

Bringing it all together



**2023
2024**





Our **STRATEGIC PRIORITIES**

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.



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 employing 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.



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**

While the past fiscal year presented many challenges, I am very optimistic about the future of Parkinson's NSW and the people we support.

We have new, well qualified and experienced people in the key leadership roles of Chief Executive Officer and Chief Operating Officer. They are working in concert with Board to overcome past challenges and move the organisation forward in ways which will benefit our community.

The challenges I referred to were those faced in the **2023-2024** fiscal year by commercial and not-for-profit sectors alike as the Consumer Price Index (CPI) peaked at **3.8** percent to put substantial pressure on household spending.

The Australian Bureau of Statistics Living Cost Indexes also reached **6.2** percent – impacting all enterprises through the rising costs in multiple sectors including insurance, financial services, foodstuffs, and real estate.

In the case of Parkinson's NSW, we worked hard to strike a balance between meeting increasing demand for our services and supports while striving like other organisations to contain costs.

After some disciplined decision-making by the Board, followed by committed execution by the Leadership Team and staff, we reduced operating expenses by **9.6** percent year-to-year.

In terms of fundraising – our key source of revenue – from a modest base we experienced a **25** percent increase in contributions by trusts and corporations, and a small decline of **1** percent in charitable donations. However, there was a significant impact on our revenue from a drop of **53** percent in charitable grants, and a reduction of **78** percent in NSW Government grants.

Through tight management of expenses, we still managed to achieve a **5.2** percent growth in total Parkinson's NSW Ltd. revenue to **\$2,607,594**.

Despite our cost reduction initiatives and this growth in revenue, the drop in grant revenues noted above resulted in our organisation declaring a loss of **\$802,787** for the **2023-2024** period. The Consolidated Group result – which included Parkinson's NSW and the Parkinson's Trust – was a loss of **\$1,206,816**.

Given these circumstances, the Board has decided to invest more in **2024-2025** to support increased government and private sector advocacy, and donor acquisition for fundraising operations – which remain crucial to underwrite the delivery of services and supports for our NSW Parkinson's community.

These actions are all part of the current Five-Year Plan which the Board has implemented and continues to closely monitor.

Governance continues to be a priority; however, it has now progressed past the issues of previous years where it was on our radar as an area of risk. The **2022-2023** fiscal year saw a measurable improvement in the compliance and transparent reporting of our Support Group network.

I am pleased to report that this has further strengthened over the past year, and we are very grateful to Support Group Leadership Teams for their ongoing efforts in these areas.

I would also like to extend our thanks to the Parkinson's NSW management team and all employees. It has been a year of challenges and change, but you have all stepped up and contributed greatly to the successful implementation of enhancements to our organisation and service delivery.

In closing, I also express my appreciation for the dedication of our volunteer Board Members to the best-practice governance and monitoring of key performance indicators in our organisation. Your diverse backgrounds, skills and life experiences contribute greatly to the success of Parkinson's NSW.

Rachel Tanny
Chair, Parkinson's NSW



Message from the **CEO**

Once again in **2023-2024** we were facing the economic headwinds of a high cost of living and the related, elevated costs of doing business for all Australian enterprises.

Although we managed to reduce operating expenses by more than **\$420,000** – which at **9.6** percent was an even greater reduction than the previous year – Parkinson's NSW Ltd declared a loss of **\$802,787** for the fiscal year.

This loss was mitigated by the receipt of **\$2,400,713** in bequests and donations, which reflected our increased focus on and investment in donor acquisition over the past year.

The consolidated group of Parkinson's NSW Ltd. and the Parkinsons Trust recorded a loss of **\$1,206,816**.

As the Chair pointed out in her message, Parkinson's NSW was strongly impacted by a substantial drop in NSW Ministry of Health grants which were supporting our work for the Parkinson's NSW community. To remedy this going forward, we have increased investments of Leadership Team time, expertise, and funds in advocacy campaigns.

We have engaged external advocacy experts and specialist grant writers on short-term, project-based contracts to improve our track record in this area. For the first time, this publication also contains a dedicated section on advocacy which outlines our affiliation and activities with the new National Parkinson's Alliance Ltd, and our ongoing outreach to key Federal and State Ministries and Members of Parliament, as well as academic institutions and research organisations.

However, the funding challenges outlined above did not impact the quality and rate of delivery of our services for the year. We performed strongly across all areas including InfoLine, nursing, counselling, Support Groups, and education.

The **2023-2024** volume of InfoLine calls exceeded monthly rates of the three prior fiscal years. There were more than **3,400** phone enquiries over the year, handled by a team of **2.5** full time equivalent staff members under the new leadership of a veteran of several service areas of Parkinson's NSW.

Our four community-based Parkinson's Specialist Nurses conducted more than **240** in-patient and clinic consultations for people living with Parkinson's and travelled an amazing **17,900** kilometers to support patients over the year.

The historically strong demand for our counselling services remained steady with **1.5** full-time equivalent staff conducting **230** sessions in-person and via telephone and Zoom teleconferencing over the year in review.

Support Group participation rates grew across the state during the year to reach more than **2,500** people living with Parkinson's and care partners in person, as well as through Zoom teleconferencing and Facebook based Groups.

The Education & Quality Assurance team leveraged our two Online Learning Modules (with another under development) to double the number of Allied Health professionals upskilled with Parkinson's patient-specific knowledge.

There was also an advantageous overlap between advocacy and education when we coordinated with Fight Parkinson's in Victoria to deliver back-to-back Research Symposiums in Melbourne and Sydney – with the presentations also available as video downloads after the events.

Given all that we have delivered over the year – and with the investments of time, expertise, and funds we have made in areas important to the health of our organisation – I can say we are looking forward to the future with optimism.

We thank our supporters, partners, and donors for their contributions to our ongoing fundraising efforts, as well as our Support Group Leaders and participants, and of course our hard-working staff.

