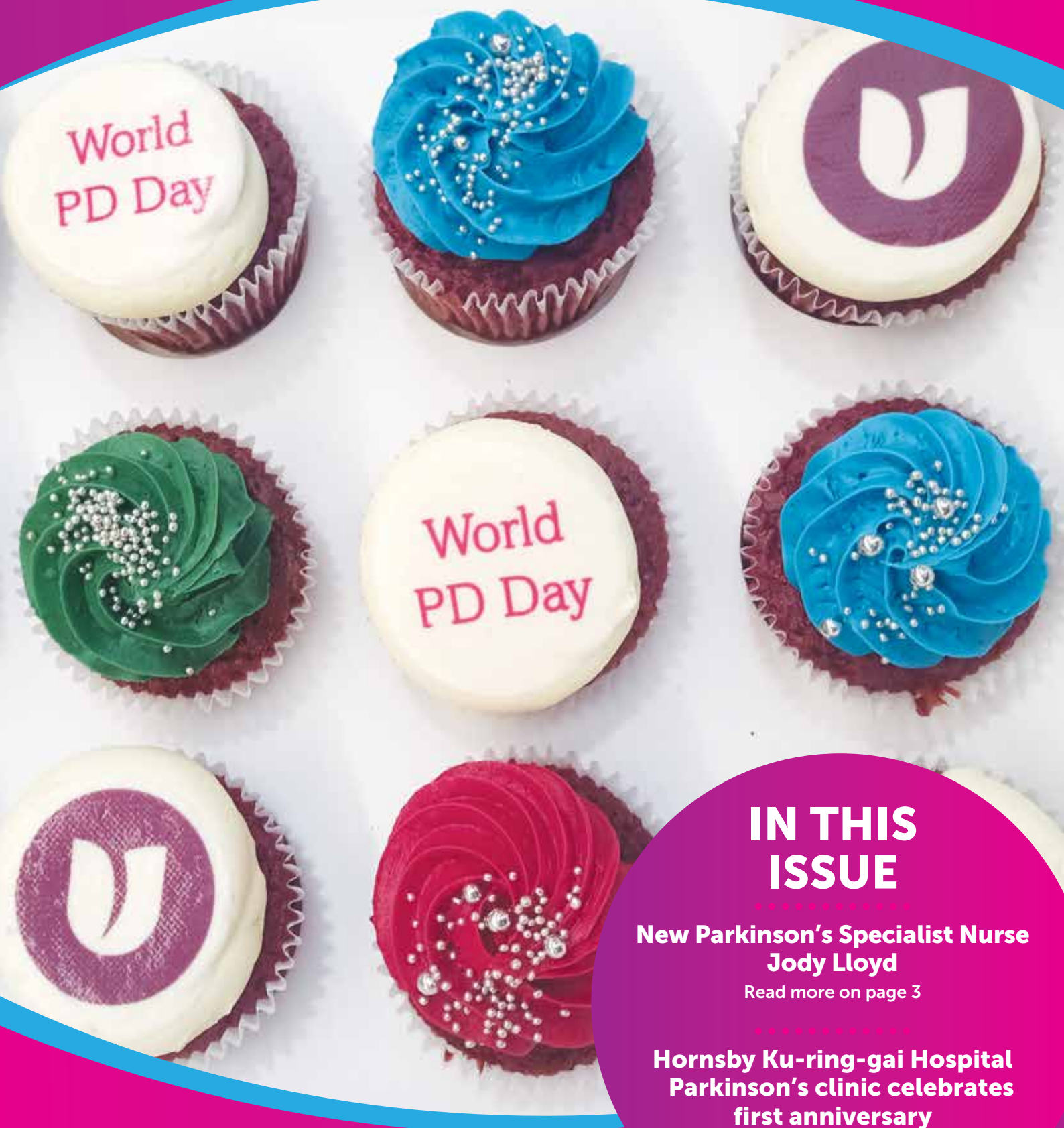


STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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Jody Lloyd**

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From the CEO

Welcome to the Winter edition of *Stand by Me*.

In our Autumn edition I mentioned how good it was to see so many Support Groups beginning to reconnect with their communities in person. Happily, that trend has continued.

