

parkinson's
NSW

IN THIS TOGETHER

In this together 2022/2023

A year of persistence to achieve better balance



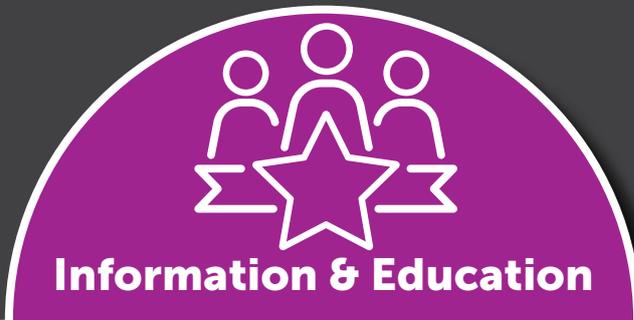
Our **Vision**

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.

Our **Strategic Priorities**



You are informed and educated to support your health & wellbeing.

Through educational excellence, quality of care is assured wherever you live.



Access to expert & quality services and supports wherever you need them.



Build and strengthen connections and alliances making us stronger together.

Through influence and partnership we advocate for what matters to you.





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Message from the Chair

The **2022/2023** fiscal year was a challenging period for Parkinson's NSW as we worked hard to achieve a better balance between revenue and expenditure, without impacting delivery of our essential services to the Parkinson's community.

The organisation continued to operate with a very low level of financial support from the NSW Government. Less than **10** percent of our operating budget comes from government grants. An ongoing, multi-year advocacy campaign aims to redress this issue.

Meanwhile, we continue to be heavily dependent on grants from charitable foundations, and hard-won community fundraising from kind families and individuals.

During the year under review, we attracted support from more than **9,700** individuals, companies, and foundations. This resulted in a total of **\$1,643,796** being raised to support the service delivery of Parkinson's NSW – an increase of **3** percent over the previous fiscal year.

However, the bequest revenue component dropped by **62** percent from the previous fiscal year. This was due to delays in the processing of donations left as gifts in wills by Estate Administrators.

Increased cost of living pressures also had a financial impact on the community we support and our organisation as a whole. Households – including those of families impacted by Parkinson's – had to cut discretionary spending by more than **10** percent as rent and mortgage interests costs climbed to record levels. These pressures were also reflected in increased operating costs for both commercial and not-for-profit sectors.

In this environment, Parkinson's NSW as a consolidated entity (including the Parkinson's Trust) declared a loss of **\$1,480,257** – an increase of **22.5** percent over the loss of the previous year.

However, we continued our strategic momentum by continuing to invest in strengthening our infrastructure under a Five-year Strategic Plan with the objective of strengthening administration, the capture and secure sharing of key data which informs our services, and service delivery to the NSW Parkinson's community.

Our Board continued its focus on governance, having made significant strides forward since previous years where it was identified as an area of risk. During the year under review, important gains were made through improved compliance and transparency of reporting by Parkinson's Support Groups.

I would particularly like to thank our Support Groups for their cooperation in addressing these issues, and their continuing engagement with Parkinson's NSW. Feedback from Groups, and their input into decision-making, keeps us focused on the vital support needs of people living with Parkinson's, their caregivers and loved ones.

I also thank our volunteer Board Members for their commitment to the strong governance of Parkinson's NSW. I particularly acknowledge the contributions of past Board Members Janina Jancu, Nicole Schleicher, and Graeme Cartwright.

In closing, I would like to extend my best wishes to our Parkinson's NSW management team and staff who worked closely to grow service delivery across our organisation, while maintaining a delicate balance between financial and human resources – and in particular capping expenditure.

Rachel Tanny
Chair, Parkinson's NSW



Message from the Acting CEO

As noted by the Chair, the ongoing Australian cost of living crisis presented challenging conditions for Parkinson's NSW over the past fiscal year. There were also external delays in processing gifts left in wills, which had the direct result of cutting anticipated bequest revenue by **62** percent.

While we were successful in holding Parkinson's NSW Ltd expenses down by **9** percent year-to-year, reduced fundraising revenue resulted in us declaring a total comprehensive loss of **\$248,129**.

Despite these challenges, our committed staff managed to grow service delivery to the Parkinson's community in **2022/2023**.

We now have **2,000** participants in Parkinson's NSW Support Groups across the state. HealthLine calls were up by **7** percent year-to-year and the number of Counselling sessions grew by **37** percent. Also, our community-based Parkinson's Specialist Nurses collectively added **523** new patients to their lists.

Our strong investment in education continued over the past year. The first two professionally produced online education modules released in the prior year have now upskilled more than **260** Allied Health professionals to equip them to meet the unique needs of people living with Parkinson's.

Work began on a third module during the year under review. It will meet the requirements of physiotherapists, exercise physiologists and fitness professionals who want training on how to tailor exercise programs for the benefit of Parkinson's patients.

Advocacy has also been a key focus area in **2022/2023**. The fact is, essential services delivered by Parkinson's NSW are not adequately supported by Government for current demand, let alone the forecast doubling of global Parkinson's diagnoses by **2040**.

More than **90** percent of Parkinson's NSW operating costs are underwritten by fundraising from generous donors and bequestors in the community.

Our message to Members of Parliament, Government Ministers, and key decision-makers in NSW Health over the past year has been that we require additional funding to build capacity and the sustainability of services. The current reliance on fundraising and bequests is not sustainable over a longer period of time.

Our strategic investments in technology continued during the year under review. We continue to realise the benefits of the technological advancements across the organisation. This commitment provides more efficient work practices, ensures regulatory compliance, supports our advocacy work, and informs growth of services and resources.