Mary Kay Walker
CEO, Parkinson's NSW



One of the year's most important advocacy initiatives was Parkinson's NSW signing up to the newly formed National Parkinson's Alliance. The Alliance includes key state-based Parkinson's organisations, along with representatives of universities and institutes focused on Parkinson's research.

Advocacy **A voice for the NSW Parkinson's community**

Advocacy is the process of attempting to influence decisions made by political parties, agencies or organisations.

The Board, management and staff of Parkinson's NSW conduct ongoing advocacy on behalf of our community – including for people living with Parkinson's, their care partners and families, and others in their local areas.

In the past fiscal year, one of the most important advocacy initiatives we were involved in was the formation of the National Parkinson's Alliance (NPA) in March **2024**. Alliance members include:

- U Parkinson's NSW
- U Fight Parkinson's (Victoria)
- U Shake It Up Australia Foundation
- U Parkinson's Tasmania
- U Walter and Eliza Hall Institute of Medical Research (WEHI)
- U Neuroscience Research Australia (NeuRA)
- U Queensland University of Technology
- U University of Tasmania
- U Wings 4 Parkinson's

The Alliance was launched by its members with a National Parkinson's Summit meeting at Parliament House, Canberra. Deputy Prime Minister Richard Marles attended, along with other Federal Ministers, Members of Parliament and senior departmental staff members.

Immediately after its formation, the Alliance successfully lobbied the Australian Government to allocate **\$800,000** to fund the development of a National Parkinson's Action Plan which seeks to identify and address policy gaps and initiatives in areas including:

- U Stigma and lack of knowledge about Parkinson's in the community.
- U Health and social care to support people living with Parkinson's and care partners.
- U Equitable access to current and new therapies and treatments.
- U Investment in research to better understand the causes, mechanisms and progression of Parkinson's, with a focus on disease-modifying therapies, health and social care and treatments.



This was in addition to ongoing outreach to 14 key State and Federal Members of Parliament in electorates covering suburban, rural and regional areas of NSW – particularly those with an interest in rural and regional health issues.

The Chair of the Board and CEO of Parkinson's NSW were also honoured by an audience with Her Excellency, the Honourable Margaret Beazley, Governor of New South Wales, who is Patron of the organisation.

Research support

Ongoing research support during the year by Parkinson's NSW included participant recruitment for and formal endorsements of studies undertaken by the University of Sydney, University of NSW, University of Queensland, University of South Australia, University of Canberra, Notre Dame University Australia, University of Melbourne, Monash University, Neuroscience Research Australia, and the Berghofer Medical Research Institute.

Parkinson's NSW also maintains working relationships with key pharmaceutical companies active in developing and supplying Parkinson's therapies.

Enhanced cooperation

The creation of the National Parkinson's Alliance has also strengthened cooperation between individual members of the organisation.

An example of this cooperation was the organisation of the first ever back-to-back Parkinson's Research Seminars for healthcare professionals and the Parkinson's communities of Melbourne and Sydney. This initiative is highlighted in the Education section of this report.

The year has also seen enhanced collaboration between all the State Parkinson's entities following the signing of an historic memorandum of understanding (MOU) in March 2024. The States meet regularly to discuss opportunities and priorities and are leveraging one another's expertise and knowledge.

New South Wales-focused advocacy also included multiple representations to the offices and departments of:

- 📌 Federal Minister for the National Disability Insurance Scheme, Bill Shorten
- 📌 Federal Minister for Health and Aged Care, Mark Butler
- 📌 NSW Minister for Health and Regional Health, Ryan Park
- 📌 NSW Minister for Mental Health and North Coast, Rose Jackson



Participation in professional organisations

Another key aspect of advocacy is the maintenance of qualifications and networks through active participation in professional organisations. Following are the organisations to which Board Members and staff of Parkinson's NSW belong.

- Leaders for Impact
- Fundraising Institute of Australia
- Australian Institute of Company Directors
- Institute of Community Directors Australia
- Financial Services Institute of Australasia
- Australasian Neurological Nurses Association (ANNA)
- International Parkinson and Movement Disorder Society
- Movement Disorder Society of Australia and New Zealand (MDSANZ)
- Australian College of Nursing
- Australian Health Practitioner Regulation Agency (AHPRA)

Client Services Team strengthened with new leadership

During fiscal **2023-2024**, Parkinson's NSW veteran Melanie Browning was appointed to the new role of Client Service Team Leader for Parkinson's NSW. Her ongoing mission is consolidating and sharpening the focus of client services – ensuring that the Parkinson's NSW InfoLine (**1800 644 189**) is a single, easy-to-use point of contact for all services and supports, both internal and external.

InfoLine Callers by Category

63%

People with Parkinson's

24%

Caregivers

4%

Allied Health providers

9%

Others



1800 644 189

The Parkinson's NSW InfoLine:

Connecting people with essential support.

The 1800 InfoLine service is the first point of contact for all services offered by Parkinson's NSW – and for connection to services by other providers which have been verified by the Quality Assurance Team.

Each call is handled with care and expertise, ensuring that callers receive the information and support they need to manage their condition effectively. The InfoLine team is dedicated to providing a listening ear, practical advice, and a compassionate touch to everyone who reaches out to us.

Typical InfoLine enquiries include:

Medication Issues

- ❑ Questions about managing medication regimens and potential side effects.
- ❑ Guidance on interactions between Parkinson's medications and other treatments.

Mental Health Support

- ❑ Support for individuals experiencing apathy, anxiety, depression, or other mental health issues related to Parkinson's.
- ❑ Connection to counselling and psychological services for further assistance.

Family and Caregiver Support

- ❑ Advice for family members and caregivers on how to best support their loved ones.
- ❑ Resources and strategies for managing caregiver stress and maintaining well-being.

NDIS Information and Advocacy

- ❑ Assistance with navigating the NDIS application process.

