

In this together

2018/19: A year of growth, change and investment

Our Vision

Quality of life now, as we work towards a community free of Parkinson's.

Our Mission

To enhance the quality of life of people living with Parkinson's.

Our Purpose

To connect people living with Parkinson's with life-enhancing support and services.

How we are delivering on our Vision, Mission and Purpose.

In 2018-19 the Board of Parkinson's NSW put in place a clear and measurable three-year strategic plan. Its objective was to position our organisation for stability and growth amid the significant ongoing reforms taking place in the health, aged care and wellbeing sectors.

This document reports on our progress against the strategic plan, broken down by our six pillars of operations.

Our new skills-based Board remains committed to best practice governance, financial planning and management – and above all, the sustainability of Parkinson's NSW.

This includes sustainability of finance, infrastructure, and the provision of evidence-based support and services for the Parkinson's community.

Over the past year, we made progress toward financial sustainability by diversifying our revenue streams. One key project was undertaking the complex process of applying to become a Registered Service Provider under the National Disability Insurance Scheme (NDIS).

Our registration was confirmed at the end of 2018-19, positioning us to begin marketing Parkinson's-specific services to eligible people under the NDIS at the beginning of the new fiscal year.

We also began monetising some of our education offerings by tapping into the new demand for training created in the aged care sector following the introduction of new Quality Standards by the Aged Care Quality and Safety Commission.

During the year we strengthened our multi-disciplinary team with the addition of one counsellor, the addition of a Support Group Coordinator with a strong background in aged care, and the redeployment of our on-staff Social Worker to the team created to deliver NDIS-funded services.

We also streamlined and refocused our InfoLine team of Registered Parkinson's Nurses, and added one more community-based Parkinson's Specialist Nurse in Port Macquarie – co-funded with the Mid North Coast Local Health District.

In the coming year we will add more Allied Health skills to our team to deliver billable assessments and therapies to people living with Parkinson's who are eligible for the NDIS.

Last year we began an advocacy program to seek funding from State and Federal Governments for additional community-based Parkinson's Specialist Nurses.

Advocacy will be broadened and accelerated in the coming year to seek additional funding which will also strengthen the viability of other essential services such as InfoLine and Education.

All of these activities will further our delivery of results under the strategic plan, and will be undertaken in consultation with the Parkinson's community.



Organisational development

In line with the organisational development plan outlined in the 2017-18 edition of this brochure, over the past year we implemented the Board Skills Matrix that was developed by an independent consultant.

The Matrix was developed in line with the recommendations of the 2017 ASX Corporate Governance Council. It provided an independent assessment of the skills and experience each candidate could bring to the new Board of Parkinson's NSW following an election.

Outcomes

Following the adoption of a new Constitution requiring a spill of the Board and an open election for all six seats, an election was held under the supervision of an independent outside provider – the Australian Election Company.

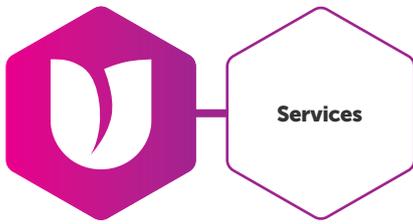
The outcome of the election was a new skills-based Board able to play an active role in governance, engagement with the Parkinson's community and advocacy in support of the Mission and Purpose of Parkinson's NSW.

Our thanks also go to three Directors who ended their terms during the year – former Vice President Professor Bryce Vissel, Director Lawrence Gray and Director Colin Hall.

Future plans

- Maintain a mix of business and sector-specific competencies on the Board, along with representation of the Parkinson's community.
- Further strengthen Board succession, retention and decision-making processes.
- Involve more Board Members in advocacy and community outreach programs.





Services

In 2017-18, Parkinson's NSW commissioned the Building for the Future review of three key services – InfoLine, Education and Counselling.

Based on the findings and recommendations of that review, work over the past year has focused on strengthening and expanding these services in a sustainable manner.

Outcomes

A new team and service delivery area called PNSW Connect launched at the beginning of the year to begin the complex and challenging process of applying to become a Registered Service Provider under the National Disability Insurance Scheme (NDIS).

The team's year-long effort was successful and Parkinson's NSW begins the new fiscal year with an additional revenue stream.

InfoLine

During the year, the InfoLine team of Parkinson's Registered Nurses handled 9,785 enquiries via email and calls to 1800 644 189.

Education Seminars

During the year, 24 education seminars were arranged, attracting more than 850 people living with Parkinson's and carers, people newly diagnosed with Parkinson's and their carers, aged care support staff and General Practitioners.

Community-based Parkinson's Specialist Nurses

Our community-based Parkinson's Specialist Nurses performed more than 2,350 consultations during the year. New referrals totalled 334.

164 NDIS applicants supported

The Parkinson's NSW NDIS Nurse Advocate supported 156 people living with Parkinson's through their journey as they applied for funding from the National Disability Insurance Scheme. The Parkinson's Specialist Nurse in Coffs Harbour supported another eight NDIS applications.

Counselling

The number of telephone counselling sessions conducted during the year grew to 217, and a further 296 face-to-face sessions took place.

The Parkinson's NSW Counsellor works from two locations in Sydney – War Memorial Hospital and Wolper Jewish Hospital. She supports people living with Parkinson's, people who are newly diagnosed, carers and family members.

Telephone counselling is accessed by people living in metropolitan, regional and rural areas. The demand for rural counselling support increased over the past year.



Community engagement

Parkinson's NSW engages with the community through its 70 Support Groups, four Carer Groups, education seminars and the annual Unity Walk in the Park event.