I cannot close this report on the fiscal year without thanking every member of our staff for their dedication and resilience as we managed multiple changes during a challenging 12 months.

My thanks also go to Support Group Leadership Teams and participants who have now emerged fully from the post-COVID period. In-person meetings and events have resumed over the past fiscal year while Zoom meetings – first initiated during the COVID lockdowns – have continued in popularity.

Virtual Groups based on social media are also flourishing. I applaud the innovation and flexibility of the Support Group Leadership Teams and participants.

In closing, thank you also to our many supporters, partners and donors who continue to donate time and money generously to the Parkinson's cause. We are looking forward to a more promising year ahead.

Mary Kay Walker
Acting Chief Executive Officer

A year of dynamic change for Support Groups

The **2022/2023** year was one of dynamic changes throughout the Parkinson's NSW Support Group network. Although some Groups closed due to dwindling participation or the leadership needing to step away, there was overall growth in the number of participants in remaining and new Groups.

Support Groups which closed include Ashfield and Berry. New Groups opened in Grenfell and Tumut.

Levels of community engagement and relationship building between Groups in adjacent geographic areas also thrived. The year ended with **63** face-to-face general Support Groups and **13** specialised Caregiver Groups. They supported an estimated **2,000** participants.

In addition there were five ongoing Zoom-based Groups in operation for:

- 👤 Young Onset
- 👤 Carers Chat
- 👤 Support Group Leadership Teams
- 👤 Let's Talk Parkinson's Disease
- 👤 Deep Brain Stimulation

Four ongoing Facebook Groups supported:

- 👤 Caregivers
- 👤 Young Onset
- 👤 Support Groups' Online Community
- 👤 Support Group Leadership Teams

Zoom was also a popular channel for hosting **27** information sessions over the past year. They were open to any Support Group participants who wanted to register (for free) and hear about a range of Parkinson's related topics.

Topics covered in these sessions included:

- 👤 Orthostatic Hypotension
- 👤 Parkinson's Medications
- 👤 Diet and Nutrition
- 👤 Working with Parkinson's
- 👤 Carers Chat: Preventing and Coping with Carer Burnout

Parkinson's Awareness Month in April was a key opportunity for Support Groups to raise awareness within their communities. We again activated the Parkinson's Community Hero campaign which resulted in **14** awards being presented to community members who had assisted and supported **11** Groups over the prior year.

Groups which participated in the Community Hero campaign included:

- 👤 Chinatown Bilingual
- 👤 Coffs Harbour South
- 👤 Inner West
- 👤 Kiama
- 👤 Lismore
- 👤 Maitland
- 👤 Nepean and Blue Mountains
- 👤 Orange
- 👤 Port Macquarie
- 👤 Southern Highlands
- 👤 Young

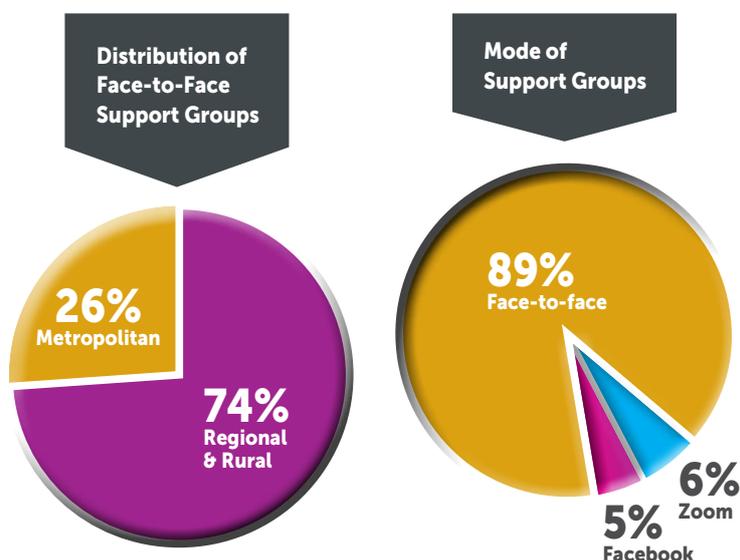
Other community outreach activities over the year included information tables at high foot traffic locations by Central Coast, Griffith, Kiama, Nepean and Blue Mountains, St George, and Tumut Groups. Tumut's effort was particularly notable – three days of community outreach in multiple central locations raised unprecedented local awareness, as well as donations of more than **\$1,900**.

Other notable fundraising efforts included the Goulburn Shakin' Cocktail Party – a much-anticipated annual event – which raised **\$14,500**.

Port Macquarie raised **\$13,000** from a raffle and kind donors to send local Parkinson's Specialist Nurse Jody Lloyd to participate in the World Parkinson Congress in Barcelona.

Maitland Support Group also hosted a successful art exhibition.

National Volunteer Week in May proved an opportunity for Parkinson's NSW to recognise the contributions of our volunteer Support Group Leadership Teams. The Support Group Coordinator visited Mid North Coast Support Groups and hosted a thank-you luncheon. There was also a morning tea hosted for Sydney-based Support Group Leaders.





Evidence-based information from **HealthLine**

The **Parkinson's NSW HealthLine (1800 644 189)** is the single point of contact for people living with Parkinson's, caregivers and family members who require evidence-based advice, information, and connection with essential services.

Over the past year, this service has received **3,285** telephone enquiries – an increase of **7** percent over the prior fiscal year.

The HealthLine is managed by qualified Parkinson's Registered Nurses, each with more than **30** years of experience in supporting people living with neurodegenerative diseases, aged care, community nursing and nurse education.

