

STANDBYME

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IN THIS TOGETHER
parkinson's
NSW

FROM THE PRESIDENT

Welcome to our winter edition of Stand By Me.

It was my absolute pleasure to host the inaugural Literary Dinner just recently in July. Our special guest of honour was Michael Robotham. Michael is a leading international author in the psychological crime-writing genre, with his main character having Parkinson's. With our other special guest, Ms. Jennifer Byrne, the impeccably well-read host of The Book Club, Michael was interviewed on stage at the State Library of NSW.

Many thanks to our guests and attendees for coming along to such a wonderful evening, which was enjoyed by all. All proceeds went to our Neurological Nurses program, which is in high demand across the state.

I am also very pleased that our new constitution was voted in by our members on the 8th June. The change from the incorporated association to a company limited by guarantee will ensure that we are agile and flexible with dealing with governance requirements under the corporations act.

I would also like to take this opportunity to invite you to this year's Unity Walk and Run being held at Sydney Olympic Park on Sunday the 27th August. This will be our 10th year and I hope to see you there to help celebrate this special occasion.

Andrew Whitton
President



FROM THE CEO

During the last six months, it has been my utmost pleasure to have visited with 12 of our support groups across NSW. The companionship, kindness, education and lifeline that these groups provide to our members is invaluable. Thank you for making me feel so welcome.

The major issue that we are currently focusing on is the lack of support in regional areas, including poor referral pathways. This includes access to nurses and, in many regions, the need to travel to Sydney, Melbourne or Brisbane to see a Parkinson's specific Neurologist.

Another concerning issue for us is how to better support people with Parkinson's and their carers in regional areas? This is an issue that we cannot address overnight; but we will be working with governments (both state and federal) and local communities to find a solution.

Also, in the next two months we will be reviewing how to increase the impact of our specialised services. We want to ensure that we can provide the maximum benefit to as many people and families living with Parkinson's as we can.

We are committed to further increasing the number of Parkinson's Nurses across New South Wales; we will also be reviewing our InfoLine, Counselling and Education activities to ensure that the help we provide through these is as useful as possible.

Many thanks to Andrew, guests of honour and attendees at our recent Literary Dinner, it was wonderful to see everyone coming together to support our Neurological Nurses program.

I look forward to seeing you at the 10th Anniversary Unity Walk.

Jo-Anne Reeves
CEO



WOLPER HOSPITAL, SHOWING THEIR SUPPORT

Wolper Jewish Hospital is a specialist medical and rehabilitation hospital set in the quiet, tree-lined streets of Woollahra in Sydney's eastern suburbs. But for our Parkinson's patients and carers Wolper has become a place where they can see our therapist for counselling and support, all at no cost.

And this is largely thanks to the amazing support of CEO John Tucker.

John became the CEO at Wolper three and a half years ago and has been a proud supporter of Parkinson's NSW ever since. It all started back in September 2014, when Parkinson's NSW successfully applied for a grant to the newly formed Wolper Jewish Hospital Health Foundation and was successful.

The Foundation agreed to support Parkinson's NSW and provide a consulting room for therapist Shushann Movsessian. A trained Counsellor/Psychotherapist working for Parkinson's NSW, with over 25 years' experience in relationship and family counselling in private practice.

John said,

"We are really pleased to be able to offer grants to both Jewish and non-Jewish community organisations. And we are especially pleased and proud to have Parkinson's NSW as a significant large, prominent, credible, charitable service provider. To count them among the organisations that the foundation supports".

In addition to providing the consulting room for Shushann, Wolper Hospital also provides space to hold the Eastern Suburbs Parkinson's NSW Support Group, which is held every second Friday of the month. This group is run by volunteer Jennifer Adams, a well-known Speech Pathologist with her own practice in the eastern suburbs.

"What we offer is an information and catch up session, where everyone in the group engages. We do fundraisers too; in fact we just did one for World Parkinson's Day. Importantly, each month I get a guest speaker along, not all are from the allied health

field. They may be pharmacists, physios, Neurologists; we've even done 'Dance for Parkinson's'. I love to do the research beforehand to make the sessions as valuable for the clients as possible".

Talking with Shushann it is easy to see why a counselling service is so necessary for our Parkinson's clients.

"Part of my work is all about helping with the shock of the diagnosis. The diagnosis itself creates a great deal of anxiety and or depression."

Shushann explained that clients often only have minutes with their Neurologist and when they leave they may not have felt able to ask questions or unpack what's actually going on for them. Often, Shushann said, patients' symptoms can change and it can throw them resulting in low confidence and difficulty adjusting.

Additionally partners, carers and adult children are also welcome to come in for counselling and often do. Relationships can change when your loved one is diagnosed and being offered the tools on how to deal with these changes is invaluable.

Wolper has been incredibly giving and helpful with her clients. "I am always able to make my clients feel so welcome at Wolper, it's a beautiful place to come to, with terrific staff, so supportive and it's a lovely building too."

We would like to thank Wolper for their ongoing support of our counselling service and providing a great place for our support group to meet



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instagram.com/parkinsons_nsw

WHO'LL KNOW YOU CARED WHEN YOU'RE GONE?

When we discuss the topic of passing away, not everyone feels comfortable. We understand that.

But at Parkinson's NSW we know that you are not afraid to discuss this important subject with us. And you trust us with your concerns, which is why we hope we can have the conversation about leaving a gift in your Will with you.

Because it is so important that we ensure that our work can continue, long after we've all gone. And it's so easy to do.

Continuing our services requires funding. We rely on our generous supporters who consider leaving us a gift. Just like you.

Firstly, let's look at why it's so important and why we are so grateful to people who leave us a gift, ensuring that we can carry on changing people's lives.

- We have a caring and well-organised support system that ensures those diagnosed with Parkinson's have an improved quality of life. By leaving a gift in your Will, these support services can continue after you have gone.
- These support services include our InfoLine, where we assist more than 4,000 people per year.
- Counselling – we offer free counselling services to anyone who has Parkinson's or their carers.
- We run 72 Support Groups across NSW.
- We provide Education, Aged Care workers, Allied Health Professionals, and Neurological Nurses. All of whom are dedicated to ensuring that you are not only up to date with the latest information on exercise, medication, mental health help, neurological advances and alternative therapies, but they make it their mission to bring you the best care that is available. Dedicating themselves to helping you.

Sadly, not everyone has access to these services. Whether that's due to living in a rural area, or a lack of available support from friends or family members. These clients need our help too and it's our mission to ensure they receive it. Because without it, their outcomes may be very poor.

SO HOW DO YOU ORGANISE LEAVING A GIFT IN YOUR WILL?

There are several steps involved, none of which are difficult and we are here to make it as simple and easy as possible for you. Whether you already have a Will in place, or simply require an update to your current Will to include Parkinson's NSW.

Peter Longhurst is our Donor Development Manager and is available to help you with any questions that you may have. He will also happily explain how to streamline the process for you.

Peter joined Parkinson's NSW in March of this year, however he comes to us with an extensive background as a Wills & Bequest Officer for the last 9 years. When discussing leaving a gift Peter will often tell donors,

"The very services that you admire that we provide to people living with Parkinson's and their carers will continue to grow with your help".

Nina Cheyne, our Neurological Nurse in the Shoalhaven told us that,

"I love that I get to make a difference to peoples lives everyday. If I can relieve pain and suffering, reduce stress and anxiety related to Parkinson's then it fulfills me as a health professional. More importantly, there needs to be more of us. More Neurological Nurses to help rural residents. Our rural residents are often so isolated and they need a lifeline in times of struggle when dealing with their Parkinson's. They need the support, love and companionship that comes with being part of a group, just like all of our clients."

If you have been thinking about leaving a gift in your Will, then we would love to hear from you. Please phone Peter Longhurst on 8051 1900 or email him at Peter.Longhurst@parkinsonsnsw.org.au Additionally, we have information sheets that we are happy to send out to you, or we can visit you in person.

We look forward to hearing from you.



SAILING FOR MY DAD - POPPY MOORE

We last featured Poppy's amazing story in our Autumn Newsletter and since then we have had so many people asking us how she is going, we needed to contact Poppy for an update on her incredible progress.

So who better to hear it from than Poppy herself!

Hi All,

I'm having a fantastic time.

Ships Log 31st May!

I departed Sydney on Scaramouch on Good Friday, we had a lovely sail up to Port Stephens, where I met up with the local Sailing Club & Parkinson's Support Group & gave a talk & fundraised.

My aim is to stop in at all the yacht clubs along my journey, take part in one of their sailing events, promote my cause, help fundraise & pick up new crew who can also help fundraise.

So far this has been a great success & I've raised just under \$6000!

My oldest crew so far was John who was 78 years old & had sailed around the world!

I've been talking to my parents & keeping them updated on the trip as my father is the reason I have undertaken this journey. They are loving seeing Australia & meeting my crew via Face Time along the way.

The boat is going really well. I've learnt a lot & completed sailing experiences that I have never done before, anchoring at secluded islands, bar crossings, coastal night sailing & navigation! We've been accompanied by dolphins & mutton-birds!

I've had tremendous support from my sponsors & businesses. Including Pantaenius Yacht Insurance, Muir, Anchor Right, Beauty Boosters, Aqualuma, Soldiers Point Marina, GCCM to mention a few!

I've had a lot of support from the local newspapers & the ABC Radio Stations & managed to get on Channel 9 News & speak at the Super Yacht Conference near Brisbane, raising \$1000!

I've stopped at Pittwater, Newcastle, Soldiers Point, Broughton Island, Port Macquarie, Trial Bay, Coffs Harbour, Yamba, South Port, Jacobs Well, Manly Brisbane & Sanctuary Cove.

I'm currently at Tangalooma Island about to depart for Mooloolaba.

Captain Poppy!

If you would like to follow Poppys' progress, then you can on Facebook
<https://www.facebook.com/Scaramouch-Sailing-for-Parkinsons-1509234962421492/>

You can also help Poppy fundraise. Go to the link below and help her reach her goal of \$12,000.00
<https://give.everydayhero.com/au/scaramouch-parkinsons>

If you are interested in becoming a crew member then please contact Poppy either through her Facebook page or here: <https://airtable.com/shrNd3z8UwxtaA9tg>



PARKINSONG

Singing does you good!

Tuesdays 4:30 – 6:00 pm
Abraham Mott Hall
17 Argyle Place Millers Point (near corner of Kent Street)

It's fun - It's therapeutic - It's sociable - It's a buzz
No need to audition

This weekly choral and voice activity is for people with Parkinson's, their carers, friends and any members of the local community who enjoy making music and strengthening their voices. Our alternating Maestros are Nadia Piave and Natalie Goonaratne.

Drop in - no formalities. Street parking is convenient

1800 644 189 for details, or
chris@chrisdavis.net.au

A BRUSH WITH PARKINSON'S

A steely resolve, borne out of a difficult childhood, having grown up in foster care, is what Paul Miller developed at an early age. Living with his grandparents as a foster child he knew he was destined for a better life.

He distinctly remembers one poignant day as a ten year old, running up to his grandmother's room and looking into her mirror. As he looked at himself, not knowing what the word 'success' meant, but knowing that it sounded like a good word, he repeated to himself, "We're going to succeed aren't we? You promise me that we'll succeed. Never give up, never give in, you must continue". You promised me we would succeed, whatever that means in all shapes and forms".

Little did Paul realise what prophetic words these were when 16 years ago at the age of 44, he was diagnosed with Parkinson's.

Paul's Parkinson's journey began when he started to notice signs of pins and needles, anxiety and rigidity. It took a long time to be diagnosed, but when he was, he found an inner strength and stubbornness. A bull-headedness that perhaps was already there, but emerged determined to fight with a very high level of persistence and fortitude against this illness.

"I feel Parkinson's affects each body, each soul, each mind, in a different way. I think some people can deal with the idea and some people have to work harder to deal with it. Sadly some people just give up". But Paul refuses to give up. He has things to do. And his most important thing to do is to continue his love of art.

Interestingly, Paul explained that when he was initially diagnosed he was so grateful that he had his love of artwork to fall back on. "What I've noticed is that when Parkinson's comes, if the person has only had their children, or work and hasn't had a great outside interest in life, it becomes very difficult for them. What do you do? Where do you go? It is so vital to develop an interest that really grabs your heart and soul and engages you – keeps you occupied. You need something to possess you".

And art, art is what possesses Paul. This year, Paul has recently entered his artwork titled 'A Cold Day for A Bush Picnic' into the Archibald for consideration. It took him 3 years to paint. It's done in egg tempera and is 120x180cm. And the reason for taking so long? He has never worked in that material in that size before. With egg tempera you need to build it up very, very slowly. Using very tiny brushes on a very big space. Paul said "I wanted this atmosphere with the smoke of the picnic fire and the bush to be a realistic thing, but also a spiritual metaphor. You've got the fire of the campfire, but you've also got the golden light of the day. There's a pagan fire and there's a divine light. It's about a spiritual approach to making it work".

Over the years, Paul has submitted numerous paintings to the Archibald for consideration and explains that when you first start submitting, there is great expectation and excitement – huge anticipation. Sometimes it's all about having the right sized picture at the right time, others it's what the judges are looking for in that particular year.

Still, for Paul, what he has realised is that his Parkinson's diagnosis has allowed him the freedom to strip away the trappings of pleasing everyone.

