

In this together 2020/2021

A year of challenges ending in success



Sustainability



Collaboration with impact



Person-centred service delivery



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

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Message from the President

The past fiscal year has been a challenge for everybody – businesses, for-purpose organisations, and individuals alike. We are working through the social and economic fallout of two rounds of COVID-19 lockdowns.

People living with Parkinson's have been particularly affected through losing vital community connections, as well as face-to-face peer support from colleagues in Parkinson's NSW Support Groups.

The new, skills-based Board – which has been in place for one year now – put in a concerted effort to navigate the organisation through social and financial turbulence and ultimately emerge stronger at the end of the fiscal year.

The Board now has a depth of skills and experience in financial management, risk management, corporate governance, not-for-profit management, service delivery planning, fundraising, law, and research and evaluation.

Our desire is to complement these skills, recruiting additional independent Directors who have a passion to provide services for people living with Parkinson's who can, with us, build our organisation to be more sustainable well into the future.

We brought this array of skills to bear as we continued with the current Five-Year Strategic Plan, while also plotting the next phase of our organisational development.

We continued to invest in strengthening our infrastructure – particularly our technology infrastructure – in order to better support fundraising, administration, and service delivery to the community we support.

In 2019-20, governance was identified as an area of risk at both Board and operational levels.

During 2020-21 the Board continued to focus on improving governance and risk management at all levels of the organisation while strengthening another two aspects of our corporate culture – disciplined measurement of outcomes and a culture of accountability.

We also began work on clarifying Membership of the organisation. Under the governance of successive Boards and management teams, a range of Membership categories had accumulated. This led to confusion around eligibility to vote at the Annual General Meeting, and varying perceptions of the benefits of Membership in addition to voting rights.

We requested validation of all Members on the Parkinson's NSW database and will be putting a new constitution to the vote at the Annual General Meeting (AGM).

During the year under review, Parkinson's NSW as a charity was able to post a net profit of \$334,748.

Since its restructuring in the prior fiscal year, the Parkinson's NSW Trust this year was also able to deliver a positive result of \$759,474.

The consolidated entity (charity and Trust) recorded a profit of \$1,094,222.

In closing, I would like to extend my best wishes to our Parkinson's NSW Support Groups. Our drive for improved governance and risk management embraced their operations as well.

Thank-you to the Support Group Leadership Teams who made the necessary changes to their banking arrangements and financial reporting in order to become more compliant for the annual financial audit. We also thank them for their ongoing efforts to support Group participants – despite the challenges of not being able to meet in person as often as they would like.

Even as they worked in particularly 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 Parkinson's NSW ended the year on a high note and is now in a stronger position than ever before.

My thanks go to each Director who volunteers their time and expertise to support our organisation, and to our excellent management team who, with us, work towards providing people living with Parkinson's a better life, every step of the way.

Margaret Scott
President, Parkinson's NSW



Message from the CEO

Sustainability is one of the key pillars of our Five-Year Strategic Plan – along with person-centred service delivery, building capacity and reach and collaboration with impact.

Fiscal 2020-21 was the fourth year of this Plan, during which the organisation definitely became more financially and operationally sustainable – despite the challenges of COVID-19 restrictions.

Our efforts over the past resulted in a profit of \$334,748, an increase of 26 percent over the previous year's result.

Underpinning these priorities in our Strategic Plan, we continued to invest in technology infrastructure – including a multi-year project to acquire, install and populate a relational database.

This is now efficiently supporting our service delivery, fundraising, administration, reporting, screening of Allied Health providers with Parkinson's experience, and financial accounting.

We are also using technology to transform our education offerings. When COVID-19 made in-person education seminars impossible, our Education team worked swiftly to develop a self-guided, online learning module.

This was required to meet the strong demand for Parkinson's training for Aged Care support workers and nurses.

Participants in Parkinson's NSW Support Groups also had to adapt to changed conditions during the year, when they were often unable to meet face to face due to health restrictions.

Support Group Leadership Teams worked closely with Parkinson's NSW staff to adopt the video-chat application called Zoom as a virtual replacement for face-to-face meetings.

Zoom also became a medium for Parkinson's NSW to deliver virtual information sessions. InfoLine Registered Parkinson's Nurses, Counsellors and our Exercise Physiologist all hosted Zoom chats and Q&A sessions – as did invited guest speakers from the Continence Foundation, the Council of the Ageing (COTA) and Carers NSW.