They are backed by a multi-skilled team which includes Parkinson's-experienced counsellors, an NDIS Advocate, and NDIS Support Coordinators.

The HealthLine can connect callers with an extensive array of resources including:

- U Support Groups (via an in-house Support Group Coordinator)
- U Specialist Movement Disorder Neurologists
- U Community-based Parkinson's Specialist Nurses
- U Counselling for people living with Parkinson's, caregivers, partners, and family
- U Verified providers of Allied Health Services including speech therapists, physiotherapists, occupational therapists, and exercise physiologists and trainers specialising in Parkinson's
- U Parkinson's clinics
- U National Disability Insurance Scheme Advocacy
- U National Disability Insurance Scheme Support Coordination

Conditions people call about:

- U Parkinson's
- U Progressive Supranuclear Palsy (PSP)
- U Multiple System Atrophy (MSA)
- U Corticobasal Degeneration (CBD)

Other enquiries handled by the HealthLine

- U Symptoms U Medications
- U Disease progression U Comorbidities
- U Parkinson's and employment – for both the employee and employer
- U Travel insurance U Holiday planning
- U Accommodation U Disability Pension
- U Aged Care placement U Aged Care Assessment
- U Parkinson's research U Planning hospital stays

Information packs provided by the HealthLine

- U Newly Diagnosed Parkinson's Packs *(available in hard copy and digital formats)*
- U Parkinson's Medication Information
- U Parkinson's Symptom Management
- U Information on Advanced Therapies
- U Information on Assistive Devices

Total Calls	3,285	%
Living with Parkinson's	2,407	73%
Caregivers	739	23%
Other	139	4%



Counselling services expand

While the Counselling team resources remained steady from year to year (at 1.5 Full Time Equivalent staff), delivery of counselling and mental health education sessions increased significantly in **2022/2023**.

The Counsellors delivered **765** individual face-to-face and telephone sessions during the period under review – a **37** percent increase over the prior year. Group counselling sessions totaled **260**, indicating full recovery from the COVID restrictions of previous years.

There was also significant growth in mental health education sessions delivering a total of **63** sessions.

The locations from which services were delivered remained as:

- U War Memorial Hospital
- U Wolper Jewish Hospital
- U Parkinson's NSW headquarters in North Ryde

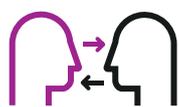
Both Counsellors continued to support people living with Parkinson's, caregivers, couples, and family members.

Typical issues addressed in all modes of counselling over the past year included:

- U Progressive loss due to Parkinson's – for both individuals and participants in Caregiver Support Groups
- U Mourning the passing of people living with Parkinson's
- U Partners and caregivers noticing increases in injury and hospitalisation from falls
- U Anxiety in people living with Parkinson's
- U Empathy fatigue among caregivers
- U Family distress in dealing with a parent with Lewy body dementia who is hallucinating



“ We are so grateful for the first session together with you. After his DBS, we have just been fighting every day and our marriage was at a tipping point. We haven't had so many fights in the past 40 years of our marriage and your support and advice from the session has turned it around completely.
 Parkinson's NSW
 Counselling Client ”



765
Individual
sessions



260
Group
sessions



63
Education
sessions



Donors continued

support despite cost of living



In a year of rapidly increasing cost of living expenses, we are thankful to the many donors who have continued to support our work for the Parkinson's community.

During the past fiscal year we attracted support from **9,726** individuals, companies, and foundations – together making **22,521** financial transactions.

Regular givers contributed **\$259,560** from **1,012** donors in over **8,988** financial transactions.

This resulted in a total of **\$1,643,796** being raised to support the service delivery of Parkinson's NSW. This figure does not include any government funding, which usually comprises less than **10** percent of our operating budget.

While advocacy to Federal and State Governments is ongoing every year, our organisation remains dependent on the generosity of individuals to underwrite the delivery of many essential services to the NSW Parkinson's community.

Services enabled by fundraising include:

- U The **1800 HealthLine** which provides a single point of access to evidence-based information, advice, and support
- U **50** percent of the cost of community-based Parkinson's Specialist Nurses
- U Support Group coordination and information sharing
- U Education for both consumers and healthcare professionals
- U NDIS Advocacy for the **20** percent of the Parkinson's community who are diagnosed with the Young Onset variant of the disease
- U Ongoing consumer and healthcare communications including a comprehensive website, multiple social media outlets, and regular digital and hardcopy publications

During the **2022/2023** fiscal year, we continued our telephone fundraising programs seeking new donors and lottery supporters. With the increase of public scams, we promptly implemented additional safety procedures to ensure donor safety and privacy.

A one-off grant from NSW Health made in the previous financial year enabled us to build a database which enhances our ability to capture in greater detail the work we do with clients and donors. This is now enabling better reporting – particularly when advocating for our Parkinson's community.



Bequests

Organisational revenue in **2022/2023** was impacted by a delay in the processing of donations left as Gifts in Wills by the Estate Administrators.

During the year we benefited from multiple bequests totalling \$382,670. We acknowledge the generosity of the following:

- U Estate of the Late Peter Lloyd Binnie
- U Estate of the Late Margaret Mary Downes
- U Estate of the Late Josephine Simelius
- U Estate of the Late Geoffrey McIntosh
- U Estate of the Late James Francis Chigwidden
- U Estate of the Late Eugene William Rue
- U Estate of the Late Raymond Browning
- U Estate of the Late Christopher John Pickering
- U Estate of the Late John Charles Lonergan

Grants and Submissions

We have been fortunate to have assistance from the Wolper Jewish Hospital Foundation for the past nine years to support our Parkinson's Specialist Counselling Service. This Service has been a great support for people coming to terms with a diagnosis, changes faced due to Parkinson's, and providing their loved ones with a safe space to discuss their concerns with a professional counsellor. The Hospital has also generously provided a space on their premises for our Eastern Suburbs Support Group to meet monthly. Thank you, Wolper.