Now, for him, it is all about doing what he wants, how he wants and simply getting on with the job. No longer is the superficial celebrity of the art world important, it is now about the challenge and ensuring that each day he is able to rise to the actual challenge of being able to paint in his beautiful sun lit studio where his inspiration is evoked and his Parkinson's is all but forgotten.

In the process of painting, Paul has also been working on a documentary "A Brush with Parkinson's". Shooting with retired film director Malcolm Smith, Paul and Malcolm are aiming to bring awareness of Paul's Parkinson's through a series of one on one interviews.

"My art and the documentary are so important to me, I am a person who needs to use my voice and my work to help others to understand Parkinson's. Getting into the Archibald again (I've been in 3) would give me an even stronger voice. I want to be a warrior for Parkinson's. I am willing to stand up and say what I think and how I feel about Parkinson's. It is so important to say this needs to be looked at".

If you would like to see the Archibald entries tickets are available through Qtix (ticketing at the Art Gallery of NSW) and the exhibit is on from the 29 July–22 October 2017.

We wish Paul all the very best with his wonderful entry.



JO'S STORY & SUPPORT FROM PARKINSON'S

It started by slow degrees. Jo's voice got softer. She was very tired and not her usual happy self. Getting out of a chair, she'd lean to the right. Her left arm stopped swinging when she walked.

Even though she was a registered nurse, she couldn't work out what was wrong. But she finally recognised things were serious when she tried to tap her left foot to the music at a 'Christmas in July' function and just couldn't do it.

A mother of four, Jo was only 47 years old when she found out she had Parkinson's. She remembers how the discovery turned life upside down for her and her family.

"I went numb. It was just sort of unbelievable, really. My partner Jim and I came home from the Neurologist feeling devastated. Nobody knew what was going to happen, it was an unknown quantity. But I'd nursed older people with Parkinson's so I realised it was going to be tough."

Finding herself in the position of patient instead of carer, Jo went through a period of grieving and denial. For a while she tried to carry on with her busy life mostly as before, shutting out the reality of what was happening within her body and her mind.

But when Jo was ready, she gratefully reached out for help from Parkinson's NSW, help that has been achievable because of amazing supporters like you enabled us to provide.

Says Jo, "I rang Parkinson's NSW and spoke to the nurses and they were good and sent information out."

Another wonderful help for Jo was being linked in with an early onset support group called the Tulip Belles, for women to connect with each other by teleconference.

She was also introduced to Nina, one of our Parkinson's Specialist Nurses, who assists people with Parkinson's and their carers who lives in Jo's area. Nina has written a special note to you about her work, enclosed. When Jo began going to a support group that Nina helps to run, she felt she'd found a place to belong.

"Other people don't really get what you are talking about, but when you have a support group they really understand. They are all traveling down the same road as you are."

"You can discuss how you're coping and your symptoms – for me at the moment, that's rigidity and slow movement and I've got a tremor in my right leg. More often than not now, my medication doesn't work and I get anxious because I can't do much but sit in a chair and wait till it does start working. Having the group to share things like this with, it's both a practical help and moral support."

"This is so important because Parkinson's is very isolating, especially if you can't drive. People can become stuck in their homes."

It was Jo's understanding of this loneliness and the power of social connections and support, which led her to make an inspiring choice. She decided to give back by volunteering for the support group she attends.

"I used to help co-ordinate it and now I'm the publicity officer. I thought, this happened for a reason, and this must be the reason. I want to make a difference."



SAVE THE DATE

Support Group Leaders Conference in Sydney

Date: Thursday 7 Friday 8 September

Venue: Hilton Sydney

Enquires: Melanie Browning

melanie@parkinsonsnsw.org.au or 02 8051 1912

Public Forum

Key Note Speaker: Professor Roger Barker

Date: Thursday 7 September 2.00pm-5pm

Venue: Hilton Hotel Sydney

Enquires: Christine McGee

christine.mcgee@parkinsonsnsw.org.au or 0400 881 779

WHO WILL YOU WALK OR RUN FOR?

Sydney Olympic Park

8km Run – 4km Run – 4km Walk

Wollongong

3km Run – 2km Walk

Every hour of every day
someone is diagnosed
with Parkinson's

10th Anniversary

UNITY

Walk & Run

SUNDAY 27 AUGUST

www.unitywalkandrun.com.au

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Donations of \$2 and over are tax deductible.

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Click the donate button at **www.parkinsonsnsw.org.au**



Over the phone by calling **1800 644 189**



Fax this completed form to **02 8051 1999**

Thank you for your support.

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.