

# In this together

Six pillars supporting the Parkinson's NSW  
community 2017/18 and into the future

# Our Vision

A community free of Parkinson's

# Our Mission

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

## How we will deliver on our Vision and Mission

Delivering on our Vision and Mission will require a clear, concise and actionable strategic plan. That's what this document is about.

The health, aged-care and wellbeing sectors providing support for people living with Parkinson's are now undergoing their most significant reforms since the introduction of Medicare in 1984.

Amid these challenges and changes, we are committed to maintaining a robust and sustainable business model. Sustainability of finances, infrastructure, and evidence-based resources around support for people living with Parkinson's and their carers are all keys in delivering on our mission.

Our Board is fully committed to best practice governance, financial planning and management. We are setting in place new processes to take Parkinson's NSW forward as an efficient, sustainable, best-practice-peak-body organisation supporting the Parkinson's community.

We are diversifying our revenue sources and implementing more efficient business practices to drive improved outcomes from existing resources.

We are expanding our multi-disciplinary teams to better support people experiencing Parkinson's within their communities.

We already have on staff a social worker, exercise physiologist, counsellors, registered nurses with Parkinson's expertise, and experts in education for people living with Parkinson's, and the aged-care, primary and allied health professionals who support them.

Within the next 18 months we plan further additions to our team including a speech pathologist, physiotherapist and occupational therapist, as well as additional neurological nurses in regional areas.

These are examples of how we will implement the new Parkinson's NSW strategic plan. This document shows pillar-by-pillar, step-by-step how we will execute on our strategy with the guidance of the Board, the energy of our staff, and in consultation with the Parkinson's community.



# Organisational development

In the past year we revised our organisational structure to ensure we have the right governance and structure, the right people and the appropriate infrastructure to support and advocate for the Parkinson's community.

We engaged an external consultant to develop a Board Skills Matrix to align with our five-year strategic plan.

## Outcomes:

The Board Skills Matrix will ensure we have directors who have appropriate skills, diversity and expertise.

It will also assist our Board with various governance processes, including skills alignment, director succession planning and nomination processes, board inductions and board evaluations.

## Future plans:

- To maintain a strategic mix of sector-specific and universal competencies on the Board
- To further strengthen Board succession, renewal, retention and decision-making processes
- To achieve an appropriate balance between Board Members' roles in governance, engagement with the Parkinson's community and advocacy in support of our Mission.



Board members Colin Hall and Rodney Chaplin



## Services

We deliver services to the Parkinson's community including information, counselling and specialist neurological nurses. We also provide referral pathways to specialists, allied health professionals and other relevant services.

### Outcomes:

We commissioned a Building for the Future review of our InfoLine, Counselling and Education services. This review identified underlying issues, challenges and risks along with a number of key recommendations.

We have a new Parkinson's specialist nursing position based at Port Macquarie commencing in October 2018. Negotiations are also underway for an additional two nursing placements in Tweed Heads and Wagga.

Specialist Parkinson's nurse positions are already resourced in Coffs Harbour, Shoalhaven and Orange. We are negotiating embedding Shoalhaven and Orange into the respective local health districts.

We delivered 18 education seminars across NSW, a 350 per cent increase from the previous year, with 1,250 attendees.

We have provided face-to-face counselling for 615 people with 91 phone assistance sessions and taken 6,650 first-point-of-contact InfoLine calls.

Our Funded Support Advisor has begun providing assistance for under-65s living with Parkinson's to apply for National Disability Insurance Scheme (NDIS) packages, and over-65s for My Aged Care packages.

We held over 200 exercise activities across the state, including 20 new classes. We presented at six seminars and awarded ten scholarships for Parkinson's-specific exercise training.

### Future plans:

- To manage and promote education seminars to maximise effectiveness and opportunities for participation
- To integrate InfoLine and counselling services to better utilise resources
- To increase assistance for people living with Parkinson's in applying for NDIS and My Aged Care packages.



From left: InfoLine Parkinson's specialist team Cathy, Julie and Margi



## Community engagement

We engage with the community through our 75-plus Parkinson's NSW support groups, a variety of education seminars and other special events such as the annual Unity Walk in the Park.

### Outcomes:

In the past year, an additional four support groups were formed, bringing the total number to more than 75 across NSW. There are six special-interest support groups and more than 900 support group meetings were held. We provide all support groups with information packs to facilitate services and offer staff-member attendance at group meetings.

We also held a support-group annual conference in Sydney where 45 groups were represented.

Participants learned about the new direction and constitution of Parkinson's NSW and heard presentations from our counsellors, Fundraising Manager, and a Professor of Clinical Neuroscience from the UK.