Grants received from funding partners during the reporting period has enabled us to:

- U Provide Community Education Seminars in regional locations
- U Support the running costs of our HealthLine and regional Nurses
- U Give our carers a well-deserved break
- U Provide social and therapeutic activities for Support Group participants

Vale -To the families and friends of supporters we have lost during the past year, we extend our deepest condolences.





“Life is nearly normal, we never thought we would ever experience normal again. We are very grateful to have your friendship and expertise on the journey.”

Parkinson’s Specialist Nurses deliver community-based services

Parkinson’s NSW Specialist Nurses are based in Coffs Harbour, Port Macquarie, and the Tweed and Goulburn regions. At the time of writing, negotiations were also underway for the placement of more nurses in under-served regions of the State.

The Nurses are based in – and co-funded with – Local Health Districts which provide them with access to regional health facilities, centralised medical records, career development opportunities, and peer support from fellow health professionals.

Parkinson’s Specialist Nurses deliver nursing care and community resources by:

- ✔ Providing professional person-centred care and support through clinics, home visits and telemedicine
- ✔ Undertaking medical assessments, developing medical plans, and liaising with GPs and Neurologists
- ✔ Connecting people living with Parkinson’s with Allied Health
- ✔ Providing peer contact and community access for people who may not have the confidence to participate
- ✔ Ongoing research opportunities including palliative care, advanced therapies, and non-motor symptoms management
- ✔ Providing clinical leadership to other Parkinson’s Nurses

During **2022/2023**, these Nurses had **2,564** patients on their lists, including **523** new patients.

They conducted **412** nurse-patient consultations in clinics as well as **213** consultations with patients in hospital. Our Nurses also made **322** home visits and participated in **279** neurological consultations.

Nurses also supported **710** device-assisted therapies including Deep Brain Stimulation (DBS) and Duodopa and Apomorphine devices. They covered **16,192** kilometres of travel over the year in support of their Parkinson’s communities.

They also participated in **45** telehealth consultations. Movement Disorder Neurologists providing these consultations were based in the St Vincent’s Body Movement Clinic, Macquarie University Hospital, Integrated Neurology Clinic, John Hunter Hospital, and Westmead Hospital.



523 new patients



412 clinic consultations



322 home visits



279 neurological consultations



710 device-assisted therapies supported



45 telehealth consultations



16,192 kilometres travelled

NDIS services are making a difference

When a diagnosis of Parkinson's disease is received before the age of 65, eligibility for the National Disability Insurance Scheme (NDIS) can make all the difference. The intended benefit of NDIS funding is to lessen the impact of a person's impairment upon their functional capacity and quality of life.

The right support from all sources – including those funded by the NDIS – particularly in the earlier stages of the disease, can reduce and or delay the impact of Parkinson's related impairments by building physical, emotional, and environmental resilience and coping mechanisms and strategies.

Funded supports for the tasks of daily living can keep people with Parkinson's in employment, active and engaged in family life and included in and contributing to their community.

To be eligible for the NDIS, evidence needs to show that the applicant has a physical, intellectual, cognitive, neurological, visual, hearing, or psychosocial impairment that:

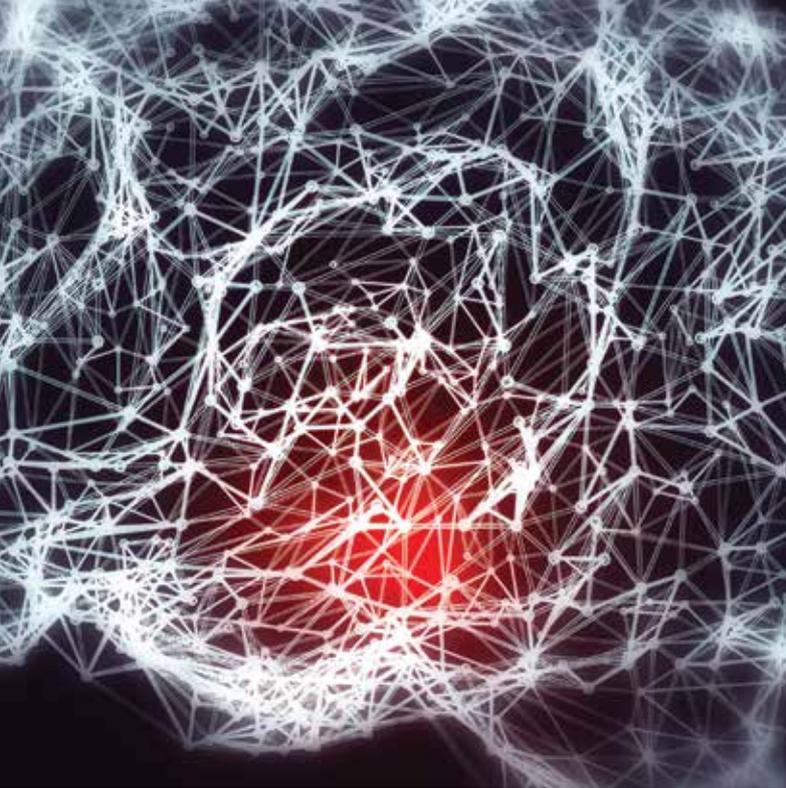
- U Is (or is likely to be) permanent
- U Substantially reduces their 'functional capacity' in one or more of the following areas: mobility, communication, social interaction, self-management, learning and self-care
- U Restricts their ability to participate in work/study, engage with peers and/or interact with their wider community (i.e. has a clear social and/or economic impact)
- U Requires lifelong NDIS support

The NDIS provides an essential source of support for the 20 percent of the Parkinson's community who are diagnosed with the Young Onset variant of the disease.



