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Parkinson's NSW Limited | Issue 131 Winter 2018
ISSN 1839-0269



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NSW

FROM THE CEO

World Parkinson's Day held on April 11th was an enormous success this year. Not only did many of our Support Groups embrace the day and fundraise, we were also thrilled to be able to announce the new appointment of a Neurological Nurse for the Port Macquarie Area.

This appointment is co funded with the Mid North Coast Local Health District and was announced at Government House by our Board President Mr. David Veness. Special thanks to Mrs. Leslie Williams, Member for Port Macquarie and Mr. Stewart Dowrick, CEO of the Mid North Coast Local Health District.

Our Education programs continue to be a strategic priority for Parkinson's NSW. Backed by the board, we are intending to roll out further programs across NSW. These groundbreaking programs will be targeting allied health professionals, consumers and G.P.'s.

Enormous and well-deserved thanks must go to Poppy Moore who has just completed her circumnavigation around Australia in her yacht 'Scaramouch'. Poppy set off in March 2017 to raise funds and awareness for Parkinson's NSW as her father has Parkinson's. She has done an outstanding job. You can read all about Poppy's story on page 3.

Jo-Anne Reeves
CEO



EDUCATION SEMINARS

Did you know that Parkinson's NSW regularly hold Educational Seminars throughout NSW? We are committed to regularly keeping you informed of the latest advances in treatments and programs to support people living with Parkinson's.

Guest speakers may include Neurologists, Exercise Physiologists, Parkinson's Nurses, Speech Therapists, Counsellors, Occupational Therapists and more. Our aim? We want to bring you a broad variety of speakers to ensure you receive excellent and up to date advice – plus have the opportunity to ask questions.

A donation of \$10 towards to the cost of the seminar to help cover catering costs, would be appreciated.

Following is a list of the upcoming education seminars being held.

Where	When	Venue
St George / Sutherland Shire	Wednesday June 27 9.30am – 2pm	Tradies Club Gymea
Kiama	Wednesday 8 August 9.30am – 2pm	Kiama Leagues Club

For full details about our education seminars, please visit our website www.parkinsonsnsw.org.au and connect with us on www.facebook.com/ParkinsonsNSW

Please contact the InfoLine on 1800 644 189 to register your attendance at any of the seminars



POPPY MOORE SAILS HOME

Many of our readers will be familiar with Poppy Moore's amazing story. Poppy's dad was diagnosed with Parkinson's in 2006 and as he was no longer able to visit from the UK, Poppy decided to not only fundraise and raise awareness for Parkinson's NSW, she decided that she would show her parents Australia via a circumnavigation of Australia in her boat, an East Coast 31 that she named Scaramouch.

Poppy set sail towards the end of March 2017. It took Poppy 1.5 years to fit out her boat, including a new engine, plumbing and electrics. Plus, she needed to undergo intensive training. Importantly, Poppy also picked up several volunteer sailors along the way. Some passengers were experienced sailors, some had no experience at all, but they were great company for her and by the end, they could all say that they had a magnificent time.

Stopping regularly at many ports along the way, Poppy spread the Parkinson's NSW message and raised more than \$14,000.

On Saturday 12th May 2018, and after sailing more than 8,000 nautical miles (15,000 kilometres), Poppy docked once again at the Balmain Sailing Club, just 15 months shy of when she had originally set off. Her friends, fellow yachties and members of the sailing club were all there to greet her as well as Channel 10 News!

Congratulations to Poppy and many thanks for your enormous fundraising effort for Parkinson's NSW.



Poppy with her mum and dad



Poppy returns home

WORLD PARKINSON'S DAY 2018

World Parkinson's Day is held on 11 April every year. It marks the birthday of Dr James Parkinson, who is most famous for publishing 'An Essay on the Shaking Palsy' in 1817 and establishing Parkinson's as an internationally recognised medical condition. This year marked 201 years since the essay was published. Which provides the perfect opportunity for the international Parkinson's community – including people affected, healthcare professionals and Parkinson's organisation's around the world – to join together and raise awareness about the condition and send the message that 200+ years is too long without a cure.

Together with Parkinson's organisation's all over the world, Parkinson's NSW celebrated this auspicious day with numerous events.

The first event was held at Government House with our Patron of Parkinson's NSW His Excellency General The Honourable David Hurley AC DSC (Ret'd), Governor of New South Wales and his wife Mrs. Hurley. Over 100 guests were invited, including The Honourable Mrs. Leslie Williams, MP for Port Macquarie, Secretary for Regional & Rural Health, Member for Port Macquarie, The Honourable Mr. Paul Toole, MP for Bathurst, Minister for Lands and Forestry, Minister for Racing and The Honourable Mr. Andrew Gee, Federal Member for Calare, NSW.

The event was also attended by support group leaders, medical and allied health group professionals, research professors, representatives of various health districts and distinguished guests.

The morning tea was held to make the very exciting announcement of the appointment of our new Neurological Nurse in the Port Macquarie Area. This appointment was announced by Parkinson's NSW President Mr. David Veness and will be jointly funded by the Mid North Coast Health District in partnership with Parkinson's NSW.



Members of the Port Macquarie support group, Jo-Anne Reeves, David Veness and Leslie Williams



Mrs Hurley

After receiving information packs on how to deal with the media and setting up various events, our Support Groups excelled in embracing the day. They not only raised funds, but also raised significant awareness for Parkinson's NSW. Morning tea stalls, raffles, fetes and dances were held by several groups. Fashion parades, and even a cocktail party in Goulburn was one of the highlights.

In Chatswood, a new support group was opened which now takes the total to over 75 groups. Mayor of Willoughby, Mayor Gail Giles-Gidney kindly opened the new support group which was held in the Chatswood RSL. Future meetings will be held at 2:30pm on the 2nd Wednesday of the month at Chatswood RSL 446 Victoria Avenue Chatswood.

Our Parkinson's NSW profile was raised significantly on World Parkinson's Day. Between numerous radio interviews on 2MCR, ABC Illawarra, and 2ST in Nowra. In addition, we had significant traction on social media with several other organisation's including us on their own social media.



Government House



L to R Mayor of Willoughby, Gail Giles-Gidney and Parkinson's CEO Jo-Anne Reeves



His Excellency General The Honourable David Hurley AC DSC (Ret'd)



SPOOKY MEN'S CHORALE

If you dare to go onto the Spooky Men's Chorale website and have a peak at exactly what it is that they do, then you may just be in for a bit of a shock. Here's how they describe themselves;

"The Spooky Men's Chorale is a vast, rumbling, steam powered and black clad behemoth, seemingly accidentally capable of rendering audiences moist eyed with mute appreciation or haplessly gurgling with merriment. Based on the twin pillars of grand foolishness and the quest for the perfect subwoofer-rattling boofchord, the Spooky Men seek to commentate on the absurdity and grandeur of the modern male armed only with their voices, a sly collection of hats and facial hair, and a twinkle in the eye.

Formed in the Blue Mountains of NSW in 2001 by Christchurch born spookmeister Stephen Taberner, the Spooky Men soon attracted attention with a judicious combination of Georgian table songs, pindrop beautiful ballads, highly inappropriate covers, and immaculate man anthems like "Don't stand between a man and his tool", all of which amounted to a manifesto for the new breed of man: happily suspended between thug and wimp."

When we discovered that within Parkinson's NSW we had our very own member that was part of the Spooky Men's Chorale, we had to do some further investigation. Warwick Bisset now lives in the Blue Mountains, however he has held a long time love affair for singing, which has helped his Parkinson's enormously.

In fact, even before his Parkinson's symptoms appeared, Warwick was singing with an acapella choir in Sydney, having found out about the group through his sons' Steiner School. It was here that Warwick realised his love for singing and how singing uses your whole body, which can be a great form of exercise for those with Parkinson's.

Diagnosed in 2014 Warwick now has a tremor in his left arm, however that hasn't stopped him from touring with the Spooky Men's Chorale. In fact, just last year he has done five tours of the UK plus Denmark.

Warwick mentioned that what he does miss is that he is not able to sing regularly, as the Spooky Men's Chorale only tend to get together before gigs or when they have new material to practice. He certainly knows that for him, his Parkinson's symptoms are linked to stress and anxiety and singing counteracts that for him. "It's a fantastic stress reliever and anxiety treatment".

"Basically we are just a bunch of ordinary blokes who celebrate being ordinary blokes in the 21st Century". "Our music is called 'spooky', because it tends to send shivers down your spine, not because it's scary".

Recently the Goulburn Support Group held a magnificent cocktail party in support of World Parkinson's Day. As part of the entertainment, The Spooky Men's Chorale kindly agreed to perform two sets which was very well received. Our staff who attended the event said they brought the house down with their songs, wit and talent.

Congratulations to Warwick and may his love for singing and entertaining audiences all around the world continue.



L to R David Gillian and Warwick

Performing at the Goulburn Support Group cocktail party

RETURN AND EARN

NOWRA PARKINSON'S SUPPORT GROUP

Have you heard about the new recycling scheme Return and Earn? As of the 15th March, 2018 more than 150 million drink containers have been refunded through the new Return and Earn recycling stations across NSW, helping to keep our environment container-free.

Whether you regularly return or are joining in for the first time, you can exchange your eligible drink containers by visiting a collection point and claiming either your 10 cent voucher or a PayPal e-payment refund from a reverse vending machine, or a cash refund from an over the counter site.

And here's what's great news for Parkinson's NSW, up until 26 August you can choose to donate your refund to the Nowra Parkinson's Support Group at the following sites:

- IGA Milton Ulladulla
- Woolworths Nowra Fair
- Woolworths Bomaderry Bowling Club
- Woolworths Ulladulla
- IGA Berry Bowling Club

It's very simple, most 150ml to 3litre drink containers will be eligible for a 10-cent refund at an approved NSW collection point. Container materials that may be eligible for a refund include:

- Glass
- Plastic
- Aluminium
- Steel
- Liquid paperboard (cartons)

Containers should be empty, uncrushed, unbroken and have the original label attached. Wine, spirits, cordial and plain milk containers are generally not eligible.

If a container isn't eligible for a refund, please use a recycling bin.

So that's it! Let's get recycling and starting raising funds for Parkinson's NSW.



QBE FOUNDATION'S GENEROUS GRANT

QBE has generously agreed to give a grant of \$10,000 towards Parkinson's NSW Research funding. This grant has been made possible due to the generosity of QBE and the extraordinary fundraising efforts of Mimi Morton, a long-time employee of QBE who recently retired.

Ron, Mimi's husband has Parkinson's, so this gives her first hand knowledge not only into the disease, but what it is like to live day to day with the illness. So, armed with this knowledge, Mimi was determined to work with QBE to raise the profile of Parkinson's, it's impact on those who have it and to fund research projects. Projects that will provide improved physical and emotional outcomes for those living with Parkinson's.

In 2017, Parkinson's NSW awarded \$310,000 to eight research projects. With support of individuals like Mimi and generosity of organisations like QBE, Parkinson's NSW hopes that in the near future, it will have the capacity to give \$1 million annually for research, while continuing its range of services for people living with Parkinson's.

Thank you again to the Morton family and to QBE for their extraordinary generosity.



Ron and Mimi Morton

Ron and Mimi meet His Excellency General The Honourable David Hurley AC DSC (Ret'd)

YOUR GIFT HAS THE POWER TO AFFECT GENERATIONS TO COME

Every day, 3 Australians under the age of 40 are diagnosed with Parkinson's and another 48 are diagnosed over the age of 65. That staggering number equates to an estimated 80,000 Australians living with Parkinson's disease.

And currently there is no known cure or cause.

With less than 1% of our funding needs coming from the Government, gifts in Wills have helped thousands of people in NSW with Parkinson's to lead a more fulfilled life. We offer over 75 Support Groups throughout NSW, Specialist Neurological Nurses, an InfoLine staffed by a team of specialised Registered Nurses, ongoing education and exercise programs. Plus, we fund world class research into improving the quality of life for those living with Parkinson's.

And to do all of this, we rely on the generous support of people just like you to continue our vital services.

Here's how our members feel about our services:

"My support group stopped me from falling into a severe depression.. I am so grateful".

"Here in the country, our Neurological Nurse is our lifeline, we simply don't have access to the facilities that everyone has in the cities".

"In addition to those who have Parkinson's, we also have a carers group, I couldn't cope if I didn't have this amazing bunch of people to help me – they always seem to know what I'm going through."

"Our support group provides great communication, support and care for each other, it's so important for us"

Your gift can change so many lives, it can strengthen our services to the Parkinson's NSW community. And many of our most helpful gifts come from the estates of our Parkinson's members and supporters.

Here are some questions that we are frequently asked:

Q. Why do I need a Will?

Every person over the age of 18 should have a Will. A Will is a legal and binding document that protects and shares your legacy according to your wishes.

Q. Can I make a gift in my Will to more than one charity?

Yes, your solicitor can arrange this for you.

Q. Do I need to leave my entire estate to Parkinson's NSW?

No, you don't have to and we strongly encourage you to ensure that you look after your family and / or loved ones first.

Q. Should I let someone at Parkinson's NSW know that I have left a gift?

Yes, by letting us know it helps us to better plan for the future and we like to meet and acknowledge our supporters when we can.

Q. Can I remain anonymous?

Yes of course. Simply advise your solicitor or us of your wishes.

Q. I have already made my Will, is it too late to change it?

No. Changing your Will and adding a gift to Parkinson's NSW is easy, all you have to do is make a 'codicil' (or a document that amends a previous executed Will) When you next see your Solicitor, just take a copy of our wording with you and they can simply update your existing Will for you. We know that leaving a gift in your Will is by no means an easy decision. And we appreciate you giving this significant decision your time and consideration.

Whilst we are not able to give you legal advice, the Parkinson's NSW donor development manager is happy to provide you with information on how a gift in your Will can make an extraordinary difference to the lives of those who are living with Parkinson's, both now and in the future.

So please, feel free to call with any questions you may have or to request a visit from our Donor Development Manager

Peter Longhurst - Donor Development Manager

Phone: 02 8051 1900

Mobile: 0435 892 985