



IN THIS TOGETHER
parkinson's
AUSTRALIA

Annual
Review

2018/2019

Parkinson's Australia Incorporated

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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 cursive script that reads "Moira 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', written in a cursive style.

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". The signature is fluid and cursive.

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.

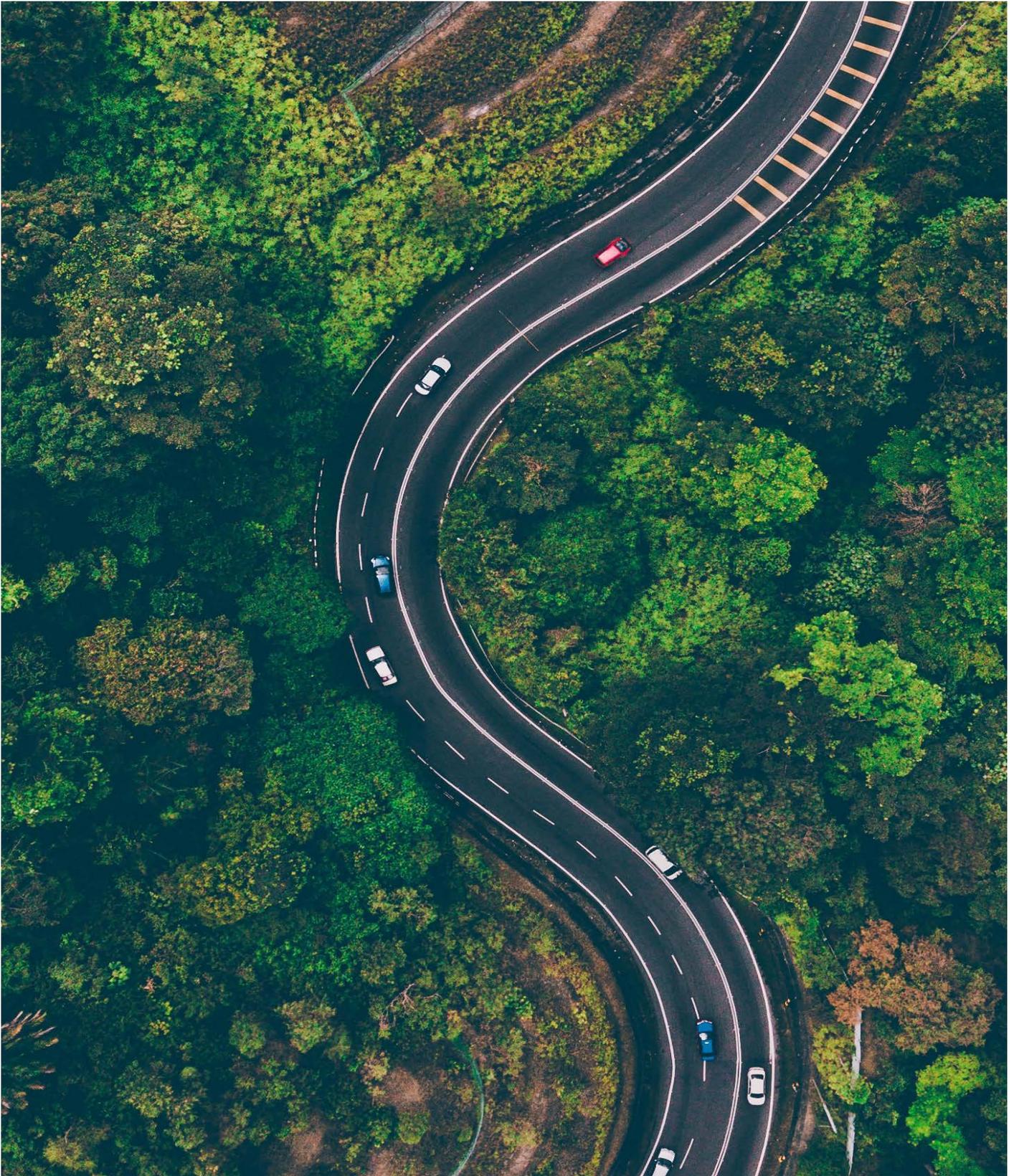
The Neurological Nurse Specialist Pilot Project will improve access to specialised nursing care in the community for people living with Parkinson's disease. This will be achieved by providing funding to pilot, in up to 15 sites, integrated nurse-led models of care in the community for this group of patients. 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**

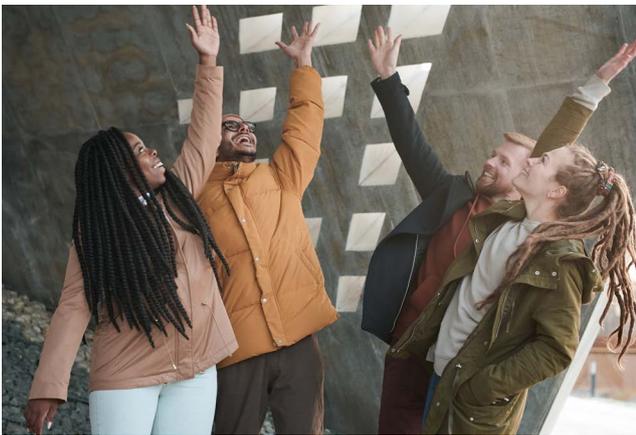
**Twitter
Impressions
39,900**

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

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

