

# In this together

**2019-2020**

**A Year of Growth with Quality**

**Sustainability**



**Person-centred service delivery**



**Collaboration with impact**



**Building capacity & reach**



**Research**



## Vision | Our Aspiration

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

## Mission | Our Focus

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

## Purpose | What We Do

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

## Our strategic priorities:



### Sustainability

To grow for the long term while maintaining good governance.

- Governance & risk management
- Prudent financial management
- Diversify sources of funding
- Govt advocacy for funding
- Relational databases built to record all client touchpoints
- Diversify fundraising tools & channels
- Strong performance accountability at all levels
- Technology fit for purpose



### Person-centred service delivery

Listen to & learn from people living with Parkinson's to enhance & grow services.

- Develop & deliver evidence-based services & referrals
- Measure outcomes:
  - InfoLine
  - Nurses
  - Counsellors
  - Education
  - Exercise program delivery
  - Support Coordination
  - NDIS advocacy
  - Referrals
  - Data collection
- Innovation & continual improvement



### Collaboration with impact

Strategic partnerships to extend, diversify & strengthen services.

- Seek partners with complementary skills & values
- Share risks & benefits
- Avoid duplication
- Align governance & processes
- Secure collaboration with agreements



### Building capacity & reach

Build additional capacity in metro & regional communities to enhance quality of life for people living with Parkinson's.

- Strengthen & grow Parkinson's NSW Support Groups across NSW
- Add carer support programs, information & services
- Increase education programs
- Identify & verify referral resources
- Build & maintain referral resource database
- Boost community engagement



### Research

To focus on making a difference now in the quality of life of people living with Parkinson's.

- Align priorities with Parkinson's Trust to collaboratively fund research
- Re-focus & revitalise independent Research Advisory Board
- Promote research progress & opportunities to participate in trials

Skills & Culture – Board, Management & Staff

Infrastructure, Systems & Processes

Brand-building & Communications

Advocacy & Community Engagement

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## Message from the President

Like all businesses – but particularly not-for-profits – Parkinson’s NSW has been affected by the COVID-19 pandemic.

However, we stayed the course set by our Five-Year Strategic Plan and continued to invest in strengthening our infrastructure – particularly our technology infrastructure – in order to sustain and grow service delivery to the community we support.

In my annual message for 2018-19, I noted that governance had been identified as an area of risk at both Board and operational levels.

Accordingly, we now have in place a very experienced, skills-based Board. It features a diverse mix of commercial, healthcare, legal, service delivery, fundraising, and not-for-profit management skills.

So welcome to our new Directors: Janina Jancu, Nicole Schleicher, Margaret Scott, and Denise Thomas.

I also thank our outgoing Directors for their contributions: Rodney Chaplin, Ramy Soussou and Jaimee Thompson.

One other governance issue was resolved over the second and third quarters of fiscal 2019-20. It related to the operations of the Parkinson’s NSW Trust which were not in alignment with the Vision, Mission and Purpose of Parkinson’s NSW.

Accordingly, the Board of Parkinson’s NSW made the decision to remove the Trustee of the Parkinson’s NSW Trust.

The Trust has its own, separate Board. However, it is a ‘related entity’ of Parkinson’s NSW and is included in our financial accounts.



During the year under review, Parkinson’s NSW as a charity was able to post a significant net profit of \$264,663.

Due to the impact of COVID-19 on financial markets, investments by the Parkinson’s NSW Trust delivered lower returns than in previous years. Although the charity (Parkinson’s NSW) delivered a profit, its consolidation with the Trust as a related entity resulted in a loss of \$309,249.

The new Trustee Board has put the investment management of the Trust funds out to tender. It will work closely with the preferred tenderer on the future investment strategy of the Trust, as well as its distribution policy – while exercising appropriate governance and compliance with the Trust’s mission and purpose.

In closing, I would like to extend my thanks to our Parkinson’s NSW Support Groups. I applaud the positive attitude and flexibility you displayed in adapting to the restrictions of the pandemic.

It was a significant achievement to keep Support Group participants supported and engaged – despite the lack of face-to-face meetings.

I also acknowledge the hard work of our staff members who made that achievement possible with their skills and adaptability – providing Support Groups with the encouragement, information, and technologies they required to stay connected.

Despite working in particularly unusual and challenging circumstances, our Senior Leadership Team and employees remained dedicated to their mission – consistently delivering high quality services to our Parkinson’s community without interruption.

The past year had its challenges, but both Parkinson’s NSW and the Parkinson’s NSW Trust are strongly positioned to continue executing our ongoing Five-Year Strategic Plan and delivering positive outcomes.

**David Veness**  
President, Parkinson’s NSW

## Message from the CEO

Fiscal 2019-20 was the third year of our Five-Year Strategic Plan. The illustration on page 2 shows the Pillars and Planks of our strategic approach.

While tight quarter-by-quarter financial goals are the norm in commercial organisations, the not-for-profit model operates slightly differently. For example, the majority of revenue for not-for-profits falls in the final two quarters of the year – not consistently by quarter.

For that reason, we need to keep our eye on the bigger picture – acknowledging the realities of the business model while exercising fiscal responsibility over the entire year. Looking at one or two early quarters as indicators of the full year’s performance is not a productive approach in our sector.

As noted above, a longer-term Strategic Plan is also required to overlay the annual goals and performance. For example, following a significant profit in fiscal 2017-18 we operated at a Board-approved loss in 2018-19.