- ❑ Advocacy support to ensure individuals receive the benefits and services they are entitled to.

Community Engagement and Resources

- ❑ Information about local support groups, events, and community resources.
- ❑ Guidance on how to stay connected and engaged within the Parkinson's community.

Lifestyle and Daily Living

- ❑ Tips and advice on managing daily activities and maintaining independence.
- ❑ Recommendations for exercise, diet, and other lifestyle adjustments to improve quality of life.

Newly Diagnosed Support

- ❑ Pre-diagnosis support.
- ❑ Pathway to counselling support.

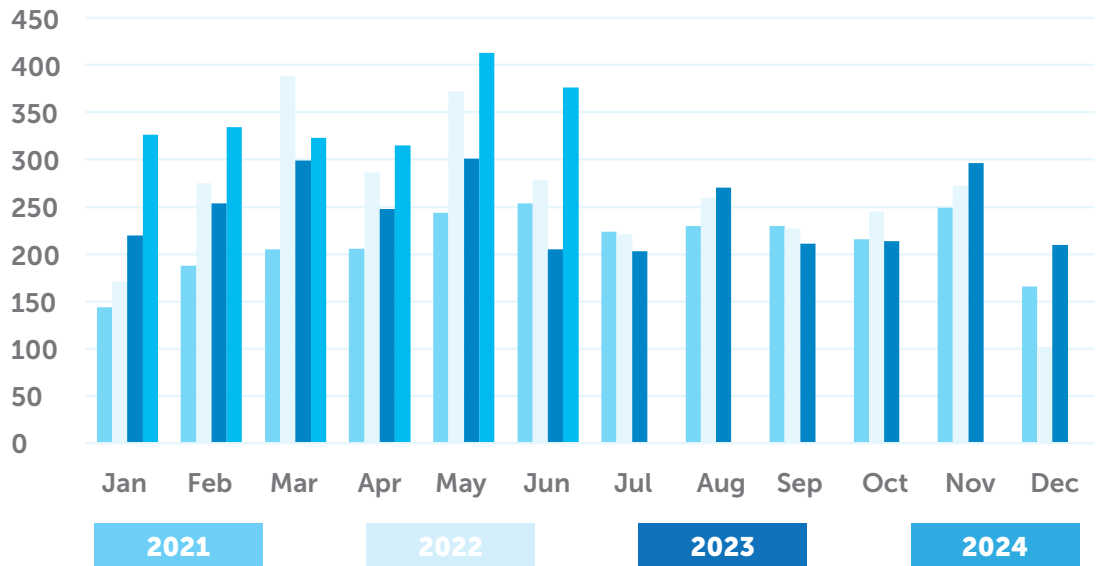
To remain current and connected with the Parkinson's provider community, the InfoLine Team meets regularly with colleagues and other service providers to share updates and build connections.

Regular videoconferencing and face-to-face meetings take place with community-based Parkinson's Specialist Nurses and other Local Health District and Public Health Network professionals, the research community, the internal Counselling and Support Group teams, and specialised external providers like PD Warrior and Advanced Rehab.

Regular supervision and debriefing sessions are made available to client-facing InfoLine and NDIS Advocacy staff – along with monthly skill development workshops.

Members of the InfoLine team also do Question and Answer sessions for Support Groups via Zoom teleconferencing. These are arranged with the assistance of the Parkinson's NSW Support Group Coordinator.

Infor Line Calls and Contacts 2021 - 2024



An InfoLine nurse's experience

I find my InfoLine role to be incredibly rewarding because my colleagues and I can make a genuine difference to someone's life and wellbeing.

The gratitude we receive is very genuine and sincere. People are often amazed this service exists and wish they had known about us years ago.

The Infoline is in a way a bridge for people in the Parkinson's community who often go for weeks to months between appointments with their neurologists experiencing little support. They leave their appointment a little lost and overwhelmed at the enormity of the Parkinson's diagnosis and what it means to their life .

During a conversation a client will often say they have taken up enough of my time. I always remind them that there is no hurry or time limit on our conversation

Some of the first questions I am asked by a newly diagnosed client include: *"what will happen to me?"*, *"How quickly will this disease progress?"* and *"what will happen to me towards the end?"*

What they are desperately seeking is for me to tell them they will be okay, that everything will be fine. It is essential in this role to provide some hope – something positive for patients and caregivers alike to gain comfort from.

This may occur through sharing evidence-based advice and information, a referral for additional support services, or just a chat. A person will immediately feel better about a situation if there is something they can do proactively to help themselves

- Melanie Ledbury, Registered Nurse



Change to National Disability Insurance Scheme (NDIS) services

As of February 14, 2024, NDIS Support Coordination services by Parkinson's NSW officially concluded.

During December 2023 and January 2024, Parkinson's NSW successfully transitioned 114 clients to other Support Coordinators. Clients were provided with a carefully curated list of Support Coordinators with available capacity, along with information about their location, areas of expertise, and experience with Parkinson's.

Clients requiring additional support were provided with the necessary assistance – including multiple check-ins if needed. Formal referrals to the new Service Providers and comprehensive end-of-service reports by the Parkinson's NSW team facilitated a seamless handover.

This change did not impact NDIS Advocacy, which is still provided by Parkinson's NSW for people with a formal diagnosis of Parkinson's who are aged under 65 years at the time of application.

Parkinson's Specialist Nurses support regional and rural patients

Parkinson's Specialist Nurses continued to be based in Coffs Harbour, Port Macquarie, Tweed region and Goulburn region during the **2023-2024** fiscal year.

They worked within the Mid North Coast, Northern NSW and Southern NSW Local Health Districts respectively. This arrangement provided the Nurses with access to regional health facilities, centralised medical records, professional development opportunities, and peer support from a range of other Primary and Allied Health professionals.