We had a high level of participation in Parkinson's Awareness Month last April. Also, we were happy to celebrate the 30th anniversaries of two Support Groups – Tamworth and Eurobodalla. Congratulations to both Groups from all of us at Parkinson's NSW.

There is also more good news in the form of two new Parkinson's Specialist Nurses.

Jody Lloyd came all the way from the U.K. to replace Rachael Mackinnon in Port Macquarie. Rachael has been promoted to the Sydney-based position of Clinical Lead – our most senior Parkinson's Nurse role.

Also, by the time you read this magazine, we will have introduced our first ever Parkinson's Specialist Nurse in the Goulburn region. This was possible thanks to the tireless fundraising of the Goulburn Support Group and its sponsors, as well as strong local advocacy.

We have increased our advocacy efforts in general, at both State and Federal levels, with the support of our refreshed Board. We are seeking recurrent government funding that will supplement our fundraising efforts and enable us to build capacity to maintain and deliver services – particularly our InfoLine and education offerings.

We will keep you up to date on progress in *Stand by Me* and our other publications.

Meanwhile, in this edition, we have stories on an automated imaging system that can diagnose Parkinson's and we relaunch the Parkinson's Passport as a handy single-page medication and information sheet to communicate with medical staff.

Enjoy the read and stay well.

Jo-Anne Reeves
Chief Executive Officer



John Watkins appointed Deputy Chair of Parkinson's NSW Board

The Hon. John Watkins AM was voted in as Deputy Chair of the Parkinson's NSW Board at its March 2022 meeting.

John, who is living with Parkinson's, had a 16-year career as a teacher until he was elected to the NSW Parliament in 1995. He was sworn in as Deputy Premier in August 2005 and was also the NSW Transport Minister and Minister for Finance when he resigned from politics in 2008.

He also held six other Ministerial appointments during his political career including State Development, Police, Education and Training, Corrective Services, Fair Trading and Sport and Recreation.

Upon leaving the political arena, John was appointed CEO of Alzheimer's Australia. He served in that role for nine years, until the company moved from a state-based entity to a national organisation – Dementia Australia. John then served as Dementia Australia Ambassador.

John has held an extensive range of Non-executive Director roles including Chair of the Board of Calvary Healthcare, Chair of the Catholic Health Australia Board, and membership of the Council of the Australian Healthcare and Hospitals Association.

He has also Chaired Mary MacKillop Today, a company that provides overseas aid and assistance to communities in the Democratic Republic of Timor-Leste, Fiji, Papua New Guinea, and Peru, in addition to supporting indigenous tertiary students throughout Australia.

John sits on the Governing Council of Neurological Research Australia NeuRA and is also a member of the Advisory Committee for the Centre for Emotional Health at Macquarie University.

He was announced as a Member of the Order of Australia (AM) in the 2015 Queens Birthday Honours List for his significant service to the community through leadership in health, education and to the Parliament of NSW.

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New Parkinson's Specialist Nurse Jody Lloyd joins Mid North Coast Local Health District

People living with Parkinson's disease in Port Macquarie, Kempsey and surrounding communities recently welcomed Parkinson's Specialist Nurse Jody Lloyd.

She replaces Specialist Nurse Rachael Mackinnon who has relocated to Sydney and now works in the role of Clinical Lead for Parkinson's NSW.

Jody is a nurse with advanced education and more than a decade of experience spanning roles in both Australia and the UK. She has experience in Parkinson's, Aged Care, Cardiology, health education and evaluation of standards of care.

Member for Port Macquarie, Leslie Williams said,

"Specialised neurological nurses are proven to have many benefits for people living with Parkinson's and their families."

Parkinson's NSW CEO Jo-Anne Reeves said the jointly funded, LHD-based Parkinson's Specialist Nurse model had already been proven to deliver benefits for people living with Parkinson's and their caregivers.

"This model permits the Specialist Nurses to work across a number of settings including hospitals, clinics, patient's homes and Aged Care facilities," she said.



"There is also evidence that this model of care helps to reduce the sense of isolation many people with Parkinson's experience, along with the high rates of depression and anxiety associated with the disease."

"Where communities have access to a Specialist Nurse, carers, and family members also show significant improvements in their own well-being, with reduced levels of depression," she said.

For information and links

visit the Parkinson's NSW website www.parkinsonