Chaired by Professor Glenda Halliday, the panellists included:**

- Dr James Peters
- Dr Paulo Silva Pelicioni
- Rachael Mackinnon – Clinical Nurse Consultant
- Emma Tinkler, who shared her lived experience of Parkinson's
- Dr Martin Ostrowski, who also shared his experience of living with Parkinson's

Excellent feedback following Symposium has informed the decision by Parkinson's NSW to hold this event annually.

## Medical and Scientist Breakfast

The Medical and Scientist Breakfast – also held on **3 May 2025** – was an exclusive session for health professionals, medical practitioners, and researchers dedicated to advancing Parkinson's care.

**Presenters were:**

- Associate Professor Richard Gordon – University of Queensland
- Dr Ben Yonker – Neurosurgeon

Both speakers shared their expertise on evolving treatments and surgical therapies for Parkinson's disease.

Attendance at this session increased significantly from 2024, reflecting growing interest and engagement in Parkinson's research. We aim to continue expanding the reach and impact of this event in the coming years.

## Carer Investment Program

Parkinson's NSW has received a Carer Investment Grant from the NSW Government to support the delivery of specialised education and professional development initiatives aligned with the NSW Carers Strategy 2020-2030.

This grant-funded program focuses on strengthening the confidence and capacity of General Practitioners (GPs) to identify the often-overlooked 'hidden' carers of people living with Parkinson's in rural and regional NSW. The aim is to encourage carers to seek timely and appropriate support, enhancing their access

to information and improving their ability to navigate essential services.

Ultimately, the program seeks to empower hidden carers and contribute to improved long-term physical and mental health outcomes.

**In addition to engaging GPs, the program also includes outreach to other health professionals and community leaders, equipping them to help identify hidden carers and connect them with services such as:**

- General practitioners
- Mental health and counselling services
- Peer support groups
- Meal delivery and practical assistance

To ensure quality and relevance, an Advisory Working Group has been established to provide consultative guidance and support to the Parkinson's NSW Education Department in the development, delivery, and evaluation of this initiative.

**Advisory Working Group Members:**

- Chair: Christine McGee – Education Manager, Parkinson's NSW
- Lauren Hogan – Clinical Nurse Consultant, Goulburn, Parkinson's NSW
- Dr Vysalan Srianandarajah – General Practitioner, Yamba Doctors
- Michelle Woolven – Project Assistant, Carer Grant Program, Parkinson's NSW
- Frank Price – Educational Consultant, Parkinson's NSW
- Ashley Young – Clinical Neuropsychologist and General Psychologist (Private Practice)
- Jan McKinnon – Carer of a person with Parkinson's, Goulburn Support Group



# Quality Assurance

The focus of the Education and Quality Assurance Manager of Parkinson’s NSW is to oversee the delivery of evidence-based, quality-assured education and training programs. This role also supports the development and implementation of internal quality standards aimed at improving procedures and processes, ensuring best practice across all educational initiatives.

Quality Assurance (QA) is integrated within the Education function to ensure all programs align with Parkinson’s NSW quality standards and reflect current, evidence-based practices. These standards are designed to uphold best practice and maintain the integrity and credibility of the services delivered by this organisation.

To ensure continued compliance and relevance, policies and procedures are regularly reviewed and updated to align with evolving standards and legislative requirements. Notably, significant work has been undertaken this year to update the Parkinson’s NSW Privacy Policy, ensuring it meets the latest recommendations outlined in the Privacy Act.

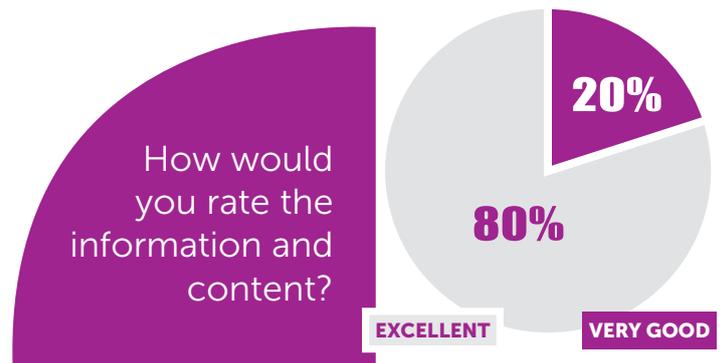
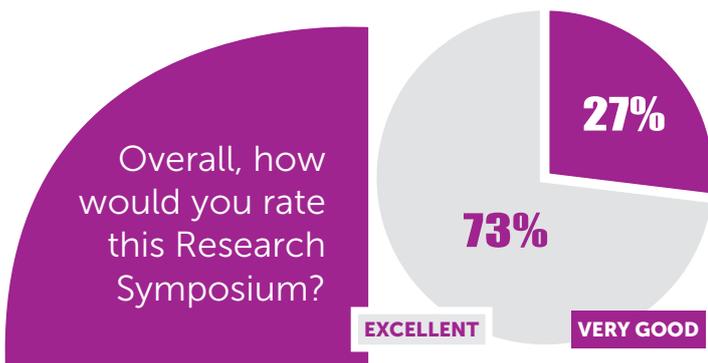
## Education and Information Seminars delivered 2024/2025

While Parkinson’s NSW is endeavouring to continue to deliver education to all members of the Parkinson’s community, the last financial year saw a reduction in obtaining Club Grants to deliver information seminars. As we move into the second half of calendar 2025, we are seeing an increase in grant approvals now that we have a dedicated Grants Manager.

Similarly, the number of seminars delivered to GPs and Health Professionals declined due to challenges in securing neurologists who were available and able to commit to scheduled dates. Addressing this barrier remains a priority as we plan future professional education sessions.

The recent Carer Investment Grant provides a dedicated budget, enabling us to actively engage neurologists and support their participation in upcoming educational activities targeting GPs and other health professionals.

Seminars /Training	Where	Number of Sessions	Number of participants	Target Audience
Newly Diagnosed face-to-face	North Ryde Goulburn	11 1	90 12	Newly diagnosed people living with Parkinson’s & their carers/ partners
Information Seminars face-to-face	NSW	2	120	People living with Parkinson’s, carers, and allied health professionals
Aged Care and Allied Health Training	Across NSW – face-to-face and online	3 4	62 106	Staff working in Aged Care facilities, Physiotherapists/ Exercise Physiologists and Dietitians
GP & Health Professional Seminars	Dubbo Port Macquarie	1 1	19 58	GPs and health professionals interested in Parkinson’s Disease



"Thank you for the new symptoms diary and the way you introduced it for my use. I truly feel I'm changing from your support. You've been like a mentor to me, taking your time, energy and patience to help me."

Thank you for your information on the support group in Wodonga. Thank you also for listening and caring, it's reassuring and lovely to have someone like you for support"

"Your constant support and care have been so important to me. I have spoken to you at times when I have had to deal with such vulnerability and uncertainty, thank you for always getting back to me and guiding me through, your support means a lot and I am so thankful to you."

"Support and care were beyond expectations. I rate it 10/10."

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"I am so grateful to have connected with Parkinson's NSW, especially you. You've opened a door for me to learn more about Parkinson's disease. Even though I missed out on early holistic rehabilitation, I believe that with your help, I'll still have a reasonable and comprehensive chance at recovery and making my Parkinson's journey more hopeful."

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"Both the NDIS Advocate and Counsellor were compassionate, professional and generous with their time."

## ...Our Impact

Of those that have experienced PNSW services over **72%** said the experience exceeded or greatly exceeded their expectations.

"Thanks again for your help on the phone yesterday and also for taking the time to email this list through. I really appreciated our chat yesterday and also knowing that you and your fabulous organisation are there to help when we need it. Thanks again. You're amazing!"

"The local Parkinsons Specialist Nurse Lauren is fabulous and should be cloned. She does an outstanding job."



# Parkinson's NSW BOARD



Chair - **Rachel Tanny** was appointed to the Board of Parkinson's NSW in November 2021. She brings a deep understanding of the aged care industry in Australia as it currently stands and insight into forthcoming changes. Rachel holds a Diploma of Business Governance from the Institute of Community Directors Australia as well as a Juris Doctor from the University of Richmond, USA.



Director - **Dr Margaret Scott** was appointed to the Board of Parkinson's NSW in November 2019 and was Chair from February 2021 to November 2022. She has more than 30 years of experience in senior fundraising roles for a variety of health and disability related not-for-profit organisations. In addition, she has operated her own business as a fundraising consultant since 2013.



Vice Chair - **Andy Esteban** was appointed to the Board of Parkinson's NSW in March 2023. He has been in the financial services industry for 45 years – including 21 years as National Manager, Trust Services for Perpetual Trustees, one of Australia's premier funds management and trustee organisations. Andy holds a Bachelor of Business Degree (Accounting Major), is a CPA, a Member of the Executor and Trustee Institute and a Member of the Institute of Company Directors.



Director - **Dr Martin Ostrowski** was elected to the Board in November 2023. He was diagnosed with Parkinson's disease in 2017 and has a long family history with the disease. He is also an active participant in several Parkinson's NSW Support Groups. Martin is an accomplished Marine scientist with over 20 years of experience working in the Tertiary Education sector. He is also Chief Science Officer of the Walking Tall research group, established to develop the Walking Tall gait training application for people living with Parkinson's.



Director - **Stephen Schiemer** was elected to the Board of Parkinson's NSW in October 2018. He is a fitness instructor and entrepreneur who has been living with Parkinson's for the past 17 years. Stephen also runs tailored fitness programs for other people living with Parkinson's. He has a Bachelor of Business degree and 30 years of experience in running his own businesses – including finance, risk management, logistics, people management, training, and digital marketing.

## Board Meeting Attendance Record 2024/2025

Name	July 24	Sep 24	Nov 25	AGM	Feb 25	Mar 25	May 25
Andy Esteban	✓	✓	Apology	✓	✓	✓	✓
Dr Martin Ostrowski	Apology	✓	Apology	✓	✓	✓	✓
Steve Schiemer	✓	✓	✓	✓	Apology	✓	✓
Dr Margaret Scott	✓	Apology	✓	✓	Apology	✓	✓
Rachel Tanny	✓	✓	✓	✓	✓	✓	✓





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