This enabled us to invest in strengthening the infrastructure of our organisation, while simultaneously growing the range and reach of services to the NSW Parkinson’s community.

Parkinson’s NSW is a service delivery organisation. That is explained and embedded in our Vision, Mission and Purpose.

During the past fiscal year, service delivery reached historically high rates.

We began generating revenue from our Registered Service Provider status with the NDIS. This NDIS relationship is both a requirement of NSW Government policy and a way of diversifying our sources of revenue.

Advocacy at Local, State and Federal levels of government continued and was successful in securing funding for more Parkinson’s Specialist Nurses.

The 0.5 Full Time Equivalent (FTE) nursing role in Coffs Harbour under the Mid North Coast Local Health District (LHD) was upgraded to a full-time position with job-sharing by two nurses.

Co-funding was also secured from the Northern NSW LHD for a full-time Parkinson’s Specialist Nurse to support people living with Parkinson’s in the Tweed region.

Our investment in information technology continued. This includes a database program that is beginning to deliver results – improving the efficiency, effectiveness, and security of service delivery.

Despite the challenges of the pandemic, during the 2019-20 financial year we were not distracted; we continued to make good progress against our goals under the Board-approved Strategic Plan.

This performance would not have been possible without the agility and resilience of Parkinson’s NSW staff who made sacrifices and quickly adapted to remote working and maintaining team productivity via videoconferencing.

My thanks also go to Support Group Leadership Teams and participants who worked with us to adapt to the absence of face-to-face meetings and experiment with video-chat technologies.

As always, our thanks also go to the many supporters and bequestors who have generously contributed to the Parkinson’s cause.

**Jo-Anne Reeves**  
Chief Executive Officer







## Building capacity & reach

### Support Groups: Vital to the NSW Parkinson's community

The Mission of Parkinson's NSW is to enhance the quality of life of people living with Parkinson's. Its Purpose is to connect people living with Parkinson's with life-enhancing support and services.

Without the cooperation and energy of the Parkinson's NSW Support Group network, neither of these would be achievable. Support Groups function within their local communities or geographic areas offering valuable peer-support but they are not isolated or autonomous.

They are legally part of Parkinson's NSW and supported by employees of the organisation – including a Support Group Coordinator, and the Senior Leadership, Marketing and Fundraising teams.

This support from the Parkinson's NSW team became even more important during the second half of fiscal 2019-20. That was when toughening COVID-19 restrictions deprived Support Group participants of valuable face-to-face meetings with like-minded people in their communities.

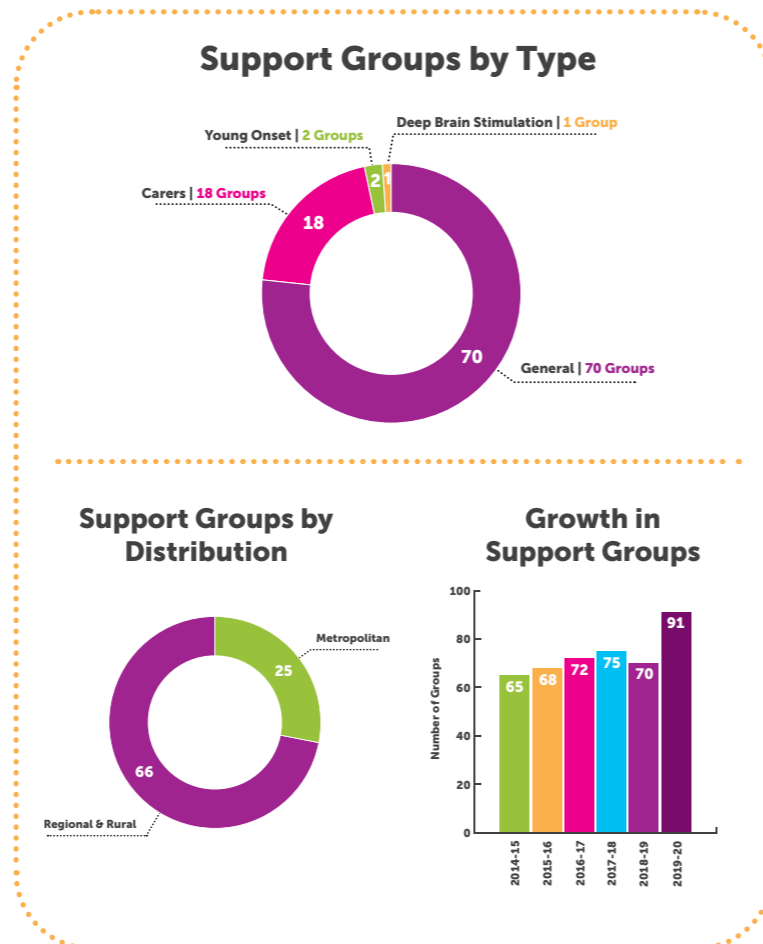
To maintain contact between different Support Groups and individual Support Group participants, Parkinson's NSW staff quickly researched, developed, and disseminated guides for setting up online video-chat meetings. These utilised the free Zoom software application which can be used on any smart phone or personal computer.

Most Groups also moved quickly to establish their own telephone and email check-in protocols to ensure that no individual was left unsupported in the absence of face-to-face contact.

Despite the pandemic, the Support Group network managed significant growth over the 2019-20 fiscal year – nine new General Groups and the same number of specialised Carer Groups started up.

There is now a total of 91 Support Groups across NSW with more than 1,850 participants. This represents a growth of 30 percent in the network.