“ Thank you everyone for the great work you do for me, I really do appreciate it. ”

- NDIS Support Coordination Client



“ We appreciate all the support you’ve given us so far, your clear communication, proactiveness and for holding space for mum and ensuring she is on the journey. ”

- Family member of Parkinson’s NSW Support Coordination client

NDIS Advocacy

During **2022/2023**, Parkinson’s NDIS Advocates assisted **113** people with Parkinson’s apply for NDIS eligibility. Of those, **48** were successful in obtaining NDIS eligibility. The remaining people are either gathering their documentation, re-submitting, or waiting for their application to be assessed.

All successful applicants have since met with a NDIS Planner, often with the additional support of our Advocate. At the meeting, an individualised package of funding to purchase reasonable and necessary supports is discussed.

Parkinson’s NSW NDIS Advocacy service continues to be in high demand. At no cost to the applicant, the Advocate supports each person and their circle of supporters to gather the evidence needed to demonstrate eligibility.

Highly valued since its inception, Parkinson’s NSW continues to raise the funds for this service resulting in a total of **642** people being supported through the NDIS application process over the past five years.

A Parkinson’s Specialist Support Coordination Service

Parkinson’s NSW first gained NDIS Registration as an approved provider in **2019**. In line with legislated compliance standards in **2023** we successfully completed the rigorous reassessment audit, gaining full NDIS registration status in all categories for a further three years.

While maintaining NDIS registration is a demanding, financial- and resource-heavy activity, Parkinson’s NSW is committed to ensuring people with Parkinson’s selecting our Support Coordination service can have confidence knowing we meet the NDIS standards as outlined in the Quality and Safeguarding Framework.

That includes, at a minimum, having mechanisms in place to identify systemic strengths and weakness, respond to complaints and ideas for improvement and maintain the quality and resourcefulness of our workforce.

Post-Covid, and in a tight labour market, maintaining and replenishing the Support Coordination team to meet growing demand for our specialist service has been a challenge. As a new professional vocation (created specifically for the NDIS), experienced Support Coordinators are in very high demand. In such a climate the engagement of two new, experienced full-time Coordinators has bolstered and reinvigorated the team.

Throughout the year the organisation has navigated shifting NDIS regulatory requirements, balancing increasing demand against constrained resources, all the while endeavoring to retain quality of service.

With no CPI indexation and no increase by the National Disability Insurance Agency (NDIA) in the claimable price per hour for the third year, Support Coordination is considered by all providers to be underfunded. With a commitment to delivering a specialist service for people living with Parkinson’s, and to continuity of service, Parkinson’s NSW has continued to invest its limited resources in this service.

Digital & Marketing team supports Parkinson's community

Pitch in for Parkinson's

Pitch in for Parkinson's is the organisation's digital awareness-building and fundraising campaign. It was launched in **2022** following Australia's emergence from the COVID restrictions and successfully continued throughout **2022/2023**.

The basic premise of Pitch in for Parkinson's is: However you choose to Pitch In, you will be helping people living with Parkinson's.

Participants have a variety of choices including:

- ✔ Creating their own personalised fundraising page using easy tools provided via the Parkinson's NSW website.
- ✔ Sharing their fundraising updates via digital and social media, and phone.
- ✔ Fundraising on special occasions like birthdays and family celebrations, inviting donations in lieu of gifts.
- ✔ Getting Active for Parkinson's by setting themselves a personal challenge and inviting sponsorship of their achievements – or piggybacking on existing challenges and events like community fun-runs. This group of activities also links in with the fact that exercise is second only to medication in effectiveness of slowing the progress of Parkinson's.
- ✔ Donations in memory of a loved one – including using online tools to develop a personalised tribute page or organising a donation collection in lieu of flowers at a funeral service.



The next phase of the Pitch in Campaign is already underway for the coming fiscal year with the first virtually-managed series of events being The Great Parkinson's Tea Party – again with tools being provided for individuals and groups to fundraise their way under this umbrella theme.

However participants choose to fundraise, their support plays a vital role in enabling this organisation to sustain and expand its life-enhancing services to people living with Parkinson's across New South Wales.

Funds raised directly support community-based Parkinson's Specialist Nurses, specialised Parkinson's counsellors, information and education sessions, and the **1800 HealthLine** which provides a single point of contact for evidence-based advice and connection with essential services.

Pilgrimage for Parkinson's

Mark Peterson from country New South Wales took the Pitch In for Parkinson's challenge more than one step further – he journeyed to Japan in April 2023 to walk the historic Shikoku 88 Temple O-Henro pilgrimage. This was his fundraising physical and spiritual challenge.

The route took in 88 Buddhist temples along a 1200-kilometre path. Mark walked all the way, taking more than six weeks.

"My grandfather had Parkinson's," he says. "When I was a teen, I watched him progressing through the various stages. Now I know more and more older people with it. I have seen the strain on families and carers. I see the difficulties that it causes in their lives and how fantastic the Support Groups are."

"I'm not Buddhist or religious but this pilgrimage is often done with prayers for healing at each temple," says Mark. "That seemed very appropriate."



Emily's SkiErg half marathon

Emily Benson decided to Pitch in for Parkinson's by setting herself a formidable physical challenge – to complete the distance of a half-marathon on a SkiErg machine.