Outcomes

Our Support Groups engaged with 1,400 participants in more than 270 meetings and community events over the past year.

An average of 9 Parkinson's NSW staff attended meetings each month throughout the state.

We also held a Support Group Annual Conference in Sydney which attracted more than 100 participants from 46 Groups.

World Parkinson's Day

Parkinson's NSW staff and 24 Support Groups joined in 33 activities that built awareness and raised funds on World Parkinson's Day and the following Parkinson's Awareness Month.

Unity Walk in the Park

The 2018 Unity Walk in the Park attracted more than 1,300 participants in Sydney and Wollongong and – for the first time – nine regional and rural locations.

It involved over 70 volunteers who contributed more than 350 hours of their time, and more than 30 sponsors. More than 2,000 donations were made.

50-50 Raffle

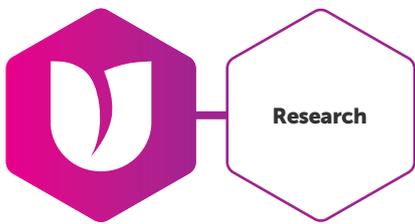
During the year, the Marketing & Digital and Fundraising teams worked together to trial a new concept raffle.

50-50 Raffle tickets were sold through a secure, purpose-built web site with the 'pot' split equally between the winner and Parkinson's NSW.

The first campaign was run over a 7-day period and the Raffle sold out in just 5 days. It was found that 40 percent of the top purchasers had never donated to Parkinson's NSW before.

This online Raffle was very effective at engaging non-traditional donors and further building the organisation's digital profile.





Research

The purpose of Parkinson's NSW is to connect people living with Parkinson's with life-enhancing support and services. Our focus is on supporting research that supports people now, as we hopefully advance towards a cure.

Outcomes

Over the past year, Parkinson's NSW funded two distinct areas of research:

- Grants totalling \$300,000 to four prominent researchers working on projects that enhance the quality of life of people living with Parkinson's.
- A study by Charles Sturt University on the benefits and potential cost savings of the community-based Parkinson's Specialist Nurse model.

This research has global significance and was recognised for its promising progress to date with an invitation to present at the World Parkinson Congress in Kyoto in June 2019.

Stage 1 of the research was a comprehensive literature review. Stage 2 involved an analysis of data and outcomes achieved by the Parkinson's NSW nurse embedded in the Coffs Harbour community.

This stage also measured the potential cost-savings to Government through this decentralised approach to supporting Parkinson's patients.

The third stage of the research project involved interviewing Parkinson's NSW Support Group participants in regional and rural areas of NSW. A final report will be published in the first fiscal quarter of 2019-20.



Sustainability

Less than 10 percent of Parkinson's NSW funding comes from government grants. Therefore, ongoing fundraising is essential to enable the uninterrupted delivery of services in support of the NSW Parkinson's community.

Outcomes

During the year under review, Parkinson's NSW became a Registered Service Provider of the National Disability Insurance (NDIS).

This means that in the coming fiscal year, we will begin delivering services to people living with Parkinson's who have been funded by the NDIS.

The National Disability Insurance Agency fixes the prices of these services and funding is tied to the individual, not the organisation.

The fees charged by Parkinson's NSW are a small supplemental source of funding, but the organisation will continue to primarily depend on donations to fund its services.

Fundraising outcomes over the past year included:

- More than **9,000** donations received
- **\$2,111,099** donated
- **\$69,896** donated by friends and organisations through individual fundraising
- **2,634** monthly donations made through regular giving program
- **\$521,564** was gifted by **10** testators through gifts in wills



Brand awareness

Branding and marketing are essential tools for raising awareness of Parkinson's and the vital services delivered by Parkinson's NSW.

We do this via our Support Groups, publications, digital and social media, and special events such as Unity Walk in the park.

Outcomes

Publications

The InTouch newsletter for Support Group participants throughout NSW was redesigned during the past year. Its content was also expanded and updated to better meet the needs of its audience.

Stand by Me continued to be our flagship publication for all stakeholders.

Social Media

Social media and the Parkinson's NSW web site have recorded significant growth.

There was 480 percent organic growth in email subscriptions over the fiscal year, with a retention rate of 95 percent.

Social channels also recorded significant growth:

Facebook	38%
Instagram	66%
LinkedIn	57%

During April we also launched a compelling video titled Dear Family and Friends which was created by the Parkinson's NSW Marketing & Digital Team.

Its objective was to raise awareness of Parkinson's by showing viewers what living with the disease really looks like.

Support Group participants Joanne, David, Robert, Dianne, James and Jane were shown looking wordlessly at the camera as key phrases from the famous Dear Family and Friends letter scrolled across the screen.

It made significant impact and was the single most popular Facebook post in April, delivering:

- Organic reach of 36,400 (the number of individual Facebook feeds it appeared on)
- 5,700 engagements (how many people liked or shared the video, or left a comment)

The Dear Family and Friends video can be viewed on Facebook or YouTube here:

www.facebook.com/parkinsonsnsw/videos/416747442460525/

<https://www.youtube.com/watch?v=B4QHmRgL1RA>



📍 Macquarie Hospital Building 17, 51 Wicks Road, North Ryde NSW 2113
☎ 1800 644 189 ✉ pnsw@parkinsonsnsw.org.au 🌐 www.parkinsonsnsw.org.au
📘 www.facebook.com/parkinsonsnsw 📷 www.instagram.com/parkinsons_nsw