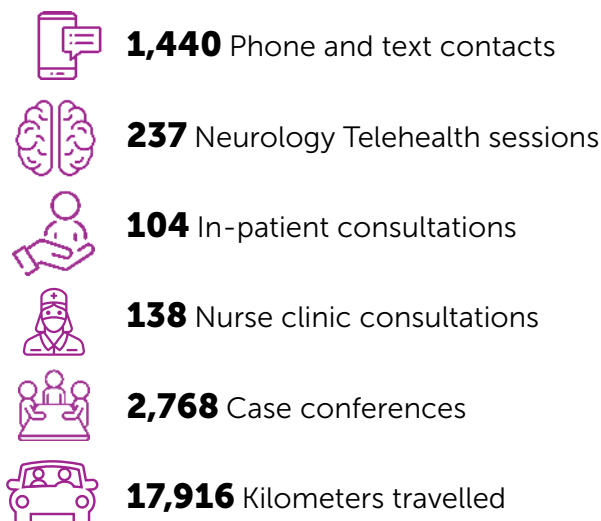
By the end of the fiscal year our Parkinson's Specialist Nurses had **2,373** patients on their books, having added an average of 43 new patients per month over that period.

Neurological Telehealth consultations supported by the Nurses grew significantly to **237** sessions over the past year, up from **45** in the previous reporting period.

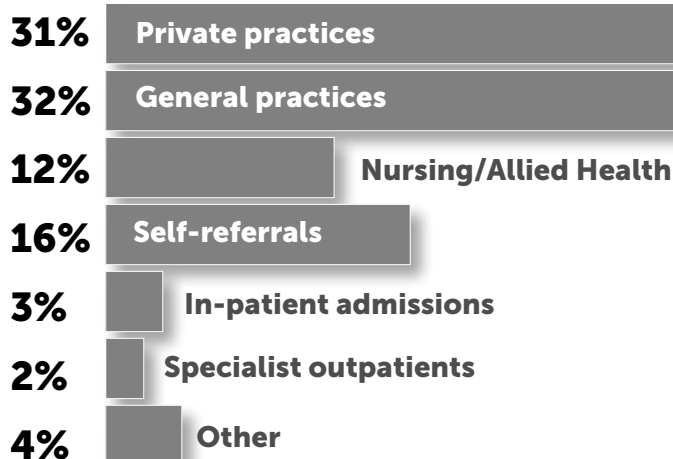
New Telehealth programs were established in Coffs Harbour and the Tweed region, anchored by a series of fly-in/fly-out clinics offering in-person consultations.

Movement Disorder Specialists providing these consultations were based in Westmead Hospital, St Vincent's Hospital, Macquarie University Hospital, and John Hunter Hospital.

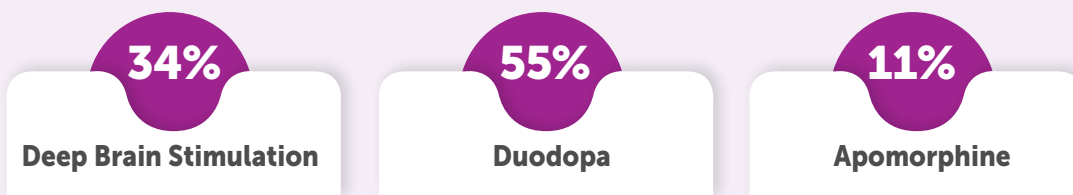
Nursing support for regional and rural patients



Sources of referrals to Nurses



555 Device Assisted Therapies supported





Demand for Counselling range of issues addressed grew

With an unchanged resource of **1.5** Full Time Equivalent staff, the Counselling team managed to grow the number of individual counselling sessions delivered by **28** percent year to year.

The number of group counselling sessions remained steady at **230** for the year under review.

Counsellors supported people living with Parkinson's, caregivers, couples and family members. Over the past year they addressed a wider range of client issues and requests than in the previous period. These included:

- U Support for newly diagnosed clients
- U Depression
- U Anxiety
- U Grief and loss
- U Suicidal ideation
- U Uncertainty about the future
- U Carer stress and carer burnout
- U Employment issues
- U Managing the progression of Parkinson's
- U Living with the physical effects of the disease
- U Dealing with treatments
- U Ensuring clear communication with doctors
- U Maintaining emotional balance to cope with negative feelings
- U Maintaining confidence and a positive self-image
- U Building and maintaining social relationships
- U Building and maintaining a strong support network when faced with an uncertain medical future

Face to face counselling sessions were delivered at three locations – War Memorial Hospital, Wolper Jewish Hospital and Parkinson's NSW headquarters in North Ryde.



For client convenience, counselling sessions were also made available via telephone and teleconferencing.

"My lifeline came from Parkinson's NSW. Counsellor Shushann Movsessian responds to my ever-evolving questions and anxieties, sharing her wisdom and experience with generosity and understanding."

"Your calm and kind empathy has helped me to verbalise my struggles to you while feeling completely safe and supported."

Fundraising refines database to better serve and thank donors

Over the **2023-2024** fiscal year, the focus of the Fundraising team was on ensuring that donors were appropriately contacted, treated with respect and dignity, and fully acknowledged for the difference they make to people living with Parkinson's.

During the year, the organisation held its first two donor acknowledgement events, with a view to doing more in the future. It also broke new ground by sending out a formal acquittal report to donors, giving people a deeper understanding of the programs and services for the Parkinson's community that their contributions make possible.

Despite sustained cost of living pressures over the **2023-2024** fiscal year, **7,345** unique donors – including individuals, companies, and foundations – made charitable donations to support the essential services delivered by Parkinson's NSW.

Of these contributions **1,011** regular givers accounted for 8,810 transactions totaling almost **\$260,000**.

The total raised from charitable giving was **\$2,400,713**

Sixty one percent of donations were derived from telephone fundraising programs which were reinforced this year by a stronger, more information-rich donor database. This enabled a focus on more carefully selected donor candidates and provided enhanced information and opportunities for thanking and retaining generous givers.

As in prior years, funding from State and Federal Governments was minimal – amounting to less than **10** percent of the organisation's operating costs.

That translates into Government funding of just **47** cents per person living with Parkinson's in New South Wales.

Ongoing advocacy efforts (described on page **6** of this publication) continued throughout the reporting period; however, Parkinson's NSW remains strongly dependent on generous donors and bequestors.

Philanthropic gifts from individuals, foundations and companies are also a key component of fundraising. During the year under review, Parkinson's NSW received gifts valued at **\$553,414**.

Over the same period, the organisation benefited from multiple bequests totaling **\$921,333**. We acknowledge the generosity of:

- U Estate of the Late Peter Lloyd Binnie
- U Estate of the Late Gina Wendy Burke
- U Estate of the Late David Frost
- U Estate of the Late Anne Kermod
- U Estate of the Late Peter Charles Irwin Lawrence
- U Estate of the Late Carolyn (June) Lyons
- U Estate of the Late John McMahon
- U Estate of the Late Michael Thompson
- U Estate of the Late Robyne Waller
- U A gift from the family of the Late Mrs Pat Hookham as part of her final wishes
- U A continuing annual legacy gift from the Keven Williams Trust

Parkinson's NSW services enabled by fundraising, include:

- U Operations and resources of the **1800** Parkinson's InfoLine service staffed by Primary and Allied Health professionals, and acting as the first point of contact, advice and service linkage for people living with Parkinson's, their partners, and caregivers.
- U Comprehensive Parkinson's education for consumers made available free of charge or at heavily subsidised rates.
- U Administration and logistics for the Parkinson's NSW network of **75** Support Groups – **79** percent of which are in high-need regional and rural areas of the state.
- U Community-based Parkinson's specialist nurses co-funded with Local Health Districts, also in regional and rural locations.
- U Specialist counselling services for people living with Parkinson's, their families, and caregivers.

PARKINSON'S NSW MOVERS AND SHAKERS TEAM



Creative volunteer fundraisers for Parkinson's NSW piggy-back their efforts on other community activities – particularly the annual Sydney City to Surf race. The Movers & Shakers team were appropriately named for their much-appreciated fundraising effort.



The Dean Team held its second Annual Parkinson's Walk for participants of all levels of ability. It raised \$12,000.

Community Fundraising

Parkinson's NSW is grateful to everyone who has donated – regardless of how large or small – to support its work during the **2023-2024** fiscal year. In a year of increasing daily costs of living, it was not taken for granted that donors found a little extra to support the organisation's essential work.

It also important for to acknowledge the effort put in by every individual who has participated in or organised a community fundraising event. We thank and acknowledge everyone who has walked, run, Stepped Up for Parkinson's, had a birthday, asked friends for support, or drank a cup of tea to support people living with Parkinson's.

Community fundraising initiatives raised more than **\$132,000** over the past year. This is a large proportion of annual fundraising revenue for Parkinson's NSW.

Here is a snapshot of community fundraising activities over the past year:

- U Coffs Harbour Parkinson's Support Group held raffles, barbecues and community events to raise awareness and funds for Parkinson's NSW programs – including the local Parkinson's Specialist Nurse.
- U Dean Laws and the Dean Team held the third Annual Parkinson's Marathon Walk raising **\$12,000**.

- U Michael Costello – who is living with Parkinson's – hosted a high tea in his retirement community, sold his artwork and held a raffle to raise **\$4,345**.
- U McPherson Plumbing hosted a golf day raising **\$7,746**.
- U Murray Glen Village in Tumut held a Melbourne Cup afternoon tea raising **\$490**.
- U Savvy held a Survivor Challenge raising **\$26,020** for Parkinson's programs and supports in the Illawarra region.
- U The annual Pump for Parkinson's promotion was held once again in Coffs Harbour by the Liberty Service Station raising **\$4,500** to help support the local Parkinson's Specialist Nurse.
- U Coffs Neuro Physio held its novel Train the Trainer session, giving Parkinson's clients the opportunity to put their physiotherapists and exercise physiologists through some of the exercise they do each session. This raised **\$456** for the local Parkinson's Specialist Nurse.
- U Goulburn Parkinson's Support Group held its popular annual Shakin' Cocktail Party raising **\$15,720** funds for the local Parkinson's Specialist Nurse.
- U Accent Benchtops in Tweed Heads held a charity golf day and shared proceeds between Parkinson's NSW and Parkinson's Queensland. The event raised more than **\$15,000**.
- U Sandy Shores Retirement Village and Forresters Beach Retirement Village held fundraising events during Parkinson's Awareness month, raising close to **\$3,000** collectively.
- U Tumut Parkinson's Support Group and Port Macquarie Parkinson's Support Group both held World Parkinson's Day raffles. Port Macquarie also organised an expo event for World Parkinson's Day showcasing the services available to people with Parkinson's in the local region.



The Coffs Harbour Parkinson's community is well supported by two local businesses – the Bailey Centre Liberty Service Station and PK Express Transport. Together they donate a set amount per litre of fuel sold in a specified 24-hour period. Funds go to supporting the Parkinson's Coffs Harbour Nurses Fund.



Port Macquarie Support Group gathered local health professionals and service providers in an expo to mark World Parkinson's Day.

Increased engagement with Support Groups

Over the past year there has been a stronger focus on developing closer engagement with Parkinson's NSW Support Group Leadership Teams through shared work on:

- 📌 Developing and releasing an updated Support Group Operations Manual
- 📌 Projects around significant dates such as World Parkinson's Day and National Volunteer Week
- 📌 Development of a formal Leadership Education Framework
- 📌 Monthly Leadership Team meetings

There has also been a drive to broaden Online Support Group options – particularly to meet the needs of the diverse caregiver community.

