

# STANDBYME

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The 10th annual Unity Walk & Run for Parkinson's NSW was held in Sydney & Wollongong. With a turnout of more than 1000 people, the event raised in excess of **\$100,000**

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### RESEARCH & SEED GRANTS

Parkinson's NSW has awarded **\$301,489** this year in research and seed grants. This gives researchers the ability to make a significant difference in the future for people with Parkinson's

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IN THIS TOGETHER  
**parkinson's**  
NSW

# FROM THE PRESIDENT

Welcome to our summer edition of Stand By Me.

I was thrilled to see how successful the recent Support Group Leaders Conference was and just how many of our leaders attended, many thanks to those who came and participated.

Neurological Nurses continue to be in high demand in our regional areas as they provide an invaluable source of expertise and support to those with Parkinson's and their carers. And to that end we are currently working extremely hard at building on the current team of nurses firstly by working with Support Groups to identify the areas of greatest need; and secondly by harnessing their contacts in attracting the funds necessary for such a program. This will be in conjunction with private funds and our lobbying of the government for funding.

Whilst the government is yet to provide any funding, the NSW National Party passed a motion at the annual conference to support the call for Neurological Nurses.

I am thrilled to see the level of excellence of the research that we continue to support. Topics include areas such as depression, exercise, Deep Brain Stimulation and Anti-Inflammatory therapies. Let's hope we make significant breakthroughs in these areas as soon as possible.

We continue to focus on important structural changes within the organisation such as changing to a company limited by guarantee and developing improved governance and board structure.

**Andrew Whitton**  
President



# FROM THE CEO

It was my absolute pleasure to host the recent Support Group Leaders Conference in September and meet so many of the wonderful leaders. The enthusiasm, support and general camaraderie that was shown was just wonderful to witness.

It has been my honour to visit 28 of the groups across NSW to date and I'm looking forward to meeting the remainder of the groups as soon as I possibly can.

We continue to focus on the importance of research and on the Thursday night at the conference it was our absolute pleasure to hand out research and seed grants worth \$301,489. I am hopeful that the brilliant work of these capable scientists will bring us ever closer to our goal of not only finding a cure for Parkinson's disease, but also medications and methods of management.

On our back page, there is a terrific article about one of our researchers, Ben Trist. Ben is at the Brain and Mind Centre at the University of Sydney. He was awarded the 2016 Young Researcher of the Year. His work has been outstanding and it all started as a tribute to his grandfather who had Parkinson's. Ben's commitment to helping those with Parkinson's is extraordinary.

I would like to wish you all a very safe, happy and joyful Christmas. I would also like to express my thanks for the enormous support I have been shown in the past year, by my colleagues, the board and all of our amazing members who make up Parkinson's NSW.

**Jo-Anne Reeves**  
CEO



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# UNITY WALK & RUN 2017

On the 27th August 2017, the 10th annual Unity Walk and Run day for Parkinson's NSW was held in Sydney Olympic Park and Stuart Park in Wollongong.

With a turnout of more than 1000 people and their furry friends attending, the event raised in excess of \$100,000 – a huge success. And with every dollar raised 50% will be contributed to research and 50% will fund support services for people living with Parkinson's and their carers.

Wollongong Event Organiser, Jennifer Gray, said "I was so thrilled and grateful to accept a cheque from Bendigo Oak Flats and Shellharbour Community Bank Branches, they surprised us with a \$1000 donation which will help us to change the lives for many people with Parkinson's. Thank you so much. And their help on the day was invaluable".

Congratulations must also be given to this year's winner of the \$200 challenge, Colin Woodcroft who single-handedly raised \$3993.36. In addition to our hard working individual sponsors, we also welcomed the wonderful support of our corporate sponsors: Transport for NSW, Telstra Health, Sydney Olympic Park, Abbvie, Medtronic & UCB.

Event Sponsors included: Platform Sports, Festival Hire, Resolution X, ANZ Stadium, Campbell's Arnott's, Appelles, Event Cinemas, Lorna Jane, Skydive Australia, KingPin, Zappia Produce, Sydney festival, Pet Stock, Kellyville Pets, Sydney Dance Company, The Trophy Store, Captain Cook Cruises & Jenolan Caves.

## **Additional donations to the event included:**

St George/Sutherland Parkinson's Support Group - \$4000

Glenn Innes Parkinson's Support Group - \$1000

John Lea Blue - \$1000

Abbvie - \$2000

Thank you all so much for your support and gifts. Your kindness and generosity means so much to our clients.

This year, to celebrate the 10th anniversary of the Sydney event, all participants were given a custom-made anniversary medallion and participation pack. We were honoured to have event founder John Silk attending to cut the 10th anniversary birthday cake.



Face painters and balloon twisters were on hand to entertain children and the furry friends were also included, receiving a doggy showbag from Pet Stock, and a bandana from Kellyville Pets.

An event like this cannot go ahead without the wonderful help of volunteers and this year we had more than 130 people generously give their time to make the event a success. Volunteers at the Wollongong event also faced the challenge of very strong winds and we especially thank them for their perseverance and good humour.

An event like the Unity Walk and Run day always needs entertainment to get the right atmosphere. So this year we were incredibly grateful to have a fabulous mixture of entertainment along the 4km walk. Along the course, you could hear The Australian Army bands ensemble "Frontline"; the amazing hip hop "PhlyCrew" (who recently returned home from competing in the Hip Hop World championship in America); African drummer and dancers from the mountains "Hands Heart & Feet"; and local Sydney singer song writer Nathan Mckenna busking in the bushes after the launch of his new EP "Subconscious Stories".

The day also included on stage demonstrations from Punchin' Parko's and PD Warrior. Both exercise programs are specifically designed for people living with Parkinson's.

For more information about how exercise can benefit people living with Parkinson's, please call Parkinson's NSW.

Food was plentiful with a multitude of food trucks, serving ribs from Burnt Ends BBQ, Spanish Tapas from Despana, Greek or Italian from Inbocca, and finished off with a fresh coffee from Grind 'n Press. All food vendors donated a percentage of their profits from the day.

Thank you to everyone who made the day so successful. Your hard work was very much appreciated.



# SUPPORT GROUP LEADERS CONFERENCE

This year the Parkinson's NSW Support Group Leaders Conference was held at the Hilton Hotel in Sydney on the 7th and 8th of September.

The aim of the conference was for Parkinson's NSW to provide support, education and guidance to the support groups throughout NSW and to build connections between the groups.

Overall 45 support groups were represented from as far north as Tweed Heads; as far south as Bega; and Griffith to the west. All participants reported back that it was the best conference they had attended and they look forward to participating again next year.

Participants were given a warm welcome by Jo-Anne Reeves, Parkinson's NSW CEO who presented an overview on the new direction, the new constitution and the importance of the support groups in delivering the new priorities for people with Parkinson's. One of the key priorities highlighted was funding the placement of more Neurological Nurses across the state.

Melanie Browning, Parkinson's NSW Support Group Co-Coordinator, introduced the groups by asking one simple but powerful question, "what makes your support group great?" This one question proved to be the highlight of the conference, with many support groups gaining insights into the workings of other groups and learning what makes them successful.

On Thursday afternoon members of the public and medical professionals were privileged to attend a seminar by keynote speaker Roger Barker, Professor of Clinical Neuroscience at the John van Geest Centre for Brain Repair and Department of Neurology in Cambridge UK. Introduced by Professor Simon Lewis, Dr Barker gave a fascinating and insightful lecture to the group on "The Emerging Therapeutic Landscape in Parkinson's Disease."

At the conference dinner on Thursday night, President of the Board, Andrew Whitton, was given the honour of presenting more than \$301,489 in research and seed grants to various worthy recipients for 2017. Parkinson's NSW are committed to ongoing research that will hopefully one day see vast and significant improvements in Parkinson's disease.

Presentations by Kirstin Robertson-Gillam, Parkinson's NSW Counsellor on dealing with difficult emotions meant a great deal to so many of the participants. Having to deal with the aspects of depression, loss, sadness, grief and anger as well as the vast array of other emotions that accompany Parkinson's is no easy task. Please contact our InfoLine 1800 644 189 for more information about counselling supports available from Parkinson's NSW.

Fiona Jessiman, Parkinson's NSW Fundraising Manager, gave an informative talk on the need for an effective fundraising program and the legal requirements. Parkinson's NSW is committed to ensuring that all elements of fundraising comply with the relevant legislation.

We would like to thank each and every support group member who attended, as well as the speakers, and researchers. We are truly grateful for your incredible input and how you all made the conference an incredible success.

We look forward to welcoming more support group representatives at the next leaders conference.



# SUPPORT GROUP LEADERS CONFERENCE

## the participants view

Dick Babb is just an all round terrific bloke. Dick became involved with Parkinson's after offering to accompany a very dear friend to a support group. Now, after 19 years of faithful service Dick is still attending meetings and continues as leader of the support group.

According to Dick "Hornsby group is just a wonderful group of people who appreciate everything that you do for them and that's why I continue to go and to be involved with them".

And that is how Dick found himself at the Support Group Leaders Conference. At Parkinson's NSW we invested time, money and considerable expertise into our recent conference. So naturally, it was important to garner feedback from participants on what they felt was helpful, what areas needing improving and what they are looking forward to in the future.

Dick was kind enough to give us his honest opinions on how the conference went.

### **Q: Firstly, how did you find the conference overall?**

Well first of all, can I just say I found the conference excellent. I got a lot out of it, as I'm sure others did too. It was very professionally done and I thought the people from other parts of NSW and the guest speakers did an admirable job. Terrific communication.

I got a lot out of listening to other people from the other support groups. I think that's one of the major benefits of these kinds of conferences. You see great leaders and then you get lots of ideas that you can take back to your own support group and I thought that was very good.

A lot of us have been very critical of Parkinson's NSW in the past and thought that the support given to the groups was very limited. But I'm starting to see a new light come out with the new people in Parkinson's. They realise that their lifeblood is the support groups and they've got to start supporting those.

I was really impressed by the enthusiasm shown by all of the staff and the board members too. They all looked enthusiastic towards the future.

### **Q: What other areas stood out for you that you enjoyed?**

For me, I really liked hearing about what other groups do the most, I got so many ideas from that, I can't wait to take them back to my group and discuss them all. From

starting with a song, to using bright colours for your emergency card. I also like the idea of a buddy system.

I also really liked Professor Roger Barker's talk and I think the demystifying between hope and hype – I thought that was a really good start of the issue there. I would like to certainly see his notes made available to all our members. I liked how he talked about stem cell research, how people are wasting their money, the ethical issues involved with embryonic stem cells, gene therapy and how he then gave the audience with Parkinson's a glimmer of hope.

Both he and Professor Lewis worked well together as a team and spoke at exactly the right level to the audience.

### **Q: What insights did you gain from the other speakers?**

With Kirsten, she did highlight there are professionals at Parkinson's NSW that you can get in touch with to help you. A lot of people in the room have Parkinson's and we all know that depression and anxiety are big problems, so I think it was good to reinforce this message.

I found the PDfit talk a little confusing; I wasn't sure how that was going to be rolled out across the state. I think I need further clarification on that. I certainly found the fundraising talk useful, especially about establishing fundraising, grants and the associated laws that go with that. Additionally the talk about Wills was also important.

### **Q: What would you like to see happen now?**

Mostly I would like to see a change in how information is provided to members. I would like the Parkinson's NSW website to be better for support groups. I'd like to be able to go online, ask questions, get support, not only from Parkinson's NSW, but from other members. Have recent information published about studies and their findings, so I can download it and hand it out or show it to the members.

Overall, it was a first class conference. Well done to Jo-Anne Reeves for her professionalism and to everyone involved. I certainly came out of the conference with a new found appreciation of just how lucky people in the city are, compared to people in the country areas. The lack of medical support in the country is dismal. I'd like to see us all try harder to fundraise for them.

Many thanks to Dick for his time and feedback, it has been truly appreciated. Thank you too for all the other participants who willing gave such insightful feedback over the course of the two-day programme.



# RESEARCH & SEED GRANTS FOR 2017

At the recent Support Group Leaders Conference held at the Hilton Hotel on September 7th 2017, several grants were awarded by Leslie Williams, Parliamentary Secretary for Regional and Rural Health, to researchers who are currently excelling in their field.

Together with Parkinson's NSW our researchers strive to make a significant difference in the future for all of those with Parkinson's. In total our research and seed grant funding for 2017 is \$301,489.

We would like to congratulate each and every team member who was awarded a well-deserved grant and we look forward to reading your work soon.



2017 Grant Recipients

Recipient	Research Title	Amount
<b>PARKINSON'S NSW RESEARCH GRANTS</b>		
Assoc Prof Antony Cooper	Validation of PD diagnostic blood biomarkers and Assessment of PD progression blood Biomarkers	\$49,400
Dr Daniel Hesselson	Repurposing carvedilol to block the progression of Parkinson's disease	\$50,000
Prof Stephen Lord	Reactive and volitional step training to reduce risk of falling in people with Parkinson's disease: A randomized controlled trial	\$48,143
Dr Asheeta Prasad	Novel chemogenetic therapy for Parkinson's disease	\$43,946
Prof Bryce Vissel	The CB2 agonist HU-308 as an antidyskinetic agent in L-dopa induced dyskinesia's	\$50,000
<b>TOTAL PARKINSON'S NSW RESEARCH GRANTS</b>		<b>\$241,489</b>
<b>SEED GRANTS</b>		
Assoc Prof Kay Double	Why does toxic Superoxide dismutase 1 aggregate in degenerating regions of the Parkinson's disease brain?	\$20,000
Dr Teri Furlong	Dopamine dysregulation syndrome in Parkinson's disease: constructing a rat model and testing the efficacy of N-acetylcysteine treatment.	\$20,000
Jin Sung Park	Deciphering the role of CHCHD2 (PARK22) in a-synuclein pathways	\$20,000
<b>TOTAL SEED GRANTS</b>		<b>\$60,000</b>
<b>TOTAL RESEARCH AND SEED GRANT FUNDING FOR 2017</b>		<b>\$301,489</b>



# MY FUTURE GIFT TO YOU

We all have wishes for the future, but for Sandra Elms, she has ensured that her wishes will be reflected when she passes away by leaving a gift in her Will to Parkinson's NSW.

"I would dearly love the money I leave Parkinson's NSW to go to research and hopefully there might be a cure or hope for some people. I'm very shocked at how the young people are affected by it. They seem to be more affected than the older people. So for me, research is a big thing".

"But on the other hand, I'd also love to see a centre, where people can all get together under one roof, a centre that encompasses lots of exercise programmes, singing, dancing, physio and people meeting up for a coffee – wouldn't that be wonderful?"

Sandra was diagnosed with Parkinson's in 2012; she doesn't think she had many symptoms long before that. She had hoped that her symptoms could be put down to a poorly functioning thyroid, but unfortunately it came back as Parkinson's.

"I was so taken aback, the Neurologist did a few cursory diagnostic tests and then just said "Oh yes, ok, you've got Parkinson's". When I asked what my prognosis was he said, "in 10 years you'll probably be in a wheelchair". I decided I wasn't going to accept that".

Sandra soon realised that keeping herself active by exercising and singing was crucial to her maintaining a healthy lifestyle. Together with a friend, she started a choir in Newcastle, knowing that singing brought her immense joy and helped with breathing, swallowing and the general symptoms of Parkinson's. The choir has now been running for three years.

"So that's what I thought, I thought, if I can leave Parkinson's NSW some money, because all of these things cost, the choir, dance, PD Warrior, Pilates, etc., they all cost money. You've got to pay for venues and you've got to pay for people in centres and I'd like to donate some money so that it carries on".

"That's the reason behind leaving money to anyone isn't it? You're trying to make life a bit better for someone"

Sandra's generous and kind act of leaving a gift in her Will ensures that her legacy will continue. Ongoing services will continue to be provided to current and future members and research will forge ahead.

If you are thinking about leaving a gift in your Will like Sandra, it is so easy to organise, however if you would like advice or require further information, please don't hesitate to contact Peter Longhurst our Donor Development Manager (02) 8051 1900 or email him at [Peter.Longhurst@parkinsonsnsw.org.au](mailto:Peter.Longhurst@parkinsonsnsw.org.au)

Thank you so much Sandra.

**LEAVE A GIFT  
TO HELP  
OTHERS WITH  
PARKINSON'S**

If you would like to give your own consideration to leaving a gift in your will to Parkinson's NSW, please contact us.