Our community-based Parkinson's Specialist Nurses maintained in-person, phone, and video-chat contact with the people they supported during the year. In 2020-21 two new nurses were placed in Local Health Districts – one in Northern NSW LHD and the other in Northern Sydney LHD.

These new roles brought Parkinson's Specialist Nurse resources in the state to 5.0 Full Time Equivalent (FTE) positions – including Coffs Harbour, Port Macquarie, Tweed, Hornsby, and the Shoalhaven region. This is an increase of 2 FTE over the previous year.

Our Counsellors were also very busy during the year, providing support for people living with Parkinson's, caregivers, and families who in many cases had been isolated from their social networks.

Parkinson's NSW Counsellors delivered 914 individual sessions and 114 group sessions during 2020-21 – an outstanding result using telephone and video-chat applications while working under COVID-19 restrictions.

Over the past year we also invested in additional fundraising resources with the goal of growing our base of regular givers through telephone outreach. This has proved to be a successful strategy, generating a 27 percent expansion in our base of generous regular givers.

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

No report on the 2020-21 fiscal year would be complete without acknowledging the agility and resilience of Parkinson's NSW staff who 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 adopt other options.

As always, our thanks also go to the many supporters and donors who have generously contributed to the Parkinson's cause. They also were affected by the COVID-19 situation, but they remained dedicated to supporting the work of Parkinson's NSW.

Jo-Anne Reeves
Chief Executive Officer



Building capacity & reach

Support Groups flourish online

Parkinson's NSW has 72 Support Groups offering more than 2,500 participants valuable peer-support in cities, regional and rural areas – and online via Facebook and Zoom video-chat sessions.

In addition to geographically located Groups, there are also 29 special interest sub-groups:

- ✔ Five for people living with Young Onset Parkinson's
- ✔ Three for men living with Parkinson's
- ✔ One for women living with Parkinson's
- ✔ 19 for caregivers
- ✔ One online only group for people who have had or who are contemplating Deep Brain Stimulation (DBS) and other advanced therapies

There are also four Facebook Groups linked with the Parkinson's NSW Facebook page:

- ✔ Support Group Online Community (203 participants)
- ✔ Support Group Leaders Community (24)
- ✔ Carers Online (105)
- ✔ Young Onset Parkinson's Community (59)

The focus over the past year has been on building the skills of Support Group Leadership Teams (also called Committees), increasing the flow of communications, and tightening governance to ensure compliance with regulatory and legislative requirements.

Distribution of Support Groups

Regional & Rural 53

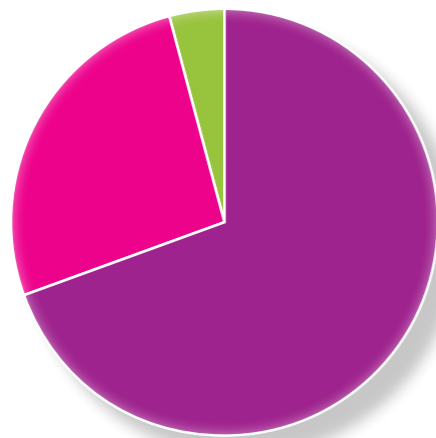
75%

City 19

25%

Types of Support Groups

- ✔ Geographic 70%
- ✔ Special Interest – Zoom 26%
- ✔ Facebook 4%



Financial transparency was improved through the opening of 19 additional Commonwealth Bank accounts – as well as the closure of some accounts where the Groups' small number and scale of transactions made them unnecessary.

A new onboarding kit was developed and distributed to provide orientation for new Leadership Teams – including the vision and purpose of Parkinson's NSW, key policies and procedures, and position descriptions to clarify each role in the Team.

Parkinson's NSW organised and hosted a total of 76 zoom meetings and information sessions over the past year. They were open to any Support Group participant who wanted to participate, and topics included:

- ✔ Deep Brain Stimulation (DBS) and advanced therapies
- ✔ InfoLine Parkinson's Registered Nurse Q&A sessions
- ✔ Caregiver chat
- ✔ Support Group leadership
- ✔ Council of the Ageing (COTA) presentation
- ✔ Continence Foundation presentation
- ✔ Carers NSW presentation
- ✔ Young Onset chat with community-based Parkinson's Specialist Nurse

To coincide with Parkinson's Awareness Month in April, all Support Groups were invited to participate in a Parkinson's Community Hero campaign.