A SkiErg is a piece of gym equipment that works the arms, legs, and core muscles. It was originally designed as a cross-country skiing training tool for Nordic skiers to build and tone their bodies.

Emily set her fundraising goal for Parkinson's NSW at \$500 but more than doubled that by attracting donations of \$1,143 – an outstanding, both physically and financially!



Digital fundraising campaign finalist in industry awards

The Parkinson's NSW Step Up for Parkinson's Challenge digital fundraising campaign was listed as a finalist in the Fundraising Institute of Australia's 2023 Awards for Excellence in Fundraising.

Step Up was recognised as an excellent 'pivot campaign' – an initiative which pivoted in response to a critical fundraising challenge. The challenge faced by Parkinson's NSW was to pivot from its historical Parkinson's Walk in the Park event to a more flexible, accessible, virtual version which was more in keeping with the post-COVID environment.

The Step Up for Parkinson's Facebook Group tells the story:

- Membership of the Facebook Group grew **151%** from May **2022** to June **2023**
- The interaction and engagement of our community of 'Steppers' elevated this year with more conversations, sharing of images and progress
- Mutual support and encouragement during the Step Up journey were a highlight of this year's campaign

Thank you Parkinsons NSW for the opportunity to take part in Step Up and I am privileged to have helped in a small way. Great to have met (online) some other like wonderful minded people. - Robyn

This has been an amazing journey!!! I am so thankful for this opportunity & for all the wonderful work of Parkinson's NSW & Step up for Parkinson's from the bottom of my heart & soles of my feet - thank you xxoo Margaret

Day 31 and that's a wrap!

2km treadmill run

4km bike and 1 hour of weights +

\$1900 raised (\$900 over target)

and 165 km on the odometer

To my reason behind this.... I LOVE you Daddy and I hope that my tiny contribution combines with all the efforts from this FABULOUS community of PD Fighters of the Good Fight to make a real difference.

To all the other participants in our Team, thank you for YOUR contribution to this incredibly worthy cause and to your friendship and support on our journey together. I've loved seeing your posts and celebrating your achievements.

Wishing everyone and their loved ones a ll the very best.

Love, thanks and bye for now....

Nadine



"Joining the Challenge meant that my husband would be disclosing his diagnosis for the first time to our wider group of family and friends. Doing that marked a level of acceptance about his condition that until then he had been grappling with.

"The support and positive response to his diagnosis and participating in the challenge was warm and strong. He set goals each day, interacted with people on the Facebook group, took up bike riding

again and enjoyed the camaraderie of other people in similar situations.

"Even though the Challenge is focused on setting goals, motivation and raising much-needed funds, it also brought a wider sweep of benefits such as acceptance, self-esteem, improved fitness, and the pleasure of being able to give back."

Laurine Croasdale



Extending our digital reach

The Parkinson's NSW website continues to attract new visitors, not just from New South Wales but also nationally and globally – including the United States, India, Canada, United Kingdom, Ireland, New Zealand, and the Philippines.

We are a trusted source of information, advice, and support for Parkinson's. This is reflected in our online metrics:



38.7% Increase in news readership on website



65% Increase in unique page views



15% Increase in new visitors to website

We also reached **17%** more people through social media channels. Close to **1.5 million** people were reached across all online touchpoints.

Digital communications

Subscription to our digital communications continues to rise with more than **2,400** new subscribers and a retention rate of **96%**.

We also logged **71,649** minutes of video views.



Step Up for Parkinson's 2023 participants

Port Macquarie Support Group held a high tea at Bago winery



Chinatown Support Group Parkinson's Community Hero presentation to 'Way in Network'

Coffs Harbour Support Groups joined forces to hold a morning tea and present their Parkinson's Community Hero

Tumut Support Group went all out with three information stands during Parkinson's Awareness month in April.



Education programs innovate and accelerate

As Australia had fully emerged from the second round of COVID-19 restrictions, the Education team was able to ramp up its face-to-face learning opportunities once again for consumers and healthcare professionals.

During the prior fiscal year, Parkinson's NSW developed and launched two online education modules to provide more people with safer and more convenient access to learning about Parkinson's.

Module 1: Introduction to Parkinson's and **Module 2:** Best Care Practices for Parkinson's were officially launched at Parliament House Sydney early in calendar **2022**.

Since their launch, these online learning modules have upskilled more than **260** Allied Health professionals. This in turn permitted Parkinson's NSW to identify and recommend more practitioners as preferred providers for people living with Parkinson's.

During **2022/2023** work began on **Module 3:** Exercise, under the guidance of the Education Advisory Committee.

This Module emphasises the benefits of exercise for people diagnosed with Parkinson's. It is being developed for physiotherapists, exercise physiologists and fitness professionals to enable them to understand and guide appropriate exercise and training for the benefit of people living with Parkinson's.

Module 3 is on track for launch in calendar **2024**.

Feedback from participants in all online learning to date has been very positive with many recommending the modules to colleagues and friends. Following are examples of feedback on what participants found most valuable about their learning experience:

"Greater knowledge of the vastness of Parkinson's symptoms e.g. constipation, loss of smell etc. These aren't talked about much in other training I have completed."

"Understanding treatments available for Parkinson's and learning about periods of medication effectiveness throughout the day. Also practical strategies to support a person through their motor difficulties."

"Each person's Parkinson's is unique to them and they need to be individually supported with interventions that work for them".

"Parkinson's is a complex condition to treat, it presents differently in each individual and requires a whole team of specialists to address the multiple ways it manifests and affects the body, mind, voice and quality of life."