In addition, due to demand, online Support Groups have been created. There are now three Facebook Groups: the Parkinson's Support Groups Online Community with 122 members, a Support Group Leaders Community with 13 members, and a Young Onset Parkinson's community with 59 members.



## Person-centred service delivery

### InfoLine: Critical source of information and referrals

The Parkinson's NSW InfoLine (1800 644 189) is the go-to contact for people living with Parkinson's, caregivers and family members who require medically-sound advice, information, and connection with essential services.

It also receives enquiries from Primary and Allied Health professionals.

The InfoLine is staffed by two Parkinson's Registered Nurses who have a collective 70 years of professional experience.

In addition to further post-graduate qualifications, their experience includes supporting people living with neurodegenerative diseases, aged care, aged care advocacy, community nursing, and nurse education.

During fiscal 2019-20, the InfoLine team actioned 4,433 calls. This does not include routine enquiries or duplicated calls or emails. The average length of call is 15 minutes.

As an indicator of the trust placed in the skills and knowledge of our InfoLine Team, Parkinson's South Australia diverted its calls to Parkinson's NSW for several months during the past financial year while its organisation restructured.

That meant the team was fielding enquiries from people living with Parkinson's in South Australia as well as the Northern Territory – which is usually serviced by Parkinson's South Australia. They also occasionally receive out-of-area calls from people in Queensland and Victoria.

#### What conditions do people call about?

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

#### What services can InfoLine connect you with?

- Counselling
- Support Groups – Support Group Coordinator
- Specialist Movement Disorder Neurologists
- Allied Health Services
- Parkinson's Clinics
- Community-based Parkinson's Specialist Nurses
- National Disability Insurance Scheme Advocacy
- National Disability Insurance Scheme Support Coordination

#### Other enquiries handled by InfoLine

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

#### What information packs can the InfoLine provide?

- Parkinson's Information Packs
- Newly Diagnosed Parkinson's Packs
- Parkinson's Medication Information
- Parkinson's Symptom Management
- Information on Advanced Therapies
- Information on Assistive Devices



## Fundraising: Essential growth of supporter base

Parkinson's NSW receives less than 10 percent of its funding from Government grants. Therefore, we could not deliver essential services to the NSW Parkinson's community without the generosity of our supporters.

During 2019-20 we continued to diversify our fundraising programs as we reached the mid-point of our 5-Year Plan.

To date we have met all Board-approved milestones and reached the break-even point of our major capital investment modernising and upgrading our fundraising strategies and tools.

Implementing new forms of fundraising – in particular through phone contacts – proved invaluable over the second half of 2019-20 when our community felt the full impact of COVID-19 restrictions.

Our telephone campaign surpassed expectations despite the impact of COVID-19, helping to build Parkinson's Partners – a group of generous supporters who have made a commitment to make regular donations.

As a result, we have been able to expand our base of generous regular supporters by 55 percent over the past fiscal year at relatively low cost.

There are lower costs associated with maintaining a regular giving program while the overheads of traditional fundraising methods continue to increase.

Professional fundraising is not a short-term proposition. Our current plan focuses on growing our supporter base while diversifying our fundraising channels.

We treat our supporters with respect and have a sophisticated database which permits tracking of individual preferences around the volume and type of communications.

It also enables us to accurately record donations, issue receipts and acknowledge the generosity of our supporters in a timely manner.

We also respect our supporters' personal circumstances. The past year has been stressful for all due to devastating bushfires closely followed by COVID-19 pandemic. For safety we cancelled fundraising events such as those associated with World Parkinson's Day.

We had tremendous support from Support Groups in the first half of the fiscal 2019-20 – including their active involvement in recycling bottles and cans when Parkinson's NSW was the official charity of the Tomra Return and Earn program. This raised more than \$19,000.

Our community has been through stressful times over the past fiscal year. Our thanks go to those who continued to give during the pandemic – and those who shared their personal stories to enable our fundraising campaigns.

### Donations in 2019-20

**4,845** donations made through the Parkinson's Partners regular giving program

**A total of \$3,158,252** was given by generous supporters through **donations and gifts in wills**



## Behind every bequest, there is life to be acknowledged

**It is a privilege for a charity to be so trusted by an individual that they are willing to leave a bequest for it to steward well after the person has gone.**

**One such person was Gladys Essie Snodgrass. This is her story.**

Gladys Snodgrass was born in Lakemba on 29 April 1927 to Harold Snodgrass, a maritime salvage operator and Ida May Snodgrass, a secretary.

Gladys excelled academically at St George Girls High School. She wrote for the Methodist Church Bulletin and taught Sunday School.

Along with her sister, she regularly sent verse into the *Sydney Morning Herald* and it was often published. After leaving school she attended the Metropolitan Business College Campsie campus, where she excelled in shorthand.

After graduating, Gladys worked in the NSW Technical Education system now known as TAFE. She worked at a number of locations including Wollongong, Temora, and Western Sydney.

She established secretarial studies at Kempsey and became head teacher. Gladys then became head teacher at Gympie Technical College and later at Canberra Technical College.

Whilst in Canberra, Gladys became an accomplished ballroom dancer. She also wrote various books that went on to be published, particularly the Pittman Shorthand Bible. Gladys also went on to develop a love for painting.

She travelled the world extensively in the early 1970's. When she returned to Australia in 1972, she returned to Wollongong Technical College as head teacher from where she ultimately went on to retire.