This campaign was designed to commemorate Parkinson's Awareness Month and provide opportunities for Support Groups to recognise their local supporters – while also raising their Groups' profiles within their communities.

The Heroes program was designed to recognise local community heroes who had assisted Support Groups. The 18 Support Groups which took advantage of this opportunity to generate publicity in their communities were:

- ✔ Chinatown Bilingual
- ✔ Dubbo
- ✔ Illawarra North
- ✔ Kiama
- ✔ Maitland
- ✔ Narrabri
- ✔ Newcastle
- ✔ Port Macquarie
- ✔ Tweed
- ✔ Coffs Harbour
- ✔ Eurobodalla
- ✔ Inner West
- ✔ Lismore
- ✔ Nambucca Valley
- ✔ Nepean/Blue Mountains
- ✔ Orange
- ✔ Snowy Monaro
- ✔ South Coast Young Onset and Nowra



Person-centred service delivery

Information and referrals via the InfoLine

The Parkinson's NSW InfoLine (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.

It also receives enquiries from Primary and Allied Health professionals.

During the past year, the InfoLine was staffed by two Parkinson's Registered Nurses who have a collective 70 years of professional experience.

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

Allied Health professionals were also added to the InfoLine team – including counsellors, a social worker, Support Coordinators, and a Parkinson's exercise specialist.

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 Co-Ordinator
- ✔ Specialist Movement Disorder Neurologists
- ✔ Vetted providers of 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
- ✔ Accommodation
- ✔ Aged Care placement
- ✔ Parkinson's research
- ✔ Holiday planning
- ✔ Disability Pension
- ✔ Aged Care Assessment
- ✔ Planning hospital stays

What information packs can the InfoLine provide?

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

No. of InfoLine calls received

TOTAL	2,237	%
<i>Living with Parkinson's</i>	1,007	45%
<i>Caregivers</i>	624	28%
<i>Other</i>	606	27%

No. of Infoline Packs Distributed

2019-20	274
2020-21	417
% change	+52%



Person-centred service delivery

Counselling services diversify and grow

The Counselling team remained at 1.5 Full Time Equivalent (FTE) professionals working across three locations in Sydney:

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

The Counselling team conducted 914 individual sessions during 2020-21, in addition to 114 group sessions. This represents a 5 percent increase in individual sessions and a 146 percent increase in group sessions over the past year.

190 of the individual sessions were conducted in person prior to the second wave of COVID-19 restrictions being imposed. The balance were by telephone and video-chat applications. The latter enabled Counsellors to support people in regional and rural areas, in addition to the Greater Sydney region.

The group sessions included face-to-face and Zoom visits with Parkinson's NSW Support Groups, and education sessions.

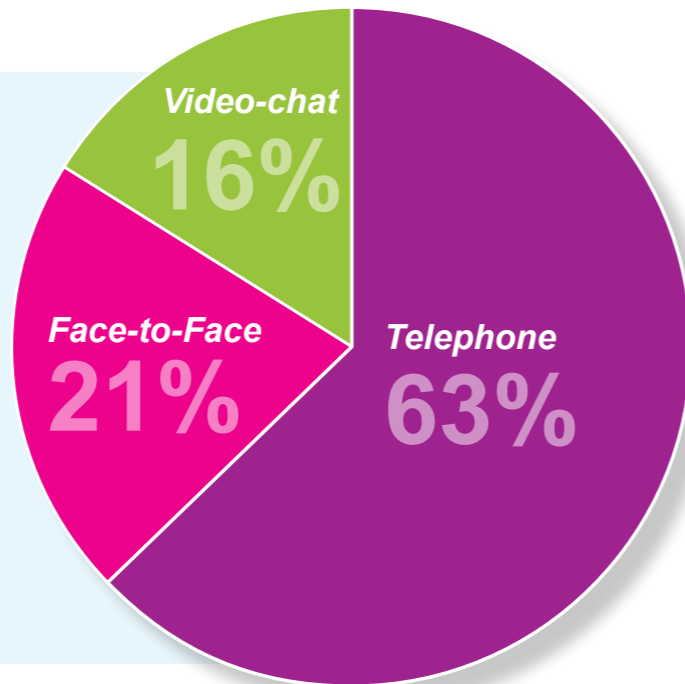
Modes of Counselling



68 Support Group Visits



46 Education Sessions



Sustainability

Fundraising grows donor 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 donors.

During 2020-21 we continued our strategies of the previous fiscal year, growing our base of donors and conducting telephone fundraising campaigns.