Over the past year, several members of the Education Advisory Committee have stepped down including Associate Professor Marguerite Bramble, Clinical Nurse Consultant Vince Carroll, Speech Pathologist Colleen Kerr, and Administrative Specialist Sarah Swarbrick.

Parkinson's NSW thanks all of these members for their professional contributions and we wish them well in their future endeavours.

Quality Assurance

Responsibility for Quality Assurance was added to the role of the Education Manager during the year under review.

Quality Assurance sits with Education in order to manage the provision of evidenced-based, quality-assured education and training programs which adhere to Parkinson's NSW Quality Standards. The development and implementation of quality standards improves processes and procedures to ensure best practice for Parkinson's NSW.

Quality Assurance involves setting up a quality management system that is the foundation for building standards, guidelines, and procedures to prevent quality issues and maintain the integrity of the service we deliver at Parkinson's NSW.



Delivery of information & education across NSW

- U Parkinson's NSW continued to work with pharmaceutical companies to deliver education to General Practitioners and other healthcare professionals by conducting five seminars during 2022/2023. There was a steady increase in participation following the lifting of COVID restrictions.
- U Seven in-person seminars were held for Aged Care support workers and nurses in facilities at Orange, Bathurst, Clement Park, Glenmore Park, and Byron Bay.
- U Ten Newly Diagnosed seminars were held for people who have been diagnosed with Parkinson's in the past two years.
- U Five face-to-face Information Seminars were held for people living with Parkinson's, caregivers and other interested members of the community including Allied Health professionals.



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.



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 15 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 – Graeme Cartwright

Graeme Cartwright has over 20 years of experience in managing Australian share portfolios for industry super funds and governments. He has expertise in finance, governance, compliance, and audit. Graeme was appointed as a Non-Executive Director to the Board of Parkinson's NSW in February 2022 until November 2022.



Director – Andy Esteban

Andy Esteban was appointed to the Board of Parkinson's NSW as a Director 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 – Janina Jancu

Janina Jancu was appointed to the Board of Parkinson's NSW in November 2019. She has more than 30 years of experience as a senior executive in the not-for-profit, government, and corporate sectors. A qualified lawyer, she brings extensive experience in the areas of risk management and corporate governance.



Director – Margaret Scott

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.



Director – Nicole Schleicher

Nicole Schleicher was appointed to the Board of Parkinson's NSW in November 2019. She has more than 20 years of experience in key roles within the not-for-profit sector. Nicole has held program development, operational and policy management roles with The Smith Family, Baptist Community Services NSW, Wesley Mission, and The Benevolent Society. She is currently General Manager of National Services for RedKite. Nicole left the Board in October 2022.



Roy Wakelin-King, AM

Roy Wakelin-King has held very senior positions across a range of government, private sector, and not-for-profit organisations. He has extensive experience in executive leadership, with a highly successful career in transport and logistics, delivering multi-billion-dollar services and infrastructure programs, particularly for communities in regional NSW.

Board Meeting attendance record 2022/2023:

Name	July 22	Sep 22	AGM	Dec 22	Feb 23	Mar 23	May 23
Graeme Cartwright	☑	☑	☑	N/A	N/A	N/A	N/A
Andy Esteban	N/A	N/A	N/A	N/A	N/A	☑	☑
Janina Jancu	Approved Leave	☑	☑	☑	☑	☑	N/A
Nicole Schleicher	☑	☑	N/A	N/A	N/A	N/A	N/A
Steve Schiemer	☑	☑	☑	☑	☑	☑	☑
Margaret Scott	☑	Approved Leave	☑	☑	☑	☑	☑
Rachel Tanny	☑	☑	☑	☑	☑	☑	☑
Roy Wakelin-King, AM	☑	☑	☑	☑	☑	☑	☑

Parkinson's NSW thanks Nicole Schleicher, Janina Jancu, and Graeme Cartwright for their service on the Board.



Advocacy for **funding and sustainability**

The Key Issue

The essential services delivered by Parkinson's NSW are not adequately supported by Government for current demand, let alone the forecast doubling of global Parkinson's diagnoses by 2040.

More than 90 percent of Parkinson's NSW operating costs are underwritten by fundraising from the community. If this is to continue, further investment is also required to boost fundraising activities.

Parkinson's NSW expenditure on direct service provision exceeds \$1.2 million per year. Annual funding support is requested from the State Government in line with the prevalence of Parkinson's, growing demand for services, and a decline in neurological services in rural areas.

Focus on sustainability

During 2022/2023, the advocacy efforts of Parkinson's NSW continued to focus on the sustainability of the organisation and its ability to continue delivering vital community supports at historically high rates.

Strategy and submission development were undertaken with the pro bono support of leading public policy and government engagement consultancy GRACosway. This resulted in a comprehensive 2022/2023 pre-Budget submission for funding to the NSW Minister for Health.

A letter writing campaign was also conducted, reaching out to Members of Parliament and key decision-makers in NSW Health across the state.

Parkinson's NSW Support Groups which expressed a desire to approach their local Members of Parliament were also provided with assistance to write appropriate requests and talking points for meetings. This ensured consistency of messaging across the various levels of advocacy undertaken during the year.

This approach was particularly effective in Goulburn where a joint approach to the Local Health District and MP Wendy Tuckerman enlisted support for the placement of a new Parkinson's Specialist Nurse in that electorate.

New alliances

During the year under review, Parkinson's NSW also formed a new and formal alliance with Parkinson's Victoria (now known as Fight Parkinson's).