After retirement Gladys spent much of her time travelling and living in London, Canada, New Zealand, and Hawaii until her health deteriorated.

Gladys never married or had children but valued her relationship with her nieces and nephews.

She was very supportive of education and worthwhile charities. She was a determined lady of very strong moral beliefs and an astute businesswoman who possessed a strong mind to the end.

We are grateful for the kindness and generosity of individuals like Gladys who enable the continuation of life saving services and supports for people living with Parkinson's.





## Building capacity & reach

# More Parkinson's Specialist Nurses, coping with COVID-19

The number of community-based Parkinson's Specialist Nurses in regional and rural areas grew in the 2019-20 fiscal year from 2.5 Full Time Equivalent (FTE) professionals in three locations to 3.0 FTE in three locations.

The part time role in Coffs Harbour was increased to a full-time position through the addition of a second nurse to share the role. Our existing Parkinson's Specialist Nurses in Port Macquarie and Shoalhaven remained in place.

In the final quarter of 2019-20, the Northern NSW Local Health District signed an agreement with Parkinson's NSW to co-fund a new position to support people living with Parkinson's in the Tweed region.

Following recruitment in the fourth quarter, an offer was made to a highly qualified candidate who will be in place in the second half of 2020.

Due to the impact of COVID-19 restrictions, the number of face-to-face consultations and home visits by nurses declined by more than 50 percent while the number of telephone consultations increased by the same amount.

However, nursing support for people receiving advanced therapies such as Apomorphine and Duodopa continued without interruption – 68 patients were supported over the year.

The number of hospital and aged care visits remained the same year to year, but with additional COVID-19 precautions under medical supervision at each site.

In the second half of the past year we partnered with St Vincent's Hospital Sydney neurologists to trial Telehealth consultations for people living with Parkinson's in rural areas – in this case the hinterland of Port Macquarie.

With the onset of COVID-19 an additional four metropolitan neurologists opted to use the Telehealth consultations for several of their patients, with the coordination and participation of our Parkinson's Specialist Nurse on site.

Parkinson's Specialist Nurses also maintained their close links with Support Groups, attending 127 meetings over the year – initially in person, and then via video-chats when COVID-19 restrictions were imposed.

The priority of Parkinson's NSW is to continue growing the number of Parkinson's Specialist Nurses in outer metropolitan, regional and rural areas.

## Parkinson's Specialist Nurses at Work



181 New Referrals



1551 Face to Face Consultations



3000 Phone Consultations



472 Home Visits



## Person-centred service delivery

# Counselling services grow and adapt

Demand for specialist Parkinson's Counselling increased during fiscal 2019-2020.

We therefore added another Counsellor to the team in the second half of the year, increasing the headcount of this key service to 1.5 Full Time Equivalent (FTE) professionals.

One of our Parkinson's Counsellors works from two locations in Sydney – War Memorial Hospital and Wolper Jewish Hospital. The other is based in the Parkinson's NSW headquarters in North Ryde.

As with our Parkinson's Specialist Nursing services, the Counselling team had to adapt quickly to manage the challenges of COVID-19 restrictions.

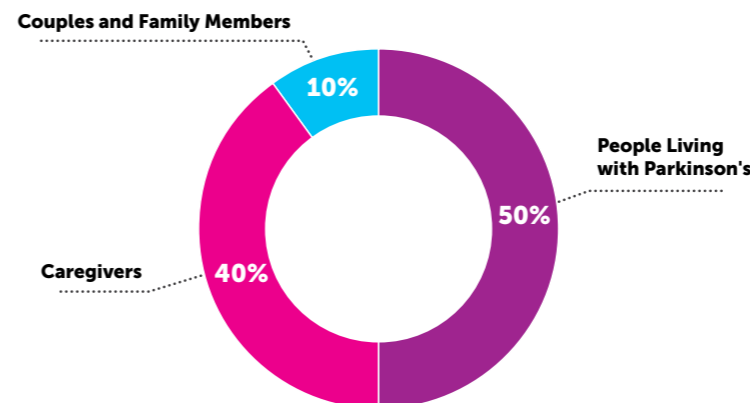
The number of face-to-face counselling sessions dropped by 30 percent while the number of telephone consultations increased by 55 percent. Video-chat sessions also increased, with 174 conducted over the fiscal year.

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

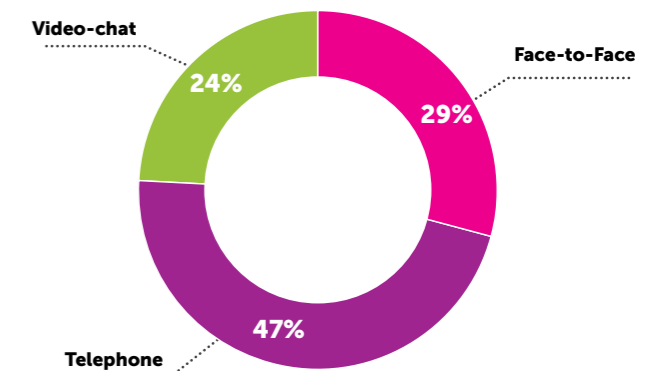
## Typical issues addressed in counselling over the past year included:

- Anxiety, fear, and depression about the impact of COVID
- Partners adjusting to the role of carer
- Grief around the loss of an equal partner
- Anticipated grief and loss around a loved one's admission into an aged care facility
- Anxiety in observing changes in partner as Parkinson's progresses
- Anxiety around the loss of cognitive function, memory loss, slowness in thinking, tiredness, and inability to focus that comes with Parkinson's
- Carer burnout

## Who Benefits from Counselling?



## Modes of Counselling







## Education adapts to new challenges

The Parkinson’s NSW Education function is managed by one part-time staff member who leads course planning, development, and administration.

She draws on the skills and knowledge of our Parkinson’s Registered Nurses, Community-based Parkinson’s Specialist Nurses and Parkinson’s Counsellors to develop and keep current the content of each course.

Our Nurses also present each course, adapting the content to meet the specific needs of each audience:

- People who are newly diagnosed with Parkinson’s and caregivers
- People living with Parkinson’s and caregivers
- General Practitioners
- Aged Care Nurses and Support Workers

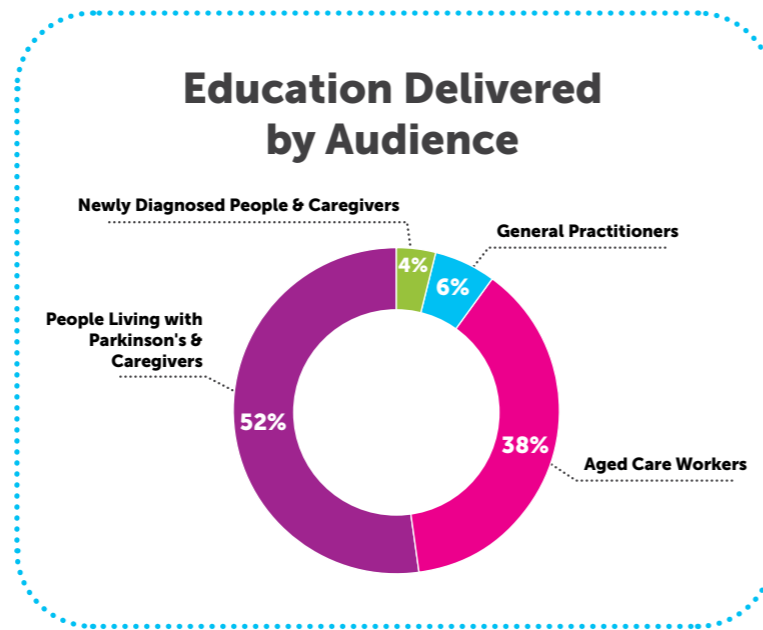
Sixteen education seminars were developed and delivered across NSW in the 2019-20 fiscal year.

This number is lower than previous years due to the impact of the catastrophic bushfire season, closely followed by the COVID-19 pandemic which resulted in wide-spread restrictions.

When it became obvious that the COVID-19 issue would not be quickly resolved, in April the Education team began development on a self-guided, Internet-accessible version of the course for Aged Care Nurses and Support Workers.

This new digital course is in its final stages. Once completed, elements of this online course will be adapted and expanded to meet the needs of other audiences willing to participate in this new form of learning.

Advice and support on the use of the technologies involved will be provided by Parkinson’s NSW to facilitate participation.



***“Much more than I expected. So well presented and easy to understand.”***

**Aged Care education participant**

***“I really valued the advice about exercise being just as important as medication.”***

**Person living with Parkinson’s**

***“This was a very well organised seminar and all good presenters. I look forward to following up on support.”***

**Newly diagnosed person living with Parkinson’s**



## Exercise: Working around COVID-19

Exercise is second only to medication in effectiveness for slowing the progression of Parkinson’s. This makes it a priority of Parkinson’s NSW.

Unfortunately, the COVID-19 restrictions on group activities and closures of gyms had a major impact on the usual exercise programs offered and supported by Parkinson’s NSW.

During the first half of the 2019-20 fiscal year (before the pandemic struck) our staff Exercise Physiologist led and coordinated with service delivery partners to deliver:

- Exercise, art, dance, and music classes for more than 450 participants
- Evaluations and recommendations of 120 Parkinson’s-specific exercise providers

COVID-19 restrictions imposed in the third quarter of fiscal 2019-20 halted face-to-face and group exercise activities. However, support needed to continue for the NSW Parkinson’s community so we:

- Published stories in our newsletters and via digital and social media recommending exercise routines that could be done at home
- Offered personal training via video-chat led by our staff Exercise Physiologist
- Offered links to YouTube videos featuring visual instruction on Parkinson’s-specific exercise routines
- Worked with Parkinson’s NSW Board Member and exercise professional Steve Schiemer to offer Zoom video-chat exercises to participants throughout NSW at subsidised rates

Development also began on a new online Parkinson’s self-guided learning module for exercise and Allied Health professionals. It is called Parkinson’s 101 and features a core module that upgrades professionals’ knowledge of the physiology, impact, and treatment of Parkinson’s.

It then leads into specialised modules for:

- Exercise professionals and Physiotherapists who need to adapt their approach to devising therapies and coaching people living with Parkinson’s
- Speech Therapists who are treating the vocal and related issues of people living with Parkinson’s
- Occupational Therapists who are developing rehabilitation programs for people living with Parkinson’s

Parkinson’s 101 will build the capacity of exercise and Allied Health professionals in NSW to more effectively support people living with Parkinson’s. It will be launched in the second quarter of fiscal 2020-21.





## Person-centred service delivery

### Expanding support via NDIS services

Parkinson's NSW gained Registered Service Provider status with the National Disability Insurance Scheme (NDIS) in the 2018-19 financial year.

This NDIS relationship expands the range of services we are able to deliver to the NSW Parkinson's community. We expanded our support for both potential and successful applicants for NDIS funding over the past fiscal year.

During 2019-20, our Parkinson's Nurse Advocate guided 292 people aged under 65 and living with Parkinson's through the complexities of applying for NDIS funding – an increase of 56 percent over the previous year.

Of these applicants 115 were successful while others are being assisted through the re-application and appeal processes.

The second component of the NDIS support services provided by Parkinson's NSW is Support Coordination.

Once an NDIS participant has Support Coordination approved in their plan, we can assist with services that are billable to the NDIS, including linking them with their community, as well as mainstream and Government services.

Our part-time Support Coordinator is currently assisting 20 participants – a growth of 63 percent within the past year.

In addition to helping people to identify and connect with the services they require, she assists participants to build skills that enable them to live the life they want and manage their own support.



**90% of participants** have Occupational Therapy, Physiotherapy, Speech Therapy and Domestic Assistance



**60% of participants** have Exercise Physiology and specialised Parkinson's exercise programs



**60% of participants** have assistance with transport



**10% of participants** have Ready Made Meals







## Marketing: Raising awareness and building connections

The ongoing role of the Marketing team is to use branding, promotions, and communications to raise awareness of Parkinson’s and Parkinson’s NSW services.

However, it developed a new priority during the second half of the 2019-20 fiscal year with the onset of the COVID-19 pandemic – building and strengthening connections while people were locked down, socially isolated and unable to access their usual peer support via Support Group meetings.

That meant immediately redirecting resources into deploying tools and building new processes to connect with people living with Parkinson’s, caregivers, and families, as well as service delivery partners, donors, and potential donors.

There was strong focus on reconnecting Support Group participants and other members of the Parkinson’s NSW community during the pandemic.

This was accomplished through the development of a strategy and support materials to encourage people to use free video-chat software such as Zoom and other video and chat applications such as WhatsApp and Facetime. This permitted virtual face-to-face contact – not a perfect replacement for face-to-face meetings, but a more communicative approach than a simple telephone call or email.

At the same time, the monthly *InTouch* newsletter for Support Group members was redeveloped into an Electronic Direct Mail (EDM) format, allowing more people to be reached, more quickly and more often thanks to a bi-monthly publishing schedule.

The electronic format still includes a Portable Document Format (PDF) version that permits users to print out the newsletter if required.

Otherwise it can easily be shared by email, and the new format also offers richer resources to readers by including links to information held on the Parkinson’s NSW and other pre-vetted websites. The adoption rate has been high with positive feedback received from our readers

**“Just love the new look and feel of *InTouch*. I think the separation of the articles piques one’s interest more... it’s a much better road map now. Congratulations to all for coming up with this innovation.”**

### Bega Support Group participants

*Stand by Me* continues to be our flagship publication for all stakeholders. Over the past year, more content of this magazine has been repurposed post-publication for digital and social media in order to reach a broader audience.

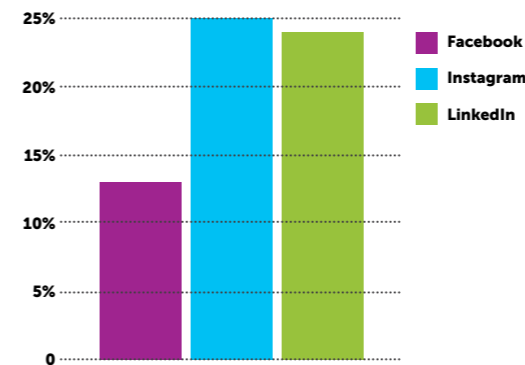
There was 52 percent organic growth in email subscriptions over the fiscal year, with a retention rate of 83 percent.

### Social Media

Social media and the Parkinson’s NSW website have again recorded significant growth, engagement and reach over the past year.

Our Facebook content organically reached (without the aid of paid advertising) more than 286,000 people this financial year.

Growth in Social Channels



Social media took on an even more important role during the latter half of the fiscal year when COVID-19 restrictions began to tighten.

Social media platforms allowed us to maintain connections with many of the family members, relatives and friends of people living with Parkinson’s – as well as a broad range of other stakeholders with an interest in Parkinson’s.

They included Primary and Allied Health practitioners, researchers, political influencers and decision-makers, and health and aged care influencers and bureaucrats.

Support Groups also began to embrace social media during the pandemic, so now there are several virtual Groups operating as Facebook communities.

### 50/50 Online Raffle

After trialling the 50/50 Online Raffle concept in the previous fiscal year, the Marketing and Fundraising teams continued to use this tactic another three times during the 2019-20 financial year.

50/50 Online Raffle tickets were sold through a secure, purpose-built website at \$10 each with the ‘pot’ split equally between the winner and Parkinson’s NSW.

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

Feedback from purchasers was positive. They liked the easy concept and cash prize, and the excitement of seeing the ‘pot’ size increase in line with ticket sales.



## Strategic partnerships and events

### No Escape Room

Parkinson's NSW worked with marketing agency Wunderman Thompson and production company AIRBAG throughout the final quarter of fiscal 2019-20 to develop an escape room campaign to raise awareness of the daily challenges of living with Parkinson's.

The campaign was launched in first month of the new financial year. The project was undertaken on a pro bono basis by the agency with the aim of educating the community about Parkinson's – particularly younger people.

An escape room is a game popular with young adults in which a team of players cooperate to discover clues, solve puzzles, and accomplish tasks in one or more rooms with the goal of escaping from the site of the game.

To attract participants in the project, the organisers put out a call on social media to fans of escape room games, offering them the opportunity to be the first to trial a new escape room.

However, what the participants didn't know was that the room was rigged with secret cameras and microphones – and that each task and puzzle represented a Parkinson's symptom including memory loss, tremor, blurry vision, stiffness, and more. View the campaign and videos at [noescaperoom.com.au](http://noescaperoom.com.au)

Seemingly simple tasks such as pouring tea, using a computer mouse, or tying shoelaces were made frustratingly difficult, emulating the challenges people with Parkinson's face every day.

When participants finished all the challenges and were able to open the final door, they were faced with a sign telling them that the room represented Parkinson's – the symptoms of which people cannot escape.

In addition to video interviews with participants on how they felt after the experience and what they had learned, the escape room is duplicated as 360-degree digital experience on a dedicated web site, allowing more people around the world to take part and gain an understanding of Parkinson's and its challenges.



### Unity Walk: Fundraising and building awareness

Parkinson's NSW special events are important for raising awareness of Parkinson's, supporting fundraising, developing community engagement, and providing social opportunities for people living with Parkinson's, caregivers, families, and friends.

Unity Walk in the Park is the major annual fundraising initiative of our organization.

Over the past 12 years this event has attracted more than 17,000 participants who have helped Parkinson's NSW raise more than \$1,100,000.

The 2019 Walk held on Sunday August 25 attracted more than 900 participants across the state with more than 1,300 donations made to help fund vital services and life enhancing research for people affected by Parkinson's.

Walks took place in Sydney, Wollongong and five regional locations: Kiama, Coffs Harbour, Nowra, Lismore, and Bathurst.

A Unity Walk 50/50 raffle was run and was drawn live at the Sydney location – the winner couldn't make the event at the last minute but was very happy to receive the phone call.

She generously donated her winnings back to Parkinson's NSW to contribute \$4,740 to the funds raised by the 2019 Unity Walk.

Our thanks go to the many volunteers, sponsors and entertainers for their support.

#### Sponsors contributed a total of \$10,000:

- AbbVie (which also matched its staff fundraising outcome of \$1900)
- Harper Bernays
- RPM Consulting and Project Management

### Unity Walk in the Park Statistics



**1,304 donations made**



**328 volunteer hours**



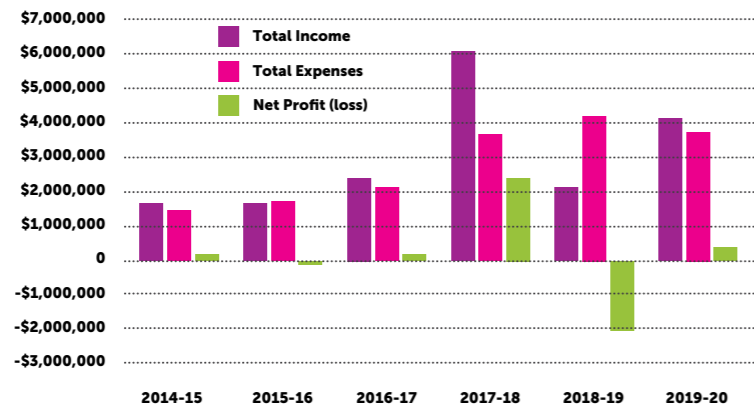
**5 regional walk locations**



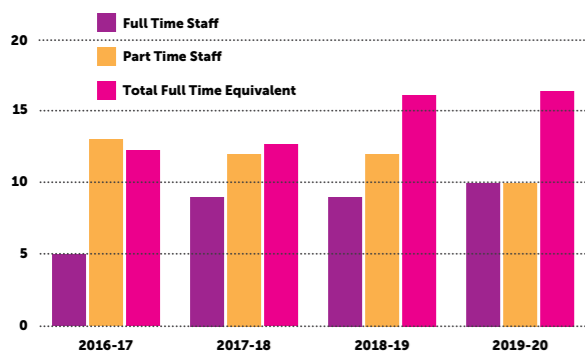


## Financial performance

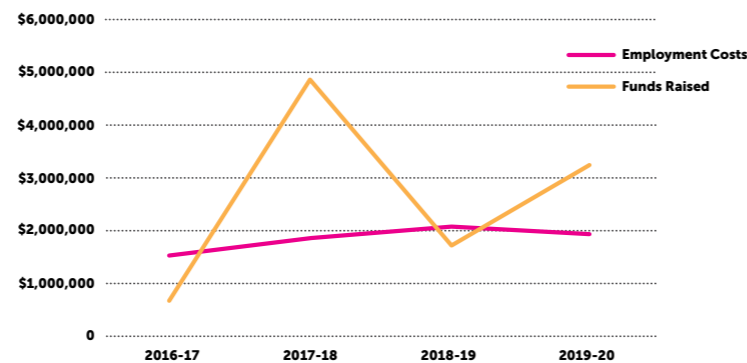
History of Financial Performance



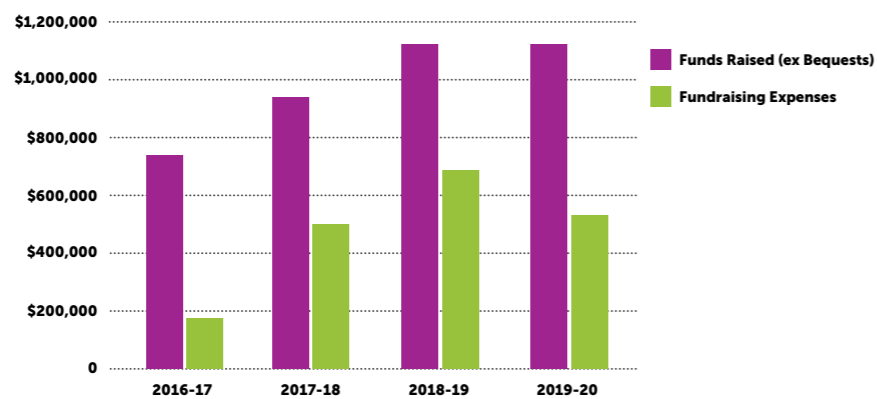
Growth in Staffing Over Past 4 Financial Years



Growth in Total Employment Costs Over Past 4 Financial Years



Non-Bequest Fundraising vs. Expenses



## Board upgraded with new skills and broader experience

Rodney Chaplin, Ramy Soussou and Jaimee Thompson resigned in the first quarter of fiscal 2019-20.

This provided an opportunity to refresh and upgrade the skills profile of the Board. An independent search consultant was engaged for this purpose.

As a result, Janina Jancu, Nicole Schleicher, and Margaret Scott were appointed to the Board in November 2019, followed by the appointment of Denise Thomas in February 2020.

### Skills Base of Current Board

- Banking and finance
- Corporate governance
- Development of clinical services in areas of need
- Fundraising
- Health and fitness (with specialisation in Parkinson's exercise)
- Healthcare executive management
- Human resources and organisation
- Law (including specialisation in Health Law)
- Management of Allied Health services
- Not-for-profit, corporate and government executive management
- Nursing
- Quality management
- Research and evaluation
- Risk management
- Service delivery and systems management

### Board Meeting attendance record

Name	Sept. 2019	Oct. 2019	March 2020	April 2020	June 2020
Rodney Chaplin	☑ P	N/A	--	--	--
Steve Schiemer	☑	☑	☑	☑	☑
Edward Shepherd	A	☑	☑	☑	A
Ramy Soussou	☑ P	N/A	--	--	--
Jaimee Thompson	☑ P	N/A	--	--	--
David Veness	☑	☑	☑	☑	☑
Janina Jancu	--	--	☑	☑	☑
Nicole Schleicher	--	--	☑	☑	☑
Margaret Scott	--	--	☑	☑	☑
Denise Thomas	--	--	☑	☑	☑

☑ = Attended  
 P = Attended via phone  
 A = Apologies

# Board profiles of current Parkinson's NSW Board Members

**President  
David Veness**



David Veness joined the Board as a non-metropolitan representative.

David was diagnosed with Parkinson's eight years ago and immediately joined his local Support Group in Bathurst. He strongly believes in and plays an active role in all of the Group's activities.

He enjoys exercise and encourages all those with Parkinson's to try and exercise regularly.

David joined the Board with a desire to represent country areas of NSW. He understands the difficulties providing direct support for those living with Parkinson's in country areas and is passionate in gaining more nurses for regional areas.

As a member of the Parkinson's NSW Board, David is willing to travel and meet Support Groups throughout NSW to help lobby politicians for more nurses.

David is retired and his background is in hospitality and banking.

**Vice President  
Margaret Scott**



Margaret Scott was appointed to the Board of Parkinson's NSW in November 2019 and as Vice President in March 2020.

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.

Margaret was on the Board of the Fundraising Institute of Australia from 1998 to 2008. She held a number of key roles on that Board over the years including Chair, Vice Chair, and Chair of multiple Committees.

She was also on the Bloom Asia Board from 2017 to 2019.

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**Director - Chair of the Finance, Risk and Audit Committee  
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 multiple sectors. A qualified lawyer she brings extensive experience in the areas of finance, risk management and corporate governance.

She is a graduate of the Australian Institute of Company Directors, served as a director of UNSW and has acted in an advisory capacity on not-for-profit boards.

Janina has previously held roles with Victor Chang Cardiac Research Institute, UNSW, the City of Sydney and Spotless Services Limited.

She is currently the Director of Operations at ReachOut Australia.

**Director  
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 eight years.

In addition to experiencing Parkinson's himself, Stephen runs tailored fitness programs for other people living with the disease.

He has a Bachelor of Business degree and 30 years of experience in running his own businesses.

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**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. Her experience includes managing service delivery and systems, quality, strategic projects, research and evaluation, and administration.

Nicole has held key 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.

**Director  
Edward Shepherd**



Edward Shepherd was elected to the Board of Parkinson's NSW in October 2018.

He has firsthand experience with Parkinson's disease within his own family and is a carer, along with his father and five siblings.

Edward has 10 years of management experience in human resources and people and culture roles.

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**Director  
Denise Thomas**



Denise Thomas was appointed to the Board of Parkinson's NSW in February 2020.

She is an accomplished senior health care executive with diverse experience in a range of health care settings and is currently the General Manager of MetroRehab Hospital.

Denise started her career as a Registered Nurse at St Vincent's Hospital Sydney and then went on to hold management and senior executive roles in both public and private sector health care and in independent hospitals, publicly listed groups, and government organisations.

In addition to being a Registered Nurse (St Vincent's Hospital), Denise has a Master's Degree in Health Law (University of Sydney), Bachelor's Degree in Health Management (University of New England), and an Acute Care Certificate (NSW College of Nursing).





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