Lessons learned from telephone outreach during the first round of COVID-19 restrictions proved invaluable during the second round of lockdowns.

In particular, the telephone campaign has surpassed expectations and has enabled us to continue building our Parkinson's Partners – people who have generously committed to making regular monthly or quarterly donations.

Over the past year, we have been able to expand our base of generous regular givers by 27 percent.

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

We are now three years into a five-year plan to grow our donor base and one of the keys to the success of this plan is the implementation of a sophisticated database.

A professional database enables us to respect the preferences of each donor – particularly around when and how we communicate with them.

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



More than 16,500 donations were received over the course of 2020-21, including 7,500 from our 916 Parkinson's Partners.

In addition, \$1,458,679 was received as gifts in wills from 11 Estates.

A total of \$1,174,586 was raised through fundraising during the year, enabling the ongoing delivery of essential services to people living with Parkinson's.





Education adapts to meet demand

Over the past 12 months, there has been a significant decrease in face-to-face delivery of Education due to COVID 19 restrictions. However, Parkinson's NSW delivered six Aged Care education sessions in the first half of 2021 in Sydney, Port Stephens, and the South Coast.

It became clear when COVID-19 restrictions were implemented in 2020 that Parkinson's NSW staff could not enter Aged Care facilities to provide much-needed training on Parkinson's.

However, there was a mandated requirement for training that had to be met. It was therefore decided to develop a self-guided, online learning module for Aged Care support workers and nurses.

The initial version took six months to develop. Its content was based on the existing face-to-face education module, then enhanced and peer-reviewed by members of staff working to a minimal budget.

The cross-functional team involved in the project included the Education Coordinator, Parkinson's Specialist Nurses, educators, members of the Communications team, the Database Manager, and an external consultant.

Since the module was launched in late February 2021, 65 participants have completed the course and at the time of writing another 25 were registered. Feedback has been positive – particularly about information on medication management and freezing of gait in Parkinson's patients.

In the coming fiscal year, Parkinson's NSW will invest in a more robust learning platform which will enhance the look and feel of the Aged Care module, providing participants with a more interactive and effective experience.

At the end of fiscal 2020-21, a formal Education Advisory Committee was established to further develop the Parkinson's NSW Education Department as it embarks on new projects to deliver an enhanced range of online education modules.

This boost in resources will ensure that new modules are kept current and relevant to meet the evolving needs of the Aged Care sector – and are aligned with the recommendations of the Royal Commission into Aged Care Quality and Safety.

In addition to key staff members, this Advisory Committee will include external members who have expertise in Allied Health and curriculum writing to assist with the development of education programs.

New ways of inspiring exercise

The need to keep people living with Parkinson's engaged with their wellbeing and exercising regularly was never greater than during COVID-19 restrictions over the past year.

Accordingly, the Parkinson's NSW staff Exercise Physiologist explored new ways of reaching out to the Parkinson's community.

104 NDIS-funded Parkinson's personal training sessions were conducted over the year – in-person when permitted and via Zoom teleconferencing when personal contact was not possible.

In partnership with the Marketing and Digital team, 22 Wellness Wednesday exercise videos were produced and promoted via social media and hosted on the Parkinson's NSW YouTube channel. These productions are an ongoing initiative.

In addition, our Exercise Physiologist contributed exercise articles for every edition of the monthly InTouch newsletter and quarterly Stand by Me magazine.

As an Allied Health professional, our Exercise Physiologist is also leading a project to identify and vet the credentials of Allied and Complementary Health service providers with Parkinson's experience throughout NSW.

This work enables the InfoLine nurses to confidently connect callers with properly vetted services in their area of the state.

To date 189 Allied Health and 26 Complementary Health service providers have been fully vetted and added to the database.

Another 92 Allied Health practices and 48 Complementary Health service providers are still in the process of being vetted.

This project will be ongoing in order to accommodate changes and additions to the state-wide list of vetted providers.

 **104** Parkinson's personal training sessions conducted

 **22** exercise videos produced

 **215** service providers vetted



Growth in Parkinson's Specialist Nurse services

In the final quarter of 2020-21 a new Parkinson's Specialist Nurse was appointed to a position at Hornsby Ku-ring-gai Hospital in Sydney – an under-served area of the metropolitan area. The position is co-funded by Parkinson's NSW and the Northern Sydney Local Health District.

