



Annual  
Review  
2018/2019



# Parkinson's Australia Incorporated

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DEAKIN WEST ACT 2600

Parkinson's Australia is registered as a Public Benevolent Institution with the Australian Charities and Not-for-Profits Commission

## About Us

Parkinson's Australia is the national peak body and charity representing more than 100,000 Australians living with Parkinson's. We advocate for the needs of people living with Parkinson's, and for their families and carers.

Parkinson's Australia represents, at the national level, the interests of its federation of state and territory members on all matters relating to Parkinson's and carer issues.

We are committed to achieving a Parkinson's-friendly society where people living with Parkinson's, their carers and family members are supported, respected, empowered, and engaged in community life.



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# President's Report

This is my first report as President of Parkinson's Australia having commenced as Chair in October 2018. I thank the previous President, Mr Vince Kelly, for his tireless work for Parkinson's Australia and the Parkinson's community, having sat on the Board for three years.



2018/19 has been an important transition year for Parkinson's Australia as we continue to advocate for better care and support for people living with Parkinson's. We continue to work with our community to ensure that Federal and State politicians are aware of the issues of people living with Parkinson's and put in place the programs that meet the needs of our Australian community. Whilst we are only a small organisation, we are having an impact and the Australian government has provided \$5.8 million for increased access to Parkinson's Specialist Nurses and an increased investment and capacity building in research for better treatments and a cure for Parkinson's of over \$30 million for the Australian Parkinson's Mission.

We do face a number of challenges over the next couple of years. We need to determine how we ensure the long-term financial viability of Parkinson's Australia and how we continue to provide the best service to our members and the Parkinson's community. The Board has put in place a process to work with our members and other significant stakeholders to progress these issues and to chart a future course for the continuing success of Parkinson's Australia.

A major change this year was the announcement that our CEO of the last few years, Mr Steve Sant, decided to pursue a different career direction. Steve played a part in many of the achievements for Parkinson's Australia and on behalf of the Board I thank him and wish him well in his future endeavours. Early in 2019 the Board of Parkinson's Australia undertook a rigorous selection process and appointed a new CEO in May, Ms Jodette Kotz, who has extensive experience in health advocacy, Australian government and political processes and is well suited to lead our collaborative efforts in political and health circles.

The achievements of Parkinson's Australia would not be possible without the generous contributions of my fellow Board members and the staff of Parkinson's Australia and I thank them for their support during this transition phase.

A handwritten signature in black ink that reads "Mo Watson".

**Dr Moira Watson**  
President & Board Chair, Parkinson's Australia

# Treasurer's Report

Parkinson's Australia remains in a solid financial position with net assets of \$651,249 at 30 June 2019, slightly up on the prior year. This includes cash and cash on deposit of \$684,708.



While revenue in the year was \$405,335, this included a bequest for \$100,000 and under the terms of the bequest these funds are to be spent on research and/or education. The Board is in the process of considering how the bequest will be spent and once approved, a provision will be recorded in the Statement of Financial Position to reflect the amounts to be spent on the research/education. Excluding this bequest, revenue was slightly up on the prior years' revenue of \$284,609.

Consistent with the prior year, the Board and Management have continued to focus on maintaining expenses at an optimal level. While expenses in the year increased to \$366,712, the majority of this increase related to additional employment costs and travel relating to the transition to our new CEO. Our new CEO commenced employment in May 2019 and Mr Steve Sant remained with PA until 30 June 2019.

And as noted above, the profit of \$38,623 needs to be considered in the context of the bequest, where the related research/education expense will flow in 2020, and possibly beyond, as incurred.

The 2020 budget has been approved by the Board. The Board considered the financial implications of employing a policy and project officer and remains confident these additional costs can be adequately funded during 2020 from the existing net assets.

A full copy of the audited financial statements is available on the Parkinson's Australia website.

A handwritten signature in black ink, appearing to read 'Steve Ferguson'.

**Steve Ferguson**  
Treasurer, Parkinson's Australia



# CEO's Report

First, I'd like to take a moment to say thanks to Mr Steve Sant, the outgoing CEO. Steve's efforts to raise the profile of Parkinson's have been significant.



The World Health Organisation observes that neurological disorders, such as Parkinson's, "are one of the greatest threats to public health".

There is much that can be done that can improve the quality of the lives of people living with Parkinson's. Advocacy can be a slow process and, in times of when there are multiple calls on the Australian Government for assistance, it is critical that we continue to work together to provide a unified voice to Federal and State Parliaments.

Our policy work has continued with the development of submissions and positions statements provided to government.

This work is not only important from an advocacy perspective but supports our collaboration with other peak bodies in the consumer and neurological space. These collaborations have produced strong pieces of advocacy work and a unified voice in Parliament for people with Parkinson's.

We have also sought significant support for services for people with Parkinson's through the Government grant processes.

I'm honoured to represent people living with Parkinson's and the one million people in Australia who are directly impacted by Parkinson's through being a carer, close relative or friend of someone living with Parkinson's.

I look forward to a productive 2019/2020 with a strong focus on improving the lives of people with Parkinson's.

A handwritten signature in blue ink that reads "Jodette Kotz".

**Jodette Kotz**  
CEO, Parkinson's Australia







# Australian Parkinson's Mission

On 30 January 2019 the Federal Minister for Health, The Hon. Greg Hunt MP, announced funding of \$30 million over five years in funding from the Medical Research Future Fund. The Australian Parkinson's Mission aligns with many of the priorities of the Medical Research Future Fund, which includes addressing areas of unmet need, genomics and developing new treatments from drug repurposing. It is hoped that this will enable the Australian Parkinson's Mission to identify desperately needed disease modifying drugs with the potential to slow the progression of Parkinson's.

The Australian Parkinson's Mission is an innovative program combining clinical trials with genomics research for people with Parkinson's, which is the largest investment in Australian Parkinson's research to date.

The Australian Parkinson's Mission will test repurposed drugs in a world-first in Parkinson's clinical trial design, which means effective person-centred treatments can be identified and fast-tracked to people with the disease. Sequencing the genome of each patient, will allow the Australian Parkinson's Mission to establish a first step toward personalised medicine for Parkinson's patients and will drive drug discovery in the future.

The Mission is an Australian-led international collaboration, developed by the Garvan Institute of Medical Research, Shake It Up Australia Foundation, Parkinson's Australia, The Cure Parkinson's Trust and The Michael J. Fox Foundation for Parkinson's research.





# Neurological Nurses

In December 2018, the Australian Government announced that it would support a Neurological Nurse Project.

The Neurological Nurse Specialist Pilot Project will improve access to specialised nursing care in the community for people living with Parkinson's disease. This will be achieved by providing funding to pilot, in up to 15 sites, integrated nurse-led models of care in the community for this group of patients. Pilot locations will focus on attracting specialist nurses in a community setting and upskilling nurses in primary care. Parkinson's Australia has advocated for rural and remote locations to be a focus of the pilot.

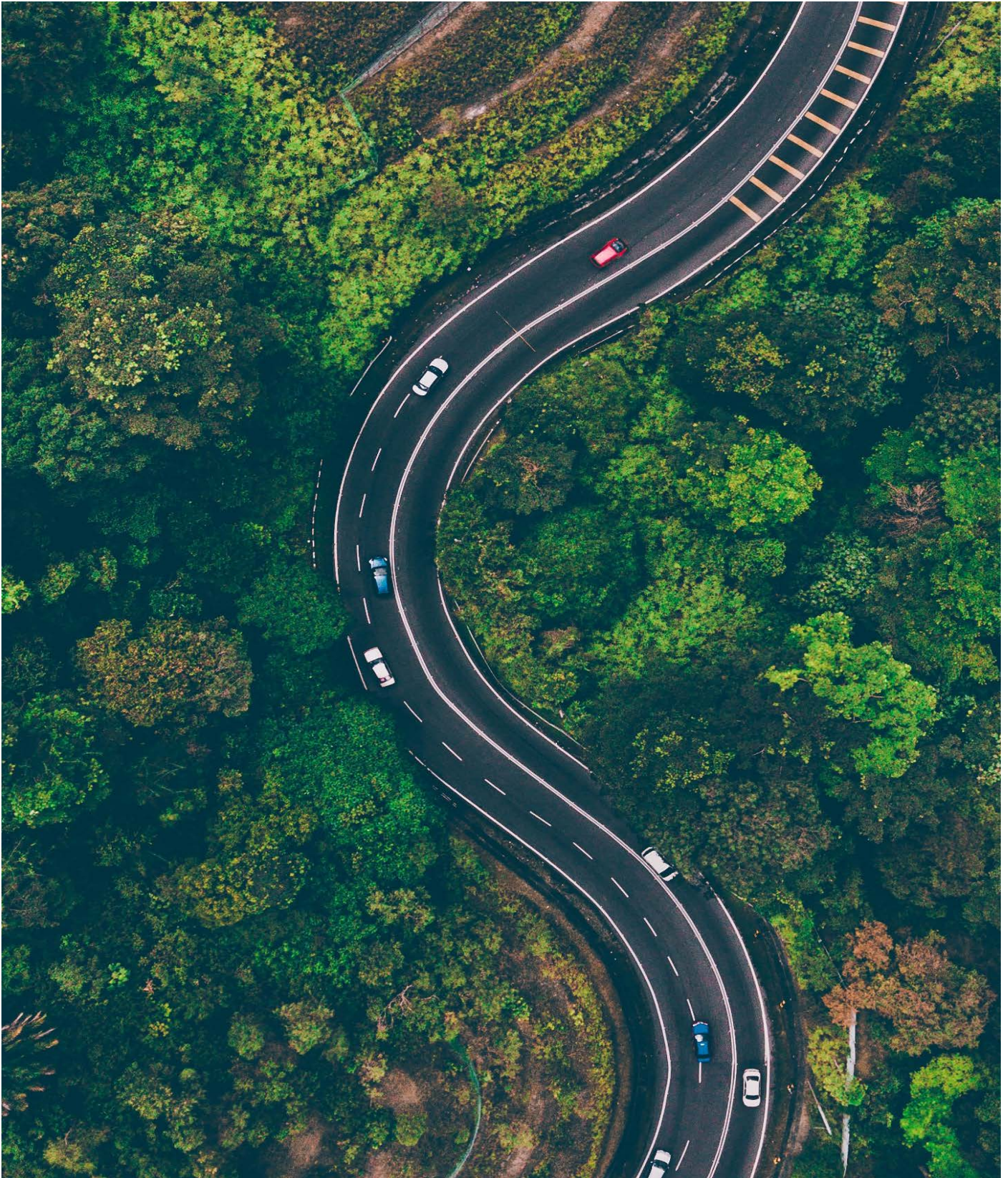
Total Commonwealth funding for this project is \$6.4 million over five years (2019-20 to 2023-24), and this includes funding for evaluation which will help us develop evidence to support nurse programs on a National level.





# Australian Parkinson's Cure Roadmap

The Australian Parkinson's Cure Roadmap provides guidance to the government, community, clinicians and the research community to help us answer critical questions about the causes of Parkinson's, the best evidence-based treatments and management approaches, and ways to slow, stop the progression of Parkinson's and the development of a cure in the not too distant future.





# Position Statements & Submissions

Parkinson's Australia represents people with Parkinson's, their carers and the Parkinson's sector to the Australian Government. To this end, a number of submissions were developed ensuring issues that impact upon people with Parkinson's were considered in the development of policy. Parkinson's Australia works collaboratively with a number of organisations such as the Consumer Health Forum, Palliative Care Australia and the Neurological Alliance Australia to develop policy submissions and position statements.

## The 2019 Pre-Budget Submission

Parkinson's Australia called for:

- Recognition of Parkinson's as a National Health Priority Area;
- Investment in better care and support for people living with Parkinson's
- Investment and capacity building in Parkinson's research
- Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's.

## Election Commitments

Parkinson's Australia developed a strong election campaign as a member of the Neurological Alliance Australia (NAA).

The NAA sought commitments from candidates from all sides of politics to address the urgent needs of adults and children living with progressive neurological or neuromuscular diseases in Australia. We develop a strong and simple message.

People with progressive neurological or neuromuscular diseases have two basic needs:

1. A Cure
2. Improved support for their treatment, care and management.



## Media

**Website  
Visitors  
68,054**

**Newsletter  
Subscribers  
2,000**



**Facebook  
Followers  
3,534**

**Twitter  
Impressions  
39,900**

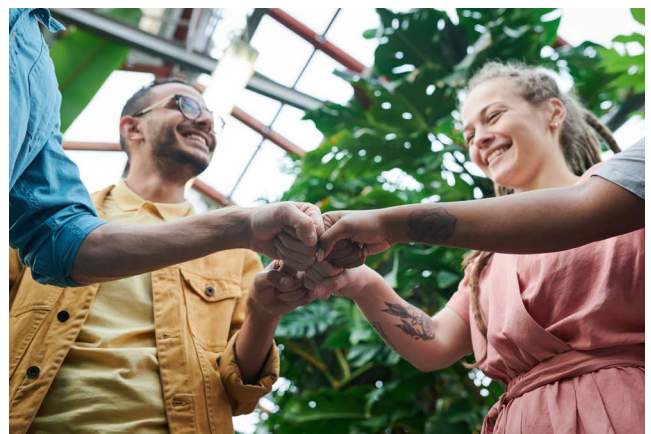
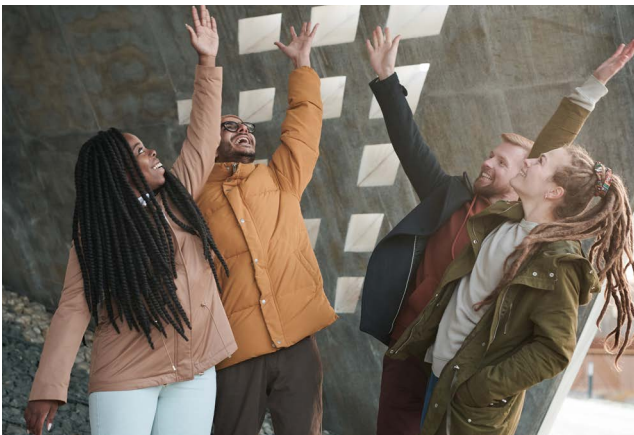


# Alliances

Parkinson's Australia is forming strong coalitions with like-minded groups. These alliances allow for broader engagement. The Neurological Alliance Australia (NAA) is an alliance of national not-for-profit peak organizations representing adults and children living with progressive neurological or neuro-muscular conditions in Australia. It provides a national voice for all people with a neurological condition.

The NAA aims to promote improved quality of life for people living with these conditions and funding to support research. Parkinson's Australia supported the development of the NAA 2019 election campaign and pre-budget submission.

Parkinson's Australia works closely in partnership with the Shake It Up Australia Foundation. We are engaged in advocacy development with international Parkinson's Organisations and we are a World Parkinson's Coalition Partner.





# Parliamentary Friends of Parkinson's

The Parliamentary Friends of Parkinson's Group ceased at the dissolution of Parliament in 2019. We extend our heartfelt thanks to Ms Ann Sudmalis, who was the member for Gilmore, NSW. Ann retired from a long career in Parliament at the expiration of her term in 2019. We also extend our thanks to the co-convenor Senator Carol Brown. The Parliamentary Friends groups provide an apolitical forum to work on solving issues for people with Parkinson's.



**Ann Sudmalis**



**Senator Carol Brown**

Our thanks are also extended to the previous members of our group, some of which have re-joined, and some of which did not return after the 2019 election.

The Parliamentary Friends of Parkinson's has reconvened. Parkinson's Australia held informative meetings with Senator Wendy Askew and Senator Catryna Bilyk who are the convenors of the group. Both Senators are very interested in helping people with Parkinson's and will be strong supporters in Parliament House.



**Senator Wendy Askew**



**Senator Catryna Bilyk**



## In Memorium



Parkinson's Australia wishes to acknowledge the donations which have been given by families and friends in memory of the following people. The thoughtfulness of the families in arranging for donations to be given to Parkinson's Australia is greatly appreciated.

### 2018/2019 Donations received in memory of

|                  |                   |                 |                  |                |
|------------------|-------------------|-----------------|------------------|----------------|
| Alex Gilroy      | Deirdre Gallagher | Joe Oakley      | Patrick Jungk    | Ted Hancock    |
| Andrew Jeffers   | Diann Cooper      | John Claughton  | Paul Hurley      | Thomas Warring |
| Anna Frichot     | Donald Hobkirk    | Joseph Catania  | Pauline Kennedy  | Warren Pearson |
| Barbara Probert  | Douglas Field     | Joy Hudspeth    | Peter Barton     | William Playle |
| Barbara Westwood | Eleni Harris      | Kim Bluett      | Phil Booth       |                |
| Barrie O'Brien   | Emilio Sasso      | Lorna Seeligar  | Richard Rowland  |                |
| Bob Shorten      | Erica Hasselmeyer | Malc McGregor   | Richard Starr    |                |
| Bruce Spender    | Fred Blacha       | Maree Larkings  | Ronald Hansen    |                |
| Carole Trevenna  | Graham Sincock    | Maureen Dunn    | Rosa Canturi     |                |
| Clem Tonkin      | Helen Donnelly    | Michael B.      | Rosaria Rendina  |                |
| Coral Coleman    | Helen Lawrence    | Michael Withall | Russell Phillips |                |
| Daphne Robinson  | Iain McDougall    | Neville Haines  | Simon Dash       |                |
| David Knight     | Ian Kidd          | Nick Karaviotis | Susan Bain       |                |
| Dawn Graham      | Jill Ruxton       | Patricia Oliver | Susan McDougall  |                |

### Parkinson's Australia also wishes to acknowledge the following people and organisations for their generous philanthropy

|  |                             |
|--|-----------------------------|
| Audrey Balmaceda                       | Roxanne Lee                 |
| Catherine Tobin                        | Samsung C&T Corporation     |
| D Heim                                 | Shreeve & Carslake Pty Ltd  |
| EY                                     | TG & JM Matthews Foundation |
| Glenn Sanders                          | William Spears              |
| June Summers                           |                             |
| Katz Family Foundation                 |                             |
| Kooweerup Secondary College            |                             |
| MGA Whittles Foundation Inc            |                             |
| Moelis Australia Foundation            |                             |
| Paul Wilson                            |                             |
| Paypal Giving Fund                     |                             |
| Richard Gordon Rowland Deceased Estate |                             |

Thank you to everyone who has chosen to make a donation, whether it be a one off donation or a regular weekly or monthly donation. No matter how small, your support is greatly appreciated.

# Governance

## The 2019/20 Board



**Dr Moira Watson**  
President  
Board Member (Independent)



**Professor George Mellick**  
Vice-President  
Board Member (QLD)



**Steve Ferguson**  
Treasurer  
Board Member (Independent)



**Brigadier John Sheldrick**  
Board Member (ACT)



**Glenn Rees**  
Board Member (Independent)



**Hon John Doyle QC AC**  
Board Member (SA)



**Rod Lillywhite**  
Board Member (WA)



**David Veness**  
Board Member (NSW)



**Mike Whitehouse OAM**  
Board Member (TAS)

## Board Members 2018/2019 financial year - Retired

**Vince Kelly**  
President  
Board Member (Independent)  
RESIGNED 28-09-18

**Andrew Whitton**  
Board Member (NSW)  
RESIGNED 24-10-18

**Helen Connor-Kendray**  
Board Member (TAS)  
RESIGNED 07-10-18

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## Members of Parkinson's Australia - 2018/2019

- Parkinson's Australia Capital Territory
- Parkinson's New South Wales
- Parkinson's Queensland
- Parkinson's South Australia
- Parkinson's Tasmania
- Parkinson's Western Australia

## Parkinson's Australia Staff - as at 30 June 2019



**Steve Sant**  
Retiring CEO & Public Officer



**Jodette Kotz**  
Incoming CEO & Public Officer



**Angela Arkadieff**  
Administration Officer



# Facts About Parkinson's

Parkinson's is the second most common neurological condition in Australia but remains one of the least understood

OVER  
**100,000**  
AUSTRALIANS HAVE  
PARKINSON'S

MORE THAN  
**1M**  
AUSTRALIANS  
ARE IMPACTED

**53%**  
ARE MALE

**47%**  
ARE FEMALE



Someone in Australia is  
diagnosed with Parkinson's  
every 47 minutes



The total economic cost  
of Parkinson's is around  
\$10.9 billion p.a.

OVER  
**35 PPL**  
DIAGNOSED  
EVERY DAY

OVER  
**12,650**  
NEW CASES  
EACH YR

OVER  
**13,200**  
OF WORKING  
AGE

OVER  
**2,530**  
ARE IN THEIR  
30s & 40s

OVER  
**10,000**  
ARE IN CARE  
FACILITIES

OVER  
**82%**  
ARE OVER  
65YRS



Based on the Deloitte Access Economics Report 2014/2015.  
These figures have been updated to reflect the estimated  
prevalence in 2018/2019