Our Unity Walk 2017 event raised awareness of the importance of exercise for people living with Parkinson's, and encouraged community participation, engagement and fundraising. Last year we raised more than \$100,000 from this event, held in two locations.

We increased community involvement and awareness through World Parkinson's Day throughout April. Many support groups held fundraising and awareness events.

A Parkinson's awareness video was created and shown on more than 4,500 screens in medical practices, hospitals and pharmacies.

### Future plans:

- To increase the number and effectiveness of support groups in NSW
- To inform and engage using diverse communication channels
- To increase participation in fundraising and awareness events and education seminars
- To provide ongoing support for key fundraising initiatives and events, education seminars and support groups.



NSW Support Group Conference: Simone, neurological nurse Nina and (front) Shoalhaven Shakers secretary and treasurer Di



## Research

We provide funds to support research that makes a difference NOW for people living with Parkinson's. We believe that evidence-based research is the best way to support people with Parkinson's to lead healthier lifestyles. Our research-funding portfolio supports and develops excellence in Parkinson's research.

### Outcomes:

In 2017/18 we funded eight different research projects for a total of \$301,489.

### Future plans:

- To establish an independent advisory board to plan, monitor and review research processes and outcomes
- To conduct focused fundraising campaigns in support of specific, evidence-based research projects
- To continue promoting and sharing Parkinson's research across a broad range of stakeholders.



## Sustainability

We undertake a range of fundraising programs to ensure financial sustainability and meet organisational needs. These programs are essential for providing services to the Parkinson's community as government grants account for less than 10 per cent of our funding.

### Outcomes:

Last year we raised \$5.6 million, a 175 per cent increase on the previous year.

### Future plans:

- To strengthen expertise in database development and management, data analysis and data-driven appeals
- To further strengthen relationships with current and potential donors including businesses, foundations and individuals
- To diversify existing fundraising channels and marketing strategies.



## Brand awareness

We use branding and marketing to raise awareness of Parkinson's and the vital services we provide. We do this through our support groups, newsletters, special events such as Unity Walk in the Park and World Parkinson's Day and through social media. Successful marketing positions us as the peak body and an authoritative voice for the Parkinson's community in New South Wales.

### Outcomes:

Last year we gained 39 per cent more visitors to the Parkinson's NSW website and a 94 per cent increase in Instagram followers. We reached more than 220,000 people on Facebook and increased our Facebook followers by 42 per cent.

### Future plans:

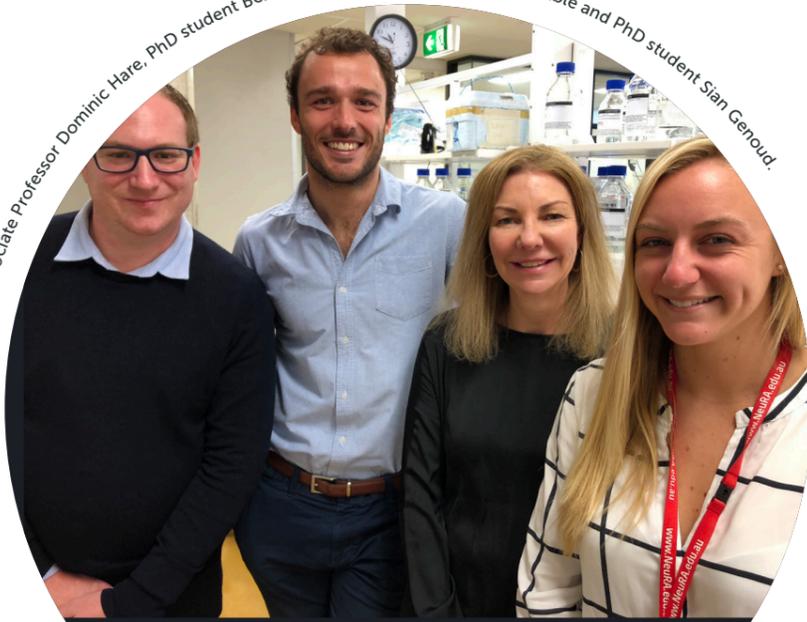
- To continue building brand awareness of Parkinson's NSW
- To develop a marketing strategy and underlying communications plan in support of the new six pillars
- To strengthen and diversify content of social media and digital and hard copy publications
- To provide ongoing communications support for key fundraising initiatives and events, education seminars and support groups.

Participants in Unity Walk 2017



Family, friends and participants share the Unity fun

From left: Associate Professor Dominic Hare, PhD student Ben Trist, Associate Professor Kay Double and PhD student Sian Genoud.





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