During fiscal **2023-2024** there were **75** face-to-face Parkinson's NSW Support Groups operating in New South Wales. The total number of individual participants in Groups jumped from **2,000** in the prior year to **2,520** during the year under review.

No Support Groups closed during the year, and a new Group opened in Inverell.

In addition to face-to-face Groups, there were five ongoing videoconferencing Groups in operation for:

- 📌 Young Onset
- 📌 Carers' Chat
- 📌 Leadership Teams
- 📌 Let's Talk Parkinson's
- 📌 Deep Brain Stimulation

Thirty-one online sessions were hosted over the year. They were open to any Support Group participants who wanted to register free of charge.

Topics covered in these sessions included:

- 📌 Young Onset – Parkinson's and Relationships, and My Parkinson's Life
- 📌 Carers' Chat – Journalling for Carer Relief and Empathy Burnout
- 📌 Let's Talk Parkinson's – Parkinson's and Speech, Incontinence and Pelvic Floor Health, and Different Exercises for Different Benefits

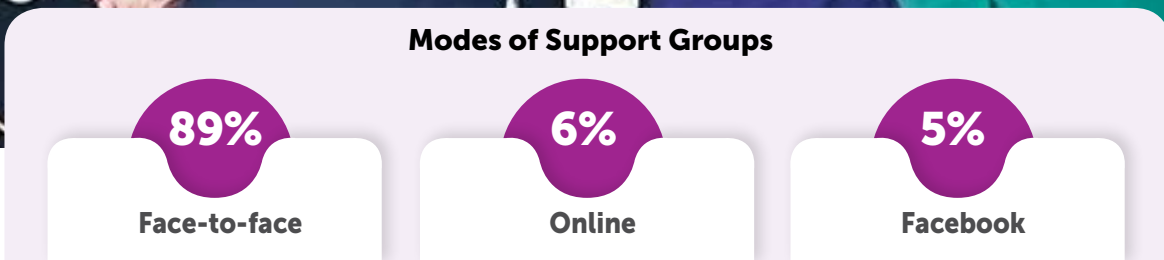
The Carers' Chat online connections have broadened and gone from strength to strength over the past 12 months. They now provide the opportunity for carers to connect outside of the monthly online sessions – in some cases people in the larger online sessions realise they live in the same area, so they begin to catch up face-to-face.

Carers are therefore having more opportunities to offer words of support to one another as they go through similar experiences.

Feedback from carers at the end of each online session has been very positive. They value the meetings, the information shared and the opportunity to connect with others in the same situation.

There were also four ongoing Facebook Groups supported during the year:

- 📌 Caregivers
- 📌 Young Onset
- 📌 Support Groups Online Community
- 📌 Support Group Leadership Teams



Parkinson’s Awareness Month in April each year is the highlight of the Support Group calendar of activities. In support of its Group network, Parkinson’s NSW once again activated its Parkinson’s Community Hero campaign in **2024**.

This initiative resulted in **16** awards being presented to selfless community members by seven Groups – all in regional and rural areas. Additional benefits included the opportunity for outreach to local media, and the raising of awareness of each local Parkinson’s community’s challenges.

Ten Support Groups also took the opportunity to hold community awareness-building activities including:

- U Information tables in shopping areas with high foot traffic
- U Information booths in hospital lobbies
- U Participation in a large expo day
- U Hosting an information seminar
- U Staging a month-long art exhibition

Parkinson’s NSW also observed National Volunteer Week in May to provide well-earned recognition to the more than **120** members of Support Group Leadership Teams across the state.

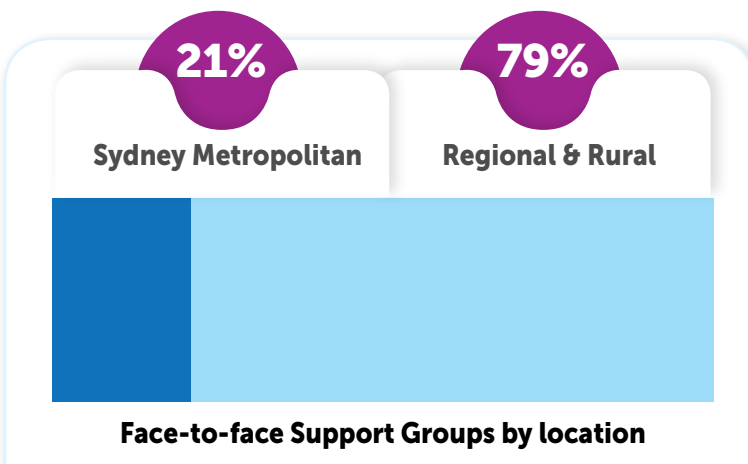
Recognition included publicity in Parkinson’s NSW print and digital publications, social media content, and two Thank You Morning Teas for leaders hosted by CEO Mary Kay Walker in Sydney and on the South Coast.

During the year under review, the Goulburn Support Group once again hosted its popular Shakin’ Cocktail Party to help raise funds for the area’s community-based Parkinson’s Specialist Nurse. The function raised **\$15,720** for local nursing services.

Participants of Maitland Support Group showed off their artistic talents and – with support from the local council – put on a month-long exhibition during April Awareness Month. The exhibition raised **\$360** for Parkinson’s NSW.

Her Excellency the Honourable Margaret Beazley AC KC, Governor of New South Wales attended an informal function on 26 June jointly hosted by the Maitland and Port Stephens Parkinson’s Support Groups.

Governor Beazley is the Patron of Parkinson’s NSW. During her visit to Maitland, more than **40** guests attended to share their experiences of living with Parkinson’s and caring for someone who does.



Digital & Marketing team

drives strong growth across channels

The responsibilities of the Parkinson's NSW Digital & Marketing function include:

- Newsletters in print and digital form delivering factual news on Parkinson's NSW and Support Group activities, and evidence-based updates on the latest therapies for Parkinson's and research progress.
- Social media communications via Facebook, Instagram, X (formerly Twitter), YouTube and LinkedIn.
- Content for the corporate website and other websites

The team also carries additional responsibilities for supporting fundraising initiatives and communications underlying community outreach and advocacy efforts.