At the same time, 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 of the fiscal year, an offer was made to a highly qualified candidate who joined in October 2020.

These new roles brought Parkinson's Specialist Nurse resources in the state to 5.0 Full Time Equivalent (FTE) positions – including Coffs Harbour, Port Macquarie, the Tweed Region, Hornsby, and the Shoalhaven region.

This is an increase of 2 FTE over the previous year.

All together over the year, Parkinson's Specialist Nurses delivered 26,614 occasions of service and added 479 new patients to their lists.

They conducted 2,013 nurse-patient consultations including 637 home visits and participated in 169 neurological consultations.

Nurses also supported 454 device-assisted therapies – including Deep Brain Stimulation (DBS), and Duodopa and Apomorphine.

Over the year, the Telehealth program grew from a pilot with St Vincent's Hospital Department of Neurology into a fully-fledged program involving three Sydney and one regional hospital, and five participating neurologists.

The Telehealth program enabled uninterrupted support, despite the challenges of distance and COVID-19. Our nurses participated in 938 Telehealth consultations during the year.

Activity	2019-20	2020-21	% Change
New referrals	181	479	+164%
Face to face consultations	1,551	2,013	+30%
Phone consultations	3,000	3,474	+16%
Home visits	472	637	+35%
Kilometres travelled	34,605	39,096	+13%



Nurse Suliana and Rebecca

At the very end of fiscal 2020-21 – after extensive advocacy and representations to the State Government – the Treasurer of NSW announced a package of \$8.6 million in the form of a one-time capacity building grant to Parkinson's NSW plus ongoing funding for Movement Disorder nurses and Allied Health staff over the next four years.

At the time of writing, negotiations on the service delivery model and placement of the new nurses were ongoing.

Modes of Counselling

-  **479** New Referrals
-  **2,013** Face to Face Consultations
-  **3,474** Phone Consultations
-  **637** Home Visits
-  **39,096** Kilometres Travelled
-  **177** GP Interactions



Person-centred service delivery

Strong growth in NDIS services

Parkinson's NSW gained Registered Service Provider status with the National Disability Insurance Scheme (NDIS) in the 2018-19 financial year. Over the two years since, we have steadily grown our range of services offered in this space.

This NDIS relationship is both a requirement of NSW Government policy and an additional source of revenue for Parkinson's NSW to help underwrite all service delivery.

NDIS Advocacy

During 2020-21, our Parkinson's NDIS Advocate guided 114 people aged under 65 and living with Parkinson's through the complexities of applying for NDIS funding.

Under NDIS rules, a diagnosis of Parkinson's alone is not enough to qualify a person for NDIS Support. Applicants need to prove the impact that Parkinson's is having on their life, which involves obtaining reports from specialists detailing this.

The Parkinson's NDIS Advocate can be your guide through this and the rest of the application processes.

At the time of writing, 86 people had been successful in their applications for NDIS packages, and the balance of applications were ongoing. Of that number, 54 people had chosen Parkinson's NSW to deliver their Support Coordination services.

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.

Over the year, we have grown our one part-time Support Coordinator role to 2 Full Time Equivalent (FTE) staff.

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

During the year under review, the Support Coordination team took on 35 new clients. This brings the total number of clients supported to 57.



93% of participants have Occupational Therapy, Physiotherapy, Speech Therapy and Domestic Assistance



75% of participants have Exercise Physiology and specialised Parkinson's exercise programs



65% of participants have assistance with transport



Collaboration with impact

Digital & Marketing team builds connections

The priorities of the Digital & Marketing team over the past year have been to:

- Support fundraising.
- Keep the Parkinson's community informed about COVID-19.
- Strengthen connections while people were socially isolated and unable to access their usual peer support via in-person Support Group meetings.
- Support ongoing advocacy for increased funding of community-based Parkinson's Specialist Nurse roles.

The lessons learned and capabilities developed during the first COVID-19 lockdown enabled a fast reaction to the second round of the pandemic.

There was strong focus on using existing tools such as email, Facebook and Zoom video-chat software to connect and keep informed Support Group participants and other members of the Parkinson's NSW community during the pandemic.

In the previous fiscal year, the monthly *InTouch* newsletter for Support Group members was redeveloped into an Electronic Direct Mail (EDM) format and delivered on a bi-monthly publishing schedule.

The format continued through until the end of the year under review, then reverted to a monthly EDM publication. It still includes a Portable Document Format (PDF) version that permits users to print out the newsletter if required.

The Stand by Me magazine continued on its quarterly schedule during the year, delivered both as an EDM and in a limited hard copy print run.

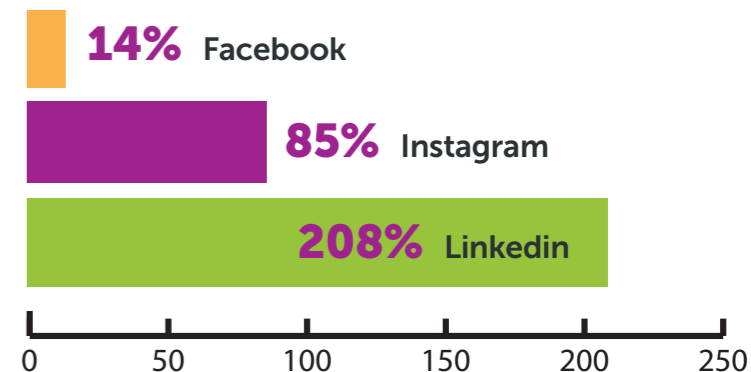
There was 62 percent organic growth in email subscriptions over the fiscal year, and the email open rate increased by 13 percent.

Social media and the Parkinson's NSW web site again recorded significant growth, engagement and reach over the past year.

The web site attracted 24,000 new visitors and repeat visits doubled. There was a 26 percent increase in blog readership.

Our social media reached 1.4 million more people in 2020-21 and achieved 25 percent more engagement with content. More than 45,300 minutes of video was viewed via social channels.

Social media follower numbers also continued to grow:



50/50 Online Raffle

Having run three 50/50 Online Raffles during the previous financial year, the Digital & Marketing and Fundraising teams offered another two Raffles over the 2020-21 year with total cash 'pots' of \$11,620.

50/50 Online Raffle tickets were sold through a secure, purpose-built web site at \$10 each and the 'pot' was split equally between the winner and Parkinson's NSW.

No Escape Room

The No Escape Room campaign developed by Parkinson's NSW with marketing agency Wunderman Thompson and production company AIRBAG came to fruition in the final quarter of fiscal 2019-20 and launched in July 2020.

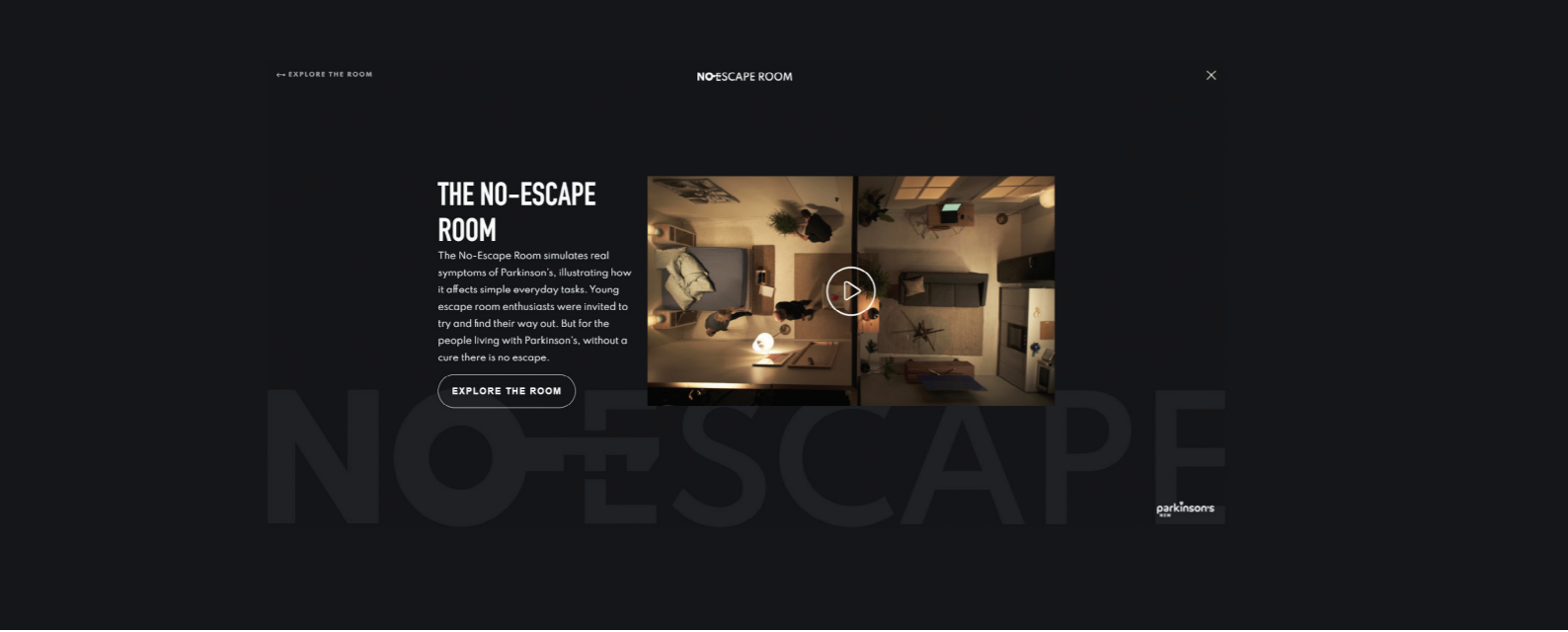
The interactive project was designed to raise awareness, giving people an insight into the daily challenges of living with Parkinson's by completing a series of puzzles representing Parkinson's symptoms.

Fifteen of Australia's top escape room experts were brought together under the guise of testing a new pop-up escape room.

However, what they 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. All captured on video and can be viewed at 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.





“The shoelace challenge, that’s pretty indicative of what it can be like if you’re having an off day,”

explains Gavin who is living with young onset Parkinson’s and is the narrator on the No Escape Room project.

An escape room is a popular game 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 usually within a set timeframe.

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 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.

The No Escape Room attracted both national and international recognition and media coverage.

Media outlets and organisations which publicised the project included *Mumbrella*, *Bandt*, *Parkinson’s Life*, the European Parkinson’s Disease Association, *Pro Bono Australia*, *MindFood* magazine, *Campaigns of the World*, *Branding in Asia*, and *The Project*.

It garnered award nominations for innovation, brand experience, creativity, and collaboration, becoming a Spikes Asia finalist and being shortlisted in the 2020 Caples Awards

Social media reached an audience in excess of 136,000 people in the first two days of the project launch and still attracts audiences locally and internationally.

Advocacy

Right at the end of 2020-21, there was an exciting outcome resulting from four years of advocacy and outreach to government and key healthcare decision-makers.


On 22 June it was announced that the 2021-22 NSW State Budget includes an \$8.6 million package to support people living with movement disorders – including Parkinson’s.

The package will fund 15 specialist nurses and Allied Health staff across NSW to improve access to treatments and quality of life for people with movement disorders – particularly in regional and rural areas.

It also includes \$650,000 in funding for Parkinson’s NSW for information, education, and service delivery.

Negotiations concerning the nursing model to be used and how the funding will be disbursed are ongoing.

 **62% growth in subscriptions**
13% increase in open rate

 **24,000 new visitors**
200% repeat visitors doubled
26% increase in blog readership

 **Reached 1.4million more people**
45,300 minutes of video viewed

Parkinson’s NSW Board



President – Margaret Scott

Margaret Scott was appointed to the Board of Parkinson’s NSW in November 2019 and President in February 2021. 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.



Vice President – David Veness

David Veness joined the Board as a non-metropolitan representative. He was diagnosed with Parkinson’s twelve 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. David enjoys exercise and encourages all those with Parkinson’s to try and exercise regularly. 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 PNSW Board, David has frequently travelled and met Support Groups throughout NSW to help lobby politicians for more nurses in regional areas. David is retired and his background is in hospitality and banking. He ends his seven years on the Board this year and will step down as of the 2020-21 Annual General Meeting.



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 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, University of NSW, the City of Sydney and Spotless Services Limited. She is currently the Director of Operations at ReachOut Australia.



Director – Steve 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 nine 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 – including finance, risk management, logistics, people management, training, and digital marketing.



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 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.

Parkinson’s NSW thanks Denise Thomas and Edward Shepherd for their service on the Board.

Name	Aug	AGM	Nov	Feb 2021	May
Janina Jancu	☑	☑	☑	☑	☑
Steve Schiemer	☑	☑	☑	☑	☑
Nicole Schleicher	☑	☑	☑	☑	☑
Margaret Scott	☑	☑	☑	☑	☑
Denise Thomas	☑	☑	N/A	N/A	N/A
David Veness	☑	☑	☑	☑	☑

Board Meeting attendance record 2020/2021:



