

STANDBYME

Parkinson's NSW Limited | Issue 133 Summer 2018
ISSN 1839-0269



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From the CEO

Welcome to the latest issue of *Stand By Me*.

Parkinson's NSW held its Annual General Meeting in October. In voting prior to and at that meeting, members elected a new Board of six Directors who will serve three-year terms.

Both past Directors and new candidates were eligible for the election which was managed by an independent external service provider – the Australian Election Company.

Past Directors re-elected to the Board are David Veness, Jaimee Thompson, Rodney Chaplin, and Ramy Soussou. First-time Directors are Stephen Schiemer and Edward Shepherd. Two of the newly-elected Board members are living with Parkinson's and another is a carer for an immediate family member with Parkinson's.

Speaking at the meeting, President David Veness thanked past and re-elected Directors for their dedication and guidance of Parkinson's NSW, and welcomed the two first-time Directors who bring new skills to the Board.

I fully support David's endorsements. As CEO charged with executing our strategy over the coming years, I will be relying on the diverse skills and strong business and sector experience of our new Board for guidance and support.

Developing and growing services for people living with Parkinson's is truly a team effort. The election of this new Board has further strengthened the Parkinson's NSW team.

Short biographies of all Directors on the new Board can be viewed at: <http://www.parkinsonsnsw.org.au/about-us/board-and-executive-2/>

Jo-Anne Reeves
Chief Executive Officer



Education seminars

During the past year, Parkinson's NSW have delivered 18 Community Education Seminars across Sydney and regional areas in New South Wales. The seminars were designed following extensive consultation with Support Groups. The feedback received from people living with Parkinson's and their carers was there is a lack of up-to-date information available about Parkinson's, its symptoms and the treatments and therapy options available to minimise the impacts and improve quality of life.

Education and information was delivered by experts in Parkinson's including neurologists, registered nurses, qualified counsellors, exercise physiologists, physiotherapists and speech therapists.

Planning of 2019 education programs is currently underway. The first seminars for the coming year will be published on the Parkinson's NSW website and on our Facebook page.

Stay up to date by choosing to receive information and news directly to your inbox. Sign up on our website www.parkinsonsnsw.org.au or call the Parkinson's NSW InfoLine on 1800 644 189



Conference draws leading researchers

More than 90 representatives from Parkinson's NSW Support Groups from across NSW recently participated in our annual Support Group Conference in Sydney.

Participants heard from speakers, received updates on the latest in research and treatments for Parkinson's, and had many opportunities to share ideas with other people living with Parkinson's.

The presenters included John Watkins AM, former Deputy Premier of NSW who has himself been diagnosed with Parkinson's and neurologist Professor Simon Lewis from the Brain & Mind Centre of the University of Sydney. Associate Professor Rachel Rossiter of Charles Sturt University – who is conducting research into the value of Parkinson's nurses based in regional communities – also gave a detailed update on her team's progress.

There were also demonstrations of music, dance, art, exercise, non-contact boxing and meditation for people living with Parkinson's. The conference included the awarding of research grants for studies aimed at improving the quality of life for people living with Parkinson's, and eventually finding a cure. Read more about the research grants awarded on page 5.

Professor Simon Lewis also spoke at a sold-out public seminar during the conference. In his topic *Is CURE a four-letter word for Parkinson's?* Professor Lewis talked beyond falls and constipation, and also answered a variety of questions from attendees in the room as well as social media followers.

You can find the video of his presentation, complete with subtitles on our website <http://www.parkinsonsnsw.org.au/media-centre/support-group-conference-2018/>



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Community Parkinson's nurse research scores goals

A major research project into the effectiveness of neurological nurses supporting people living with Parkinson's in regional communities has passed another major milestone.

Stage 1 – a literature review – has been completed and is already attracting keen interest. Stage 2 is now well underway. This involves an analysis of data and outcomes achieved by the Parkinson's NSW nurse embedded in the Coffs Harbour community. It will enable a comparison of two different nursing models.

The research is being conducted on behalf of Parkinson's NSW by the School of Nursing, Midwifery and Indigenous Health of Charles Sturt University (CSU).

The project – the first of its kind in Australia – is also measuring the potential cost-savings to Government through this decentralised approach to supporting Parkinson's patients.

This research has global significance and is being considered for presentation at the Parkinson World Congress in Kyoto, Japan, in June next year.

The third and final stage of the research project will involve interviewing people who participate in

Government grant supports Parkinson's nurse research

The NSW Government has made a \$30,000 grant towards Parkinson's NSW research into the value and potential cost savings of community-based neurological nurses.

A cheque was presented at Parliament House Sydney by John Barilaro MP, Deputy Premier and Leader of the Nationals, to David Veness, President of Parkinson's NSW.

Parkinson's NSW has engaged the School of Nursing, Midwifery and Indigenous Health of Charles Sturt University to conduct research into the effectiveness of nurses supporting Parkinson's patients at home in rural and regional communities.

The project – the first of its kind in Australia – is also measuring the potential cost-savings to Government through this decentralised approach to supporting Parkinson's patients. Work presented to date has already attracted international attention from researchers and healthcare providers in the Parkinson's community.

Parkinson's NSW Support Groups in regional areas of NSW.

This stage will identify why people affected by Parkinson's attend Support Groups, how they benefit from participating, and what regional healthcare needs are currently not being met.

The entire research project is expected to be completed by the end of 2019 and results will be shared with all Support Groups, as well as GPs, Neurologists, allied health professionals, Local Health Districts and State and Local Government.

Read more about the research project on our website.

<http://www.parkinsonsnsw.org.au/media-centre/parkinsons-nurse-research-scores-goals/>



"We believe evidence gathered during this project will support our view that the placement of neurological nurses in rural and regional NSW will improve the quality of life of people living with Parkinson's, and achieve significant savings in the State health budget," said David Veness.

To have this research considered for presentation at the World Parkinson Congress is a great achievement for Australian researchers.

John Barilaro MP with David Veness, President of Parkinson's NSW



\$300,000 in research grants awarded

Parkinson's NSW awarded grants totalling \$300,000 to four prominent researchers at the Support Group Conference Annual Dinner in Sydney last month.

A number of leading Parkinson's researchers, their publications and ongoing research projects were assessed by the Research Advisory Board of Parkinson's NSW before the final recipients were selected.

The grants were awarded on the night by Jo-Anne Reeves, CEO of Parkinson's NSW and David Veness, President of Parkinson's NSW.

Associate Professor Antony Cooper

of the Garvan Institute of Medical Research was awarded a grant of \$100,000 for his work on Blood RNA biomarkers to measure the progression of Parkinson's.

Why this is important:

Since no treatment has been identified that can slow or stop the progression of Parkinson's, it is important to identify a reliable method of tracking the progress of the disease, so medication can be prescribed appropriately. This research seeks to identify sets of blood biomarkers which would track the severity of Parkinson's symptoms including motor/movement, cognition, anxiety and depression.

Dr Natalie Allen was awarded a \$100,000 grant for her Integrate: Safe Mobility in PD program. Dr Allen is a lecturer in Neurological Physiotherapy at the University of Sydney.

Why this is important: People with advancing Parkinson's experience worsening mobility and falls in spite of medical management of symptoms. This research aims to develop an integrated environmental, behavioural and exercise program to improve safe mobility for people with Parkinson's. It could be delivered in their homes by expert therapists, enabling people with Parkinson's to live safely at home for longer.



Dr Michal Lubomski, a PhD candidate at the University of Sydney, was awarded a seed grant of \$50,000 for his research into gut microbiome changes in Parkinson's disease.

Why this is important:

The gut microbiome profiles the bacteria living within the gastrointestinal tract of an individual. It is sensitive to biological and environmental changes and may be related to the progression and management of Parkinson's as it advances. Monitoring gut microbiome changes can provide information on how to improve the administration of therapies.

Dr Milena Gandy was awarded a \$50,000 seed grant for her research into supporting emotional and cognitive wellbeing in adults with Parkinson's. Dr Gandy is a Postdoctoral Research Fellow and Clinical Psychologist at Macquarie University.

Why this is important:

This project involves the development and evaluation of a free online program to support the mental health and cognitive function of people with Parkinson's.



Pump for Parkinson's raises \$5000 in Coffs Harbour

The Coffs Harbour community rallied to support a novel Pump for Parkinson's fundraiser initiated by a local service station. It pledged to donate 10 cents per litre of petrol sold over a 24-hour period.

Bailey Centre Liberty Service Station ran the fundraiser for the second year in a row. This year, local freight and courier company P.K. Express joined in with a pledge of an additional 5 cents per litre sold.

The result was a combined donation of \$5000 to support the ongoing work of our Parkinson's neurological nurse based in Coffs Harbour.

More than 30,000 litres of fuel were sold during the 24-hour fundraising period – 5,000 litres more than usual day sales.

"Our goal was to exceed last year's result of \$3000. We were delighted to top that by more than 60 percent," said Tim Winders of Coffs Harbour Younger Person Parkinson's Support Group.

"Our thanks go to the Bailey Centre Liberty Service Station and P.K. Express for their generosity, and to our friends in the Coffs community who came out to Pump for Parkinson's."

Planning a Parkinson's fundraiser in your community?

Before undertaking any fundraising, please contact Fiona Jessiman, Fundraising Manager Parkinson's NSW. Tel: 1800 644 189 Email: pnswn@parkinsonsnsw.org.au

Fiona will guide you through the requirements of the Charitable Fundraising Act 1991. This Act applies to any fundraising carried out by Parkinson's NSW, Parkinson's NSW Support Groups and any other organisations or individuals planning to fundraise in the name of our organisation.



Please add us to your email address book

Thank you for your interest in this magazine and Parkinson's NSW.

In order to open the door to all our resources and information, that you've signed up to receive directly into your email inbox, please add us to your address book.

Ensure you receive our regular publications, updates and information by adding marketing@parkinsonsnsw.org.au and events@parkinsonsnsw.org.au to your email address book or safe sender list.



Poetry dedicated to people with Parkinson's

Poet Sarah Day, born in England and grew up in Tasmania, has just published the ninth book of her work titled *Towards Light*. This volume is dedicated to all of those who research and support people living with Parkinson's.

Towards Light features a sequence of poems about the nature of Parkinson's and its impact on the person living with the disease and their loved ones.

To the right is an excerpt from the poem "Parkinson's" from the suite called "The Grammar of Undoing" by Sarah Day in her book *Towards Light*

The book can be purchased online at: www.puncherandwattmann.com/books/book/towards-light-other-poems/

*And what I know is here – my breath, a table
and a chair, the sky, the morning light that
brings*

me to each day – an introduction as if

*the first, each morning. What makes sense – a
voice?*

– a face? Sometimes these shaking hands.

Disease pulls me away, to light and dark.

I lose my way again. The children fade.

These shaking hands are all I have to guide me.

Peter's 400-kilometre paddle to fundraise for Parkinson's

Peter Shears of Sydney is a man on a mission.

He has signed up for the Massive Murray Paddle – a 5-day, 404-kilometre kayak race down the Murray River – to raise money for people living with Parkinson's.

"Recently, Parkinson's disease has touched both family members and close friends, and my wife Pamela and I have seen first-hand how this debilitating disease impacts both those experiencing Parkinson's and those who provide care.

It has long been a goal of mine to challenge myself by participating in this event that has been raising money for important causes for the past 50 years. This spirit of giving has made this an iconic and wonderful event to be involved in," Peter said.

Peter and his wife will be wearing Parkinson's NSW t-shirts during the event and have our decals on their kayak as they raise awareness and try to attract donations along the way.

If you would like to show your support, please donate online to Pete's Paddle for Parkinson's www.parkinsonsnsw.org.au



"Most of the time I just try to get through each day"

It was just before Christmas 2015 when 43-year-old Graham – single father of two teenaged daughters – was diagnosed with Parkinson's.

Apart from worrying over the future of his family, Graham was struggling to cope with tremors, stiffness and anxiety related to his Parkinson's. Fortunately, he picked up a pamphlet at a medical clinic that introduced him to the support of Parkinson's NSW.

Graham's long-term love of sport and exercise has now taken a new turn. He is a keen participant in Parkinson's NSW non-contact boxing classes, as well as other daily exercise aimed at slowing the progression of Parkinson's.

He is working closely with Vince, our local Parkinson's Nurse Consultant who supports Graham in his home, enables him to continue working to support his family – and participates in boxing classes with him. Participating in a Parkinson's NSW Support Group also provides Graham with support from other people experiencing Parkinson's.

"Being able to see my daughters Zara and Rhianna through high school – being there and able to support them – is what I worry about when I think about the future. But most of the time I just try to get through the day," he said.

Please consider a donation today to help our Parkinson's nurses support more people like Graham living with Parkinson's and their families and carers.



parkinson's
NSW

IN THIS TOGETHER

YES, I would like to help improve the lives of people living with Parkinson's and their families...

Please accept my donation of the following amount:

\$15 \$30 \$50 Other \$_____

I would like to make a monthly donation of \$_____ (\$15 minimum)
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below) Visa Mastercard American Express

Card number _____

Name on card _____

Signature _____

Exp date _____

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

**THANK YOU
FOR YOUR SUPPORT**
Donations of \$2
and over are tax
deductible