Increases in readership and digital reach

The organisation's digital touchpoints doubled year-to-year to reach more than **2.1** million people. This included a **23** percent increase in news readership.

Consumption of video content rose by **266** percent to achieve more than **152,000** viewing minutes via multiple channels including YouTube, other social media platforms, and the corporate website.

Some of the most popular video content included health and wellbeing topics, particularly:

- Living well with the right nutrition
- Understanding postural instability and balance
- Fatigue and Parkinson's

The Parkinson's NSW website continued to attract readers from all over the globe, including the United States, India, United Kingdom, Canada, Philippines, and Germany.



Total digital touchpoints grew **200%**

Touchpoints reached **2.1** million people

Video content consumption up by **266%**

152,000 viewing minutes of video content



The Great Parkinson's Tea Party fundraiser involved 44 committed volunteers hosting gatherings with a variety of fun themes including Mad Hatter parties.

Great Parkinson's Tea Party brewed success

The inaugural Great Parkinson's Tea Party fundraising campaign was conducted throughout October of **2023**, underpinned by easily accessible digital assets.

It was organised, tracked and promoted via a purpose-built web page which resulted in **44** hosts volunteering to organise gatherings which raised **\$19,498** to fund the ongoing delivery of Parkinson's NSW services.

Participating tea parties took place as far afield as Dubbo, Lismore, the Southern Highlands, Albury, Newcastle, the Nepean and Blue Mountain regions, and Port Macquarie.

Many participants created themes for their gatherings – including Mad Hatters, Alice in Wonderland, High Tea, Garden Tea, Picnic in the Park, and a Seafood Luncheon. Some generous people even converted their own birthday parties into Tea Party fundraisers.

"This experience showed that if you have a strong, core idea supported by the right resources, people will pick up a fundraising theme and run with it while adding their creative twists along the way," said Mirelle Brockett, Digital Marketing Manager of Parkinson's NSW.

The Great Parkinson's Tea Party will once again be held late in calendar 2024.



Celebrating

World Parkinson's Day

April 11 is World Parkinson's Day – part of the annual global Parkinson's Awareness Month. It is celebrated on this date to acknowledge the birthday and discoveries of Dr James Parkinson – the surgeon, scientist and social activist who first described Parkinson's disease in an essay written in 1817.

World Parkinson's Day is an annual opportunity for all who are impacted by the disease to raise awareness and urge unity towards finally ending Parkinson's.

Raising awareness helps to remove the stigma around Parkinson's and focus on increased funding and resources for essential services and research which together can put Parkinson's in the past.

A wide range of activities took place around NSW on **April 11, 2024**, involving the Parkinson's NSW team, Parkinson's Support Groups, donors and volunteers. These activities included:

- U Awareness stalls
- U Information forums
- U Public noticeboards and posters
- U Art exhibitions
- U Open days
- U Morning teas
- U Raffles

A purpose-built Ways You Can Get Involved web page was launched and publicised well prior to Parkinson's Awareness Month.

It offered facts, statistics and tools to enable the Parkinson's community and its supporters to share information about Parkinson's through their own channels and networks. Specific offerings included:

- U A ready-to-print and share media release
- U Social media assets
- U Ready-to-share talking points and presentations about Parkinson's, its symptoms and impact on daily life

The page also offered free access to the Introduction to Parkinson's online education module to help build knowledge and raise awareness about Parkinson's and share practical ways to improve quality of life.

A link was also provided to the Step Up for Parkinson's web page, offering opportunities to build health and fitness, get and stay active in daily life, and contribute to fundraising. The timing allowed the Step Up campaign to be rolled out in May, immediately following Parkinson's Awareness Month.



Talented musicians Geoff Grundy (left) and Martin Pryor – both of whom are living with Parkinson's – celebrated World Parkinson's Day with a performance for fellow residents of their retirement village in Forresters Beach.



Participants of the Nepean-Blue Mountains Parkinson's Support Group joined in to recognise and promote World Parkinson's Day on 11 April 2024.

Third year of

Step Up For Parkinson's campaign

2023-2024 was the third year in which the Step Up for Parkinson's campaign had been run. It is the organisation's signature fundraising event.

To date, the campaign has raised \$277,146 to support the essential services delivered by Parkinson's NSW. We are grateful for the imagination, enthusiasm and high rate of participation exhibited by our community and supporters.

Participants from across NSW arranged and joined a wide variety of activities including:

- U Bike riding
- U Pilates
- U Yoga
- U Running
- U Walking

In addition to raising funds, Step Up plays a vital role in raising awareness and understanding of Parkinson's. It unites communities, and gives people a platform to have conversations, share stories and remember loved ones.

What inspires our community to Step Up for Parkinson's

As part of the digital support for Step Up for Parkinson's, a 'virtual wall' was created where participants could post on who or what inspired them to get active and join this campaign.



Myself today and tomorrow

I want to continue to advocate for all, including me. Early Onset Parkinson's is something I must live with for the rest of my life. I'm still smiling!

Myself

This is my third year of Stepping Up and eight years since I was diagnosed. I'm stepping up for everyone who is living with Parkinson's.

My dad

I'm stepping up for my dad who was diagnosed with Parkinson's a while ago. We need to raise money for this wonderful cause.

My dad and family friend

I'm stepping up to help spread awareness and raise money. It's a charity very close to my heart as my dad and a close family friend and neighbour has this condition.

My husband

I am stepping up for my beautiful husband who was diagnosed when he was 48 years old with Young Onset Parkinson's.

My Mamabear

I am stepping up for my beautiful Mamabear, Lorraine. I am so proud of how much she has embraced this new chapter of her life and won't allow this disorder to defeat her. She really is such an inspiration to all those she meets.



