

STANDBYME

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A big thank you to the Parkinson's NSW Support Groups and the many community fundraisers who Pitched In for Parkinson's on World Parkinson's Day.

Read more on page 5

From the CEO

By the time you read this magazine, 30 Support Group members and some Parkinson's NSW staff will be in Kyoto, Japan, attending the World Parkinson Congress 2019.

These events are held every three years and provide an international forum for learning and discussion around the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's disease.

The Congress aims to provide opportunities for cross-pollination between members of the international Parkinson's community to expedite the discovery of a cure and cultivate best treatment practices for this disease.

Australians will make a major contribution to this year's Congress. Home-grown Parkinson's researchers, clinical neurologists, allied health professionals and experts on dance and music therapy for Parkinson's are all well-represented on the list of keynote speakers and workshop leaders at the event.

We are also excited that research commissioned by Parkinson's NSW on the value and effectiveness of community-based Parkinson's Specialist Nurses will be presented to the international audience at the Congress. See page 7 for the full story.

On page 6, read about another kind of research that says men who aren't physically active are at greater risk of developing Parkinson's. We encourage all men to play an active part in their health especially during Men's Health Week which is celebrated in the month of June.

But don't worry, while a few of our team members are in the international spotlight next month, others will still be busy delivering services as usual back in Australia.

Jo-Anne Reeves
Chief Executive Officer



Events & Education

Want to register or learn more about the following events and education seminars?

Make a free call to the Parkinson's NSW InfoLine:
1800 644 189

4-7 June: World Parkinson Congress in Kyoto, Japan

Held every three years to provide an international forum for learning and discussion around the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's disease.

17 June: Art for Parkinson's workshop at Concord-Massey Park Golf Club

Art for Parkinson's is an art-as-therapy program of Parkinson's NSW and is designed especially for people living with Parkinson's.

Parkinson's symptoms can be alleviated during the art-making process and this can improve mental and physical well-being. These workshops also provide social connections with others in the Parkinson's community.

1 July: Parkinson's Education Seminar in Bega at Bega Valley Commemorative Centre

Information for people living with Parkinson's, family members, carers and other interested parties.

25 August: Unity Walk in the Park

Registrations now open
www.unitywalkinthepark.com.au

17-18 September: 2019 Parkinson's NSW Support Group Conference in Sydney at Sydney Hilton Hotel.

Future events to be confirmed:

July: Parkinson's Education Seminar, Port Macquarie

September: Parkinson's Education Seminar, Wagga Wagga

October: Parkinson's Education Seminar, Coffs Harbour

November: Parkinson's Education Seminar, Wollongong

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Behind the scenes of Unity Walk

Unity Walk in the Park is the major annual fundraising initiative of Parkinson's NSW to support vital research and services for people affected by Parkinson's.

Everyone is welcome as walkers and supporters – friends, family, work mates, kids, and pets – particularly dogs. It is a great opportunity to come together to show support for loved ones and remember those whose lives are touched by Parkinson's.

Over the past 11 years this event has attracted 16,700 participants who have helped Parkinson's NSW raise more than \$1,000,000.

Organising the annual Unity Walk is a major task managed each year by Events Executive Terri Herlings.

"No sooner has the dust settled after one Unity Walk, we start organising the next," said Terri. "The process takes 11 months of planning, negotiation, paperwork, coordination and execution."

Fortunately, Terri has the background for this complex task. Prior to joining Parkinson's NSW two years ago, she had accumulated 12 years of experience in the staging of large cultural events in Australia and overseas. In one memorable year, Terri travelled to 36 different cities in 11 countries touring nine different shows.

Here she works with a mixed team of industry professionals who donate their time or discount their services, Parkinson's NSW staff and Support Group members to bring the Unity Walk to life in Sydney, Wollongong and – increasingly – in a variety of regional locations.

Last year the large Walks in Sydney and Wollongong – along with nine regional locations – attracted more than 1,300 participants. This year there will be newly named Regional Walks in even more locations.

Nine months prior to the big event, Terri and her colleagues plan, develop and order branding, merchandise, instructions and guidelines for participants, fundraising tools and processes, and web, social media and print content to recruit participants and donors.

There is also a huge volume of paperwork required for insurance, permission from Local Government and other bodies, site safety and accessibility, transport, parking, and first aid support.

Three months prior Terri begins recruiting volunteers to help out on the day. The closer we draw to the Walk date, the longer the workdays of Terri and her team become.

"It's hard work, but so worth it when we see the enjoyment and bonding people experience on the day," said Terri. "I also get a kick out of the number of people who both participate and set up their fundraising online. Each one has a different story to tell about who they are walking for and what motivates them."

Online fundraising for your participation in Unity Walk in the Park is quick and easy to set up. For more information, go to www.unitywalkinthepark.com.au

Terri (left) with some of the Unity Walk set up team



Inbocca has been supporting the event for the past few years

Some of the Parkinson's NSW staff volunteers



Getting the word out in Parkinson's Awareness Month

Parkinson's NSW and 24 Support Groups undertook 33 activities to build awareness and raise funds in April, Parkinson's Awareness Month.

This year the activities included information stands, craft stalls, quizzes, morning teas and lunches, a cocktail party and an awareness walk. Support materials including 15,000 quiz card drink coasters were distributed across NSW.

Griffith Support Group attracted 79 people to its Morning Coffee Fundraiser and raised more than \$900.

"A lot of the guests commented that they didn't realise how many people in Griffith are living with Parkinson's," said Group Leader Louisa Feltracco.

"I explained to them that the people here are the ones who come to our meetings but there are a lot more who are not ready to join us yet."

Nepean Blue Mountains Parkinson's Support Group successfully reached out to local media. The local paper did a story on the Group and its monthly meetings, its picnic and dance class.

The craft stall of Newcastle Parkinson's Support Group did well due to its location in the lobby of John Hunter Hospital. Members raised more than \$600.

Similarly, Tomaree Support Group set up its information stall in a high traffic area – Salamander Bay shopping centre.

Meanwhile, Goulburn's Shakin' Cocktail Party attracted almost 300 people and featured a performance by the Spooky Men's Chorale.

In Coffs Harbour, it was Parkinson's quizzes that attracted attention. Coffs Harbour Support Group conducted the James Parkinson Games, pitting people living with Parkinson's against the local Geriatric Medicine Team.

After a series of rounds answering questions about Parkinson's symptoms and treatment, the team of people living with Parkinson's scored a narrow win.



Coffs Harbour support group James Parkinson Games



Goulburn support group cocktail party



Port Macquarie support group awareness walk



Newcastle support group craft stall



Coffs Harbour support group James Parkinson Games



Nepean Blue Mountains support group picnic

Reaching out to local communities

A big thank you to our Parkinson's NSW Support groups and the many community fundraisers who Pitched In for Parkinson's on World Parkinson's Day and throughout the month of April.

A range of activities and events took place including morning teas, awareness walks, raffles, picnic, information and awareness stands, craft stalls, busking, sausage sizzle, shaving head for Parkinson's, trivia competition and thousands of Parkinson's quiz cards distributed all to raise awareness and funds in local communities across NSW.

Kiama support group stand on Terralong St Kiama



Yass support group members lunch



Shoalhaven Shakers support group at Jellybean Park



David shaves his hair for Parkinson's

Tomaree support group information stall



Hornsby Ku-ring-gai support group information stall



Griffith support group morning tea



Macarthur support group picnic in the park



Macarthur support group awareness stall



Exercise cuts Parkinson's risk for men

Current research says that men who aren't physically active are at greater risk of developing Parkinson's.

It is timely to discuss this because it is Men's Health Week in mid-June, and its theme is: Keeping boys and men healthy.

We know that exercise is second only to medication in the treatment of Parkinson's symptoms but according to a paper published by the Journal of the American Medical Association, men who exercise are less likely to develop Parkinson's in the first place.

Encouragingly, research tells us that even moderate exercise can be enough to counteract the risk.

Over the past 20 years several studies have focused on the effect of lifestyle factors on Parkinson's, including exercise. However, it has been found that such studies can often be inconsistent in their methodology and data interpretation.

A recent review of the literature by two independent investigators has delivered more rigorous results. They looked at eight studies involving 554,336 participants (including 2,192 people with Parkinson's) with an average follow-up period of 12 years that focussed on the link between Parkinson's risk and physical activity.

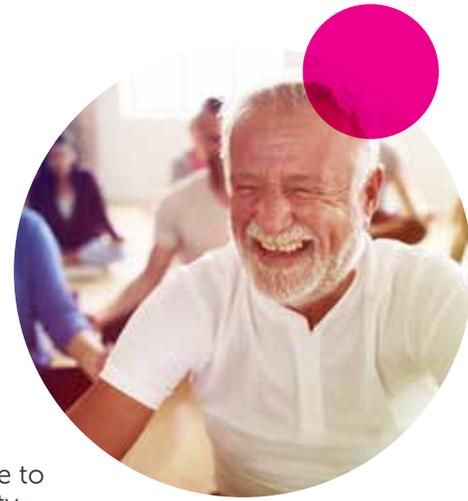
Data collated from all the studies showed that participants in the top category of physical activity had a 29 percent lower risk of developing Parkinson's, compared with those who did not engage in any moderate to vigorous physical activity.

Also, analysis showed that geographical location, follow-up duration, population size or study quality had no influence on the risk of Parkinson's.

However, it is affected by gender. The connection between exercise and Parkinson's risk was stronger among men than women, regardless of physical activity levels.

The collective analysis of more than 500,000 adults showed that the benefits of exercise were substantial for men but less notable among women.

Clearly, exercise is of great benefit to your health both before and after a Parkinson's diagnosis with exercise controlling the symptoms of Parkinson's. This particularly applies to men.



Parkinson's NSW becomes Major Donation Partner of Return and Earn

Parkinson's NSW has become a Major Donation Partner of the NSW Government Return and Earn program for a three-month period between May and August 2019.

Return and Earn is a container deposit scheme that aims to reduce the volume of litter in NSW by 40 percent by 2020.

The scheme provides more than 640 reverse vending machines across NSW where bottles, cans and cartons can be returned for recycling. A refund of 10 cents per eligible container is paid out in the form of retail vouchers, electronic refund to a PayPal account or as a donation to a not-for-profit organisation.

As a Major Donation Partner, Parkinson's NSW appears as a payment option on the screen of every Return and Earn reverse vending machine in the state.

The scheme was launched in December 2017 and by December 2018 one billion containers had been returned through Return and Earn, and more than 26 million containers were being recycled every week.

"Participation in the Return and Earn is a win-win for Parkinson's NSW and the State Government. By signing on as a Major Donation Partner we do our bit as a good corporate citizen to create incentives to reduce the volume of litter in NSW.

"At the same time, we benefit from new opportunities to receive donations from people across the state who may not previously have engaged with Parkinson's NSW."

Return and Earn participants who choose to donate to Parkinson's NSW will help us meet our target of raising \$30,000 in three months. This will fund the ongoing work of one Parkinson's Specialist Nurse in a regional community for four months.



Wolper welcomes people living with Parkinson's

Wolper Jewish Hospital in the Eastern Suburbs of Sydney is the only not-for-profit Jewish hospital in Australia. It provides rehabilitation, medical and palliative care to the general community within a framework of Jewish culture, religious and dietary requirements.

"Everyone is welcome at Wolper Jewish Hospital," said CEO John Tucker (pictured). "We remain true to our founders' principles of dignity, compassion and outstanding quality care for all."

People living with Parkinson's are among those benefiting from Wolper's care and compassion. The hospital hosts a thriving Parkinson's NSW Support Group and provides an office where people can benefit from the support of Parkinson's NSW Counsellor, Shushann Movsessian (wearing pink scarf in photo), for no charge.

Wolper has been a staunch supporter of Parkinson's NSW since late 2014, when it successfully applied for a grant from the Wolper Jewish Hospital Health Foundation.

"We are really pleased to be able to offer grants to both Jewish and non-Jewish community organisations. And we are especially pleased to support Parkinson's NSW because its work complements Wolper's services – particularly rehabilitation of older people with complex needs," said John Tucker.



Parkinson's Specialist Nurse Research presented at 5th World Parkinson's Congress

Research by Parkinson's NSW, Charles Sturt University and the Mid North Coast Local Health District has been recognised with an invitation to present at the prestigious 5th World Parkinson's Congress in Kyoto, Japan, in June.

"The research project aimed to evaluate the potential benefits of placing more specialist Parkinson's nurses in regional areas of need. It also assessed the potential to achieve significant savings in the NSW health budget while improving quality of life for people living with Parkinson's," said Associate Professor Rachel Rossiter of the School of Nursing, Midwifery and Indigenous Health of Charles Sturt University and leader of the research team.

The first phase of the project was a literature review which identified the largest costs to Government and individuals as acute care and residential aged care expenses, and indirect costs from lost productivity.

In the first component of the second phase, the research team interviewed specialist Parkinson's nurses, consumers of the specialist nursing services, and other health professionals in the two areas where a specialist



Wolper Jewish Hospital also provides space for meetings of the Eastern Suburbs Parkinson's NSW Support Group, which is held every second Friday of the month.

Shushann explained that both counselling and participation in a Support Group are valuable for people living with Parkinson's, as well as their carers and family members,

"Part of my work involves helping with the shock of the Parkinson's diagnosis. The diagnosis itself creates a great deal of anxiety and or depression," she said

"People often only have minutes with their Neurologist and when they leave they may not have felt able to ask questions or process what's actually going on for them. Also, people's symptoms can change, which can result in loss of confidence and difficulty adjusting."

Partners, carers and adult children are also welcome to participate in counselling. Relationships can change when a loved one is diagnosed and being offered the tools on how to deal with these changes is invaluable.

"I am always able to make my clients feel so welcome at Wolper. It's a beautiful place to come to, with terrific supportive staff and it's a lovely building too," said Shushann.

Parkinson's nurse was already in place – Coffs Harbour covering the Coffs Harbour, Bellingen and Nambucca Local Government Areas (LGAs) and Nowra covering the Kiama and Shoalhaven LGAs.

Consumers and carers at both sites were unanimous in describing the positive impact of the specialist Parkinson's nurse position.

"Approximately 25 percent of people in NSW live outside cities however 93 percent of neurologists are based in major cities. As a result, access to specialist services for people with Parkinson's living in rural and regional Australia is extremely limited," said Jo-Anne Reeves, CEO of Parkinson's NSW.

Research evidence points to the benefits of early intervention and self-management strategies in reducing the burden of disease and caregiver stress. Specialised Parkinson's nurses can support early intervention and self-management for people living with this disease. The research also identified enhanced effectiveness when the role is situated within the NSW public health system.

No one wants to be defined by Parkinson's

However, as Parkinson's progresses it becomes disabling, expensive and disruptive.

In order to maintain quality of life, people need services like exercise physiology, occupational therapy, speech therapy and physiotherapy.

These services require funding from My Aged Care or the National Disability Insurance Scheme.

The PNSW Connect Team of Parkinson's NSW was established to advocate for people who want to apply for funding, then connect them with the services they need as soon as their funding is approved.

Your donation will keep the PNSW Connect team working, guiding people living with Parkinson's to the services that enable a life they want and deserve.



Lisa is 57 and a mum of 5 living with Parkinson's

parkinson's
NSW

IN THIS TOGETHER

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

Title: _____ First Name: _____ Last Name: _____

Address: _____

Email: _____ Phone: _____

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