As a result, a joint pre-Budget submission was developed for the Australian Government Department of Health & Aged Care. This advocated for increased spending on Parkinson's support both in the community – particularly in regional and rural areas – and within the Aged Care system.

We are continuing to explore new alliances with other organisations with shared objectives and ideals, joint advocacy programs, and partnerships with Government entities – including but not limited to Local Health Districts (LHDs) and Primary Health Networks (PHNs).

“ Thank you for our session with you yesterday. It helped us a great deal to remain positive and to take the doctor's comments in balance with our own feelings about how I am going.

I must admit that before you took up this role, I wondered how a Parkinson's nurse would be helpful. After we had the session with you yesterday, I now realise how important it is to have a professional at hand to deal with problems as they arise and thus stop them from escalating.”

- Person living with Parkinson's

“ My satisfaction in the leadership role comes from the joy of having a social and happy environment for people living with Parkinson's and their carers. New friendships are formed and everyone is there for each other.”

- Metropolitan Support Group Leader

“ Thanks again for your gracious response to me when I missed appointment. I was mortified! It's not who I am. Especially since you are such a good Support Coordinator!”

- NDIS Support Coordination Client

“ I just wanted to acknowledge and thank you again for your wonderful work in the development of the partnership with Western Sydney Local Health District – and Westmead Hospital – in particular, regarding the Movement Disorders Service that was launched in Coffs Harbour last week.

The benefits for our community are significant, and I am aware that you and your colleagues have been a driving force to see this partnership formalised – well done and congratulations.

The Launch itself was so thoughtfully considered and was a celebration of the sometimes-small things that can make such a difference to our Parkinson's patients and their families. ”

- Lydia Dennett, Acting Chief Executive
Mid-North Coast Local Health District

“ Thanks! You made the whole procedure [face-to-face plan reassessment] easy and stressless. We appreciate your input and chat. ”

- NDIS Support
Coordination Client

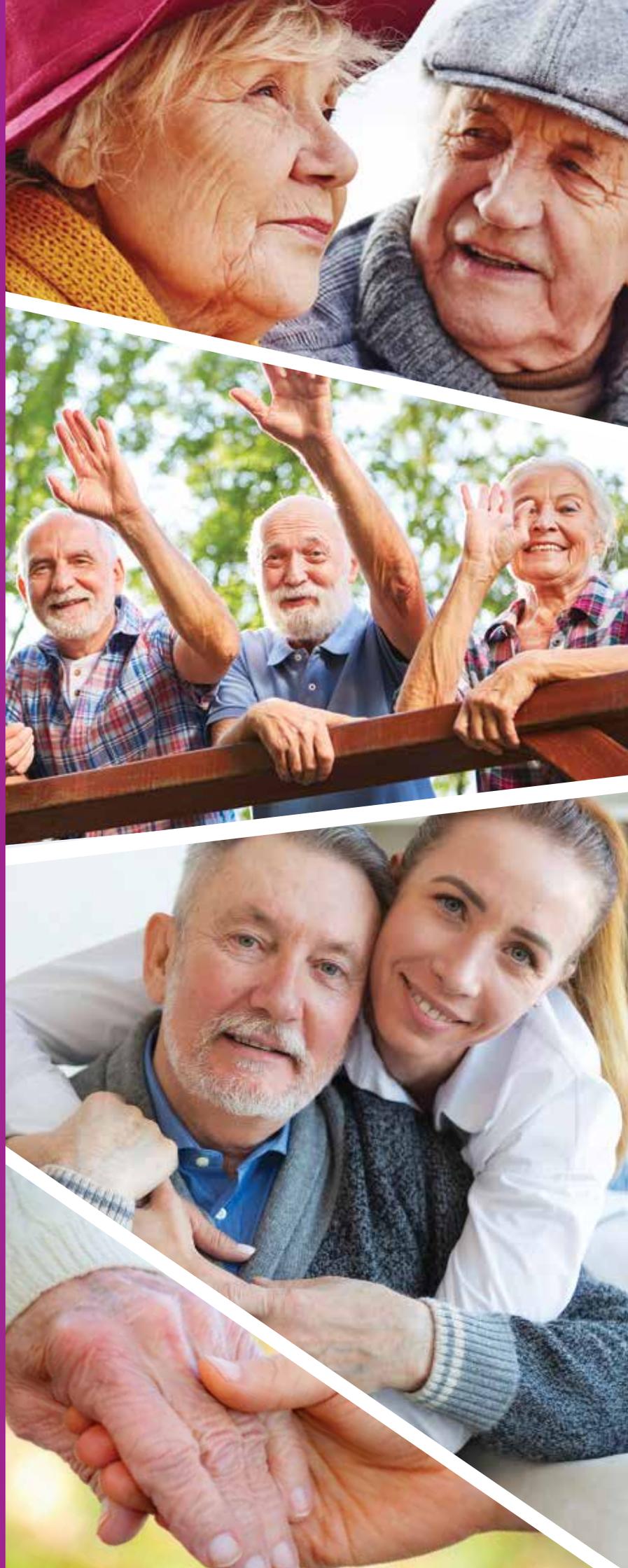
“ Can't fault the service. The nurse is terrific and follows everything up and is very helpful. ”

- Person living
with Parkinson's

“ Our Support Group makes our journey more manageable. Being in a Support Group, we see people going through so many similar challenges. This is very reassuring. My husband was diagnosed in 2020 and we joined the Support Group for him to communicate with like-minded people. During that time the information and support we received has been exceptional.

I volunteered to take on the Leadership role in March 2021. I personally gain self-satisfaction from helping members and making sure that they are all feel supported. ”

- Rural Support Group Leader



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