Stepping up for the Parkinson's community

Step Up for Parkinson's is the organisation's signature community fundraising event. It both builds awareness and raises funds for services to the Parkinson's community.



Education and Quality Assurance combine to add value

The addition of the Quality Assurance role to the Education team in fiscal **2023** delivered significant benefits to people supported by Parkinson's NSW in the **2024** year under review.

Two Online Learning Modules were deployed in the **2023** fiscal year. This past year they resulted in the upskilling of **551** Allied Health professionals – twice the number of participants previously reached by this technology.

Since the health professionals registered their interest in learning more about Parkinson's and then committed to the online education process, Quality Assurance staff were then able to start a verification process to confirm them as Preferred Providers of Parkinson's support in their areas of professional expertise. These included physiotherapy, speech therapy, exercise science, dietetics, and occupational therapy.

In a separate but related initiative, **87** Aged Care support workers across NSW received face-to-face training on caring for residents living with Parkinson's.






Parkinson's NSW Education initiatives during the year also benefited from the organisation's new membership of the National Parkinson's Alliance.

The Alliance is a national collaboration of key stakeholders and leaders in the Parkinson's community in Australia who have come together to shape policies, strategies, and initiatives that will change the lives of individuals affected by Parkinson's across the country.

In collaboration with another Alliance member – Fight Parkinson's based in Victoria – Parkinson's NSW enriched its education offerings to present its first ever Research Symposium.

The one-day Sydney event incorporated updates by specialists in Parkinson's clinical research over two sessions – one for healthcare professionals and one for the general public.

The healthcare professional's session attracted **24** registrations and **100** participants attended the public session.

-  **12** Newly Diagnosed seminars with **112** participants
-  **6** Community Information seminars with **343** participants across NSW
-  **5** Aged Care training seminars with **87** participants across NSW
-  **6** GP Seminars with **155** participants across NSW
-  **2** online training modules completed by **551** participants

Overall Ratings of Research Symposium



Ratings for Information Shared at Symposium



Module	Topic	Availability
Module 1	Introduction to Parkinson's	Now. For general public.
Module 2	Best Care Practices for Parkinson's	Now. For Allied Health professionals.
Module 3	Exercise for Parkinson's	2024. For exercise professionals.

"I very much appreciate the helpful Newly Diagnosed education program. I'm sorry I did not know about it sooner".

Education

"I can't believe you manage to put these Newly Diagnosed seminars on when you do not receive government funding! Thank you for a very well organised and informative seminar."

"I spoke to Nurse Melanie on Monday, and she was so calming and reassuring. Can I please speak to her again?"

InfoLine

"The Newly Diagnosed seminar was absolutely fantastic and informative on so many fronts. I left with a far higher level of understanding and comfort. Thank you so much".

"I was diagnosed about 12 years ago and received the package of information from the InfoLine this week. I have read so much about Parkinson's and learned so much just from this package. Wish I had reached out when I was first diagnosed so that I knew what I know now!"

"We are both so appreciative of your help in getting us ready for our NDIS meeting today, and your preparedness. A huge thank you."

NDIS Advocacy

"Thank you so much for all your support and assistance with submitting my NDIS appeal and advocating on my behalf. You have been so helpful, understanding and knowledgeable and so lovely and incredible to deal with. There should be more people like you and Nurse Melanie in this world!"

"Thank you so much!
Whatever info I need
you always come up
with either the answer,
or the name of a
contact who will help."

General Support

"Thank you so much for the support and assistance you gave us both during Phillip's illness. It was a great help just knowing that I could ring you when things were tough. You do an amazing job given the large numbers of clients you would have. We always felt that we were getting 100% from you. The reassurance certainly helped me care for Phillip."

Community-based Parkinson's Specialist Nurses

"Thanks so much for all you do. The great thing is that Dad is feeling well supported thanks to you, the physios and your upbeat and caring professionalism. As a result, he has moved to a way happier and more positive place."

"The assistance I've received from Parkinsons NSW has been exceptional. I feel blessed to have access to them for counselling, medical advice, support groups and general information".

"I very much appreciated Parkinson's NSW's help three years ago when I was first diagnosed. You then helped me find the PD Warrior program, speech therapy and physio providers. Parkinsons NSW was also instrumental in obtaining my NDIS support. I could not have done this without your advice and advocacy".

Counselling

"I recently had to call on Counsellor Shushann's expertise again, as my husband's condition has continued to deteriorate further. Her in-depth knowledge of Parkinson's itself, and the many contacts and treatment modalities she has sourced in this field, have helped us enormously in finding both new practitioners and treatments for him which have been invaluable in giving us hope for restoring some quality of life for him (and me)."

PARKINSON'S NSW BOARD



Chair – Rachel Tanny

Rachel Tanny was appointed to the Board of Parkinson's NSW in November 2021. She brings a deep understanding of both 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

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 – Stephen Schiemer

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 16 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.



Director – Dr Martin Ostrowski

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 – Andy Esteban

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.

Board Meeting Attendance Record 2023/2024

Name	July23	Sep23	AGM	Dec23	Feb 24	Mar24	May24
Andy Esteban	✓	Approved Leave	✓	✓	✓	✓	✓
Martin Ostrowski	N/A	N/A	N/A	N/A	✓	✓	✓
Janina Jancu	✓	✓	N/A	N/A	N/A	N/A	N/A
Steve Schiemer	✓	✓	✓	✓	✓	Apology	✓
Margaret Scott	✓	✓	✓	✓	✓	✓	✓
Rachel Tanny	✓	✓	✓	✓	✓	✓	✓
Roy Wakelin-King, AM	Approved Leave	✓	N/A	N/A	N/A	N/A	N/A



IN THIS TOGETHER
parkinson's
 NSW
 ...our **Community**






**Bringing it
all together**

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