

STANDBYME

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IN THIS ISSUE

WALKING UNITED

More than 1,300 people joined the 11th annual Unity Walk fundraiser on 26 August.

Read more on pages 4 - 5

YOUR QUESTIONS ANSWERED

Parkinson's NSW's InfoLine service provides expert support for anyone touched by Parkinson's.

Read more on page 6

IN THIS TOGETHER
parkinson's
NSW

From the CEO

Welcome to the Spring issue of "Stand By Me".

The Parkinson's NSW Annual Report shows pleasing results, confirming the six pillars of our strategic direction are meeting the requirements of the Parkinson's community. In the last financial year, we recorded total revenue of over \$5.6 million and a surplus of over \$2.1 million – essential for funding the development and growth of our services.

Our Annual General Meeting (AGM) will take place on 24 October. There will also be an election for six member-elected seats. Information about the AGM and election process can be found on our website: www.parkinsonsnsw.org.au/about-us/agm

Good news: We have placed a new specialist neurological nurse in Port Macquarie to support the local community. We are also negotiating the co-funding and placement of three additional nurses in other communities. More news about this once details are finalised.

One of our registered nurses at Parkinson's NSW is now dedicated to advocating for people applying to the National Disability Insurance Scheme (NDIS). See the story on page 7.

There is also a story on page 4 about how a new approach to our annual Unity Walk in the Park saw ten walks across NSW and yielded donations of more than \$147,000 that will go toward vital research and services. Thank you to everyone who walked, volunteered and supported us in communities across NSW.

In closing, I welcome Razia Osman as the new Support Group Coordinator. Melanie Browning (previously in this role) is not going anywhere. She will ensure a smooth transition to Razia, then take up a new role that will keep her very visible and connected with the NSW Parkinson's community.

There's a lot happening! I'm looking forward to giving you a full update as each initiative falls into place.

Jo-Anne Reeves
Chief Executive Officer



Upcoming education seminars

18 October: Parkinson's Public Forum

In conjunction with the upcoming Support Group Conference, Parkinson's NSW is offering a public forum featuring keynote speaker Professor Simon Lewis.

Prof Lewis is an NHMRC-ARC Dementia Fellow who works as a Consultant Neurologist at the Royal Prince Alfred Hospital and is Professor of Cognitive Neuroscience at the University of Sydney.

He is the Director of the Parkinson's Disease Research Clinic at the Brain and Mind Centre at the University of Sydney and heads the NSW Movement Disorders Brain Donor program.

Registrations are now closed. Stay up to date with future events www.facebook.com/parkinsonsnsw

24 October: Southern Highlands Time: 10am Location: Mittagong RSL Club

Parkinson's NSW education seminars provide updates and opportunities to hear from local neurologists, exercise physiologists, neurological nurses, exercise groups, GP's, geriatricians and many other health and wellbeing professionals.

Guest speakers at the seminar will include:

- Dr Mariese Hely, Neurologist
- Matthew Ott, Physiotherapist
- Pamela Parker, Speech Pathologist
- Nina Cheyne, Parkinson's NSW Nurse
- Alyson Banks, Parkinson's NSW Exercise Physiologist

The cost of participating in this seminar is \$25 plus booking fee. Bookings are essential. Call 1800 644 189 to register.

2 November: Armidale Time: 10am Location: Armidale Services Club

Details will be posted on the Parkinson's NSW Facebook page and events calendar as soon as they are available.

**Facebook: www.facebook.com/parkinsonsnsw
Website: www.parkinsonsnsw.org.au/media-centre/event/**

Going to the World Parkinson Congress?

The 5th World Parkinson Congress (WPC) will take place in Kyoto, Japan from June 4 to 7 in 2019.

WPC is specifically designed for people living with Parkinson's. Past attendees said they met competent and optimistic patients and scientists, made life-long friends, and found the Congress both fun and inspiring.

June next year may seem a long way away, but now is the perfect time to start making plans if you would like to attend.

There will be a limit of 4,000 attendees at the Kyoto Congress. The last WPC in the U.S. attracted 4,500 participants and attendance has been increasing at every Congress since 2006.

Are you in or out of My Health Record?

This year you will have a My Health Record automatically created by the Australian Government.

If you don't want a record created for you, you have until 15 November 2018 to opt out by visiting the My Health Record website or by calling 1800 723 471 for phone based assistance.

My Health Record will be of value to people living with Parkinson's who are likely to have regular interactions with GPs, specialists and hospital and clinic staff. Their records will include information like diagnoses, current medications (so allergic reactions and drug interactions can be avoided), referrals, next of kin, and organ donation information.

All of this data will be immediately available to doctors and medical staff, regardless of where people living with Parkinson's present for treatment.

You can choose to opt out, but if a My Health Record is created for you then doctors will automatically upload your health information unless you specifically ask them not to.

Access to your My Health Record is limited to registered healthcare providers and people who are authorised to provide you with medical care. Private health insurers and other organisations will not have access.

You can opt out of My Health Record by:

- Visiting the web site www.myhealthrecord.gov.au and following the instructions on how to opt out.
- Managing the process by phone. Call 1800 723 471
- Completing a paper form. These forms are available from your local Australia Post office.

Parkinson's NSW will help you plan by publishing regular updates in our publications Stand by Me and InTouch. The information we share will help you understand the benefits of participating, and how to make the most of your time at WPC and in the host city of Kyoto.

If you are planning to attend the WPC (or indeed taking a long flight anywhere), this video from Professor Simon Lewis might prove useful: www.profsimonlewis.com/long-haul-travel/

**For more information, contact:
Alyson Blanks
(02) 8051 1900
pnswn@parkinsonsnsw.org.au**



Other uses of My Health Record data

Data collected through initiatives like My Health Record may also have value in large-scale research projects.

One example was reported in the international medical journal Cell. It described how researchers in New York had used a computer algorithm to review the records of three million patients at large hospitals and capture 7.4 familial relationships – just from the next of kin data in online health records. (Identification of individual patients was removed).

This enabled the mapping of family trees spanning multiple generations, allowing researchers to link information on relatives with patients' hospital. This enabled them to track how diseases may be inherited.

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Walking the walk

More than 1,300 people joined the 11th annual Unity Walk fundraiser on 26 August.

This year the event raised more than \$147,000. Over the past decade, Unity Walks have involved more than 15,000 people raising in excess of \$1 million - all of which is contributed to vital research and services for people affected by Parkinson's.

People with Parkinson's, multiple generations of families and friends, and a lot of excited dogs took part in walks at Sydney Park, in Sydney's inner west, and Stuart Park in North Wollongong.

'Virtual walks' were conducted by enthusiastic Parkinson's NSW Support Groups in Bathurst, Coffs Harbour, Cooma, Griffith, Kiama, Lismore, Mudgee and the Shoalhaven district. The walkers were real, but all fundraising took place virtually - through internet appeals created for each location.

Great supporters AbbVie (a biopharmaceutical company developing therapies for Parkinson's) couldn't make it to our Sydney Walk this year. Instead, they created a virtual walk during their national conference on the Gold Coast. More than 50 staff members participated.

For the first time this year we had an official Unity Walk in Park theme song, selected by popular public vote. It was the bouncy "Walking on Sunshine" by Katrina & The Waves - a great sound track for the warm-up and start of the Walk.

The distributed nature and flexible format of this year's Unity Walk in the Park enabled local communities to create events which best suited their needs and involved contributors from that region.

Wollongong

The Wollongong walk took place in fair weather along the recently opened Blue Mile Walk with breath-taking views of North Wollongong beach.

Coffee was available from the Bar Pellegrini Coffee Van, and the walker warm-up session was led by exercise physiologists from Body Dynamics. Following the Walk there was a sausage sizzle provided by the Wollongong Lions Club while hand and neck massages were available from Purple Sister Massage in return for a gold coin donation.

This Walk - the fifth to be held in Wollongong - attracted more than 250 participants. It was run entirely by volunteers under the guidance of Jen Gray who has a deep personal commitment to fundraising because her father is living with Parkinson's.

AbbVie virtual walk on the Gold Coast



Mudgee virtual walk participant June Ritar



Sydney

In Sydney walkers had a choice of refreshments and fuel from the Grind n Press Coffee Crew, Inbocca Italian street food stall, and the Sydney Park Kiosk. All food vendors donated a percentage of their profits from the day.

New this year was the participation of the Art for Parkinson's team. Participants were provided with art materials to create team signs which were on proud display during the Walk.

The Australian Army Band ensemble Frontline once again set the beat for the walk, while the hip-hop group Phly Crew made the warm-up fun and gave the start and finish a party atmosphere. Big smiles all around.

Following the walk, participants were entertained by folk singer Kay Proudlove and comedic juggler James Buster. Professor Simon Lewis also spoke, providing an insight into the research conducted by the Brain and Mind Centre of the University of Sydney.

A big thank-you also goes to our generous sponsors: Harper Bernays, Festival Hire, Webstercare, and Elgood & Son Printers.

Voices from virtual walks

"It was the first time we have conducted this event and it was very successful. Next year we are confident that we can develop it into something even bigger and better."

Trevor Lyons, Coffs Harbour Young Onset Parkinson's Support Group

"I was humbled to have so many people coming forward to help on the day, willingly giving time and sharing their experience. This is what makes Cooma so special."

Sharyn Crockett, Snowy Monaro Parkinson's Support Group

"In addition to organising our first Walk, we sold Italian crostoli, cakes, biscuits and scones on the day. Not one crumb was left by the end of the event; we sold out."

Louisa Feltracco, Griffith Parkinson's Support Group

"Council decided to put the sprinklers on, so we had clear skies but still got a bit damp!"

Jennifer Mannell, Bathurst Parkinson's Support Group

"Here in Kiama about 50 people walked from Surf Beach to Kendall's Beach and back raising about \$4,000."

Lesley Errington, Kiama Parkinson's Support Group

"We had 30ml of rain so our eight walkers did a shortened walk before having coffee at Club Mudgee."

June Ritar, Mid-Western Parkinson's Support Group

"Some of our 29 participants walked while others 'walked sitting down' on their mobility scooters, and we were also joined by carers and friends. We had great support from the local Lions and RSL Clubs. Vince Carroll, our Parkinson's Nurse, and his wife Toni also joined us."

Robbie Handcock, Nambucca Valley Parkinson's Support Group

"About 50 people walked near the Shoalhaven River then had lunch and socialized. The café where we ate generously donated additional funds for our cause."

Nina Cheyne, Parkinson's NSW Nurse, Shoalhaven Region

"A group of more than 55 AbbVie staff joined our Gold Coast Virtual Walk; we were at a conference there. That means half of the conference participants participated!"

Todd Arneman, AbbVie, Gold Coast Virtual Walk

"My wonderful work friends organised a surprise rollup to join our Virtual Bushwalk at Glenbrook on Sunday. We didn't know they were coming; they even had team shirts for everyone!"

Wendy Symington, Glenbrook virtual walk

In memory of John Silk

The Parkinson's community were sad to say goodbye to John Silk last month. John was elected President of Parkinson's NSW in 2006, held this position for four years and remained a Board Member until November 2015.

During his time as President, John was instrumental in securing seed funding for the Parkinson's NSW Nurse in the Shoalhaven, a position that continues today. He also introduced Unity Walk which is still held each year across the state celebrating the Parkinson's community.

In 2010 John was awarded the Order of Australia Medal (OAM) for service to people living with Parkinson's through administrative and support roles and was inducted as a Life Member of Parkinson's NSW in 2011 for his contribution to the organisation.

We extend our sympathies to his wife Rebecca and family.

John at Government House on World Parkinson's Day pictured with his wife Rebecca and Governor of NSW The Honourable David Hurley



Sharyn Crockett leads the virtual walk in Cooma



Many questions? Call this number for answers

Parkinson's NSW's InfoLine service provides expert support for anyone touched by Parkinson's.

When you call the InfoLine on **1800 644 189** you will be speaking to Registered Nurses experienced on the topic of Parkinson's – not a call centre staffed by generalists.

Our InfoLine nurses can provide evidence-based information, advice and referrals, and connect you with other Parkinson's NSW support services.

These include regional specialist neurological nurses, counsellors, an exercise physiologist, a social worker and an NDIS Nurse Advocate who can guide you through the complexities of the National Disability Insurance Scheme.

Who will you talk to?

Sandra Stanton, our Customer Service Coordinator, will be your first point of contact. She will direct your call to the nurse most appropriate to answer your questions.



Sandra can also help with general information about the services offered by Parkinson's NSW, provide information and take enrolments for education seminars.

Registered Nurse Cathy Melton has more than 40 years of experience in community nursing in city and regional areas, including over 25 years in aged care nursing.



Registered Nurse Margi Edmondson is our resident NDIS Advocate. She has been a nurse and nurse educator for over 35 years, including long stints in aged care and acute care nursing for elderly patients. She has been at Parkinson's NSW for five years.

Registered Nurse Julie Austin has more 30 years of experience including 15 years in aged care as a nurse, consultant and educator. She has been with Parkinson's NSW for 9 years and has additional qualifications in adult education, gerontology and neurodegenerative diseases.



Opportunity to join Parkinson's research

Researchers at Neuroscience Research Australia (NeuRA) and The University of New South Wales are seeking people with Parkinson's as research volunteers.

Their research project aims to learn more about reactive and volitional step training to reduce falls among people living with Parkinson's.

Ideal candidates for participating in the study would be 40 years or older, diagnosed with mild to moderate Parkinson's, living independently and have not had deep-brain stimulation surgery in the past six months.

Candidates must have been stable on anti-Parkinson's medications for at least one month and had less than 12 falls (one fall per week) in the past three months.

If you are selected for this research project you will be invited to visit NeuRA for assessment before being given reactive stepping training in a safe environment. This would be followed by further step training at home to improve your ability to avoid trips and slips for a period of 12 weeks.

There will be a follow-up assessment at NeuRA after three months, and you will be given summary results of your physiological and clinical assessments.

If you wish to volunteer for this study or to find out more information, contact:

Paulo Pelicioni
Tel: 02 9399 1024
E: p.pelicioni@neura.edu.au



Need help with NDIS? Call our Nurse Advocate

Parkinson's NSW now has a registered nurse devoted to advocating for people with Parkinson's applying for the National Disability Insurance Scheme (NDIS).

Margi Edmondson is a nurse and nurse educator with more than 35 years of experience – including five at Parkinson's NSW. She is available via the InfoLine on 1800 644 189 to provide advice and support on navigating the complexities of the NDIS.

"Anyone under 65 with a diagnosis of Parkinson's can apply for support from the NDIS," explained Margi. "However, given that the role of the NDIS is to provide support not otherwise available through Medicare, applications by people with Parkinson's can be complex."

Margi can explain how the NDIS works, who is eligible and how to enrol – then advocate for you throughout your journey toward securing funding.

She has developed tools to support you along the way, including checklists that will guide you through the application process and confirm what supporting documents will be required at each step.

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New Support Group formed in Kiama

Kiama on the South Coast of NSW now has a Parkinson's Support Group.

It was established in April 2018 and now has 30 members comprising both people living with Parkinson's and carers.

"Some of us had been attending a Solutions for Wellbeing exercise class and the idea for a Kiama Support Group came from that," said Lesley Errington who was diagnosed with Parkinson's in 2016 and coordinates the Group.

"As a group, our priorities are peer support and sharing of practical information – particularly tips on what people with Parkinson's are entitled to in terms of financial support, what to do when we must go to hospital, and information on medications.

"Nina Cheyne, the Shoalhaven Parkinson's nurse, joins us. She is a wealth of information and willingly answers all of our questions."

Lesley and her colleagues in Kiama understand the importance of exercise. When Stand by Me interviewed her, she was about to head off to a drumming class to help improve coordination of all four limbs.

Margi will advise on the clinical assessments you will require – including those from neurologists, speech therapists, and physiotherapists. She can also recommend the appropriate primary and allied health practitioners to consult in your area.

She can also connect you to people with Parkinson's who have already been through the process and now generously make themselves available to share their experiences.

"Navigating the NDIS processes can be challenging and frustrating, but it is a journey worth taking to obtain the support you require," said Margi. "Even if your application is initially declined it is not the end of the story; there are ways of reapplying or appealing. We'll be with you all the way."

Margi will help navigate the NDIS



Walkers united to raise funds

The Kiama Virtual Walk in the Park on August 26 was attended by about 50 people and has raised more than \$4,000. The Walkers met at Surf Beach and walked around the headland to Kendall's beach before heading back to Coronation Park Surf Beach.

To connect with the Kiama support group, please call the Parkinson's NSW InfoLine 1800 644 189

Kiama Support Group take part in the Unity virtual walk



Help us meet growing demand for services

The annual Parkinson's NSW Unity Walk in the Park attracted more than 1,300 walkers and volunteers across NSW on 26 August. Thanks to their combined efforts it was once again a successful fundraising event.

Although the Walk is over, demand for the services of Parkinson's NSW is ongoing and growing.

We receive less than 10 per cent of our funding from Government grants. Ongoing donations are essential for maintaining and growing life-enhancing services for people living with Parkinson's.

Our resources already include a social worker, exercise physiologist, counsellors, registered nurses with Parkinson's expertise, and experts in education for people living with Parkinson's – as well as their primary and allied health providers.

Soon we will add a speech pathologist, physiotherapist and occupational therapist, as well as additional neurological nurses in regional areas. You can help.

Please consider a donation today to support ongoing essential services for people with Parkinson's. Your gift of any size would make a real difference.



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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:

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Credit Card (details below) Visa Mastercard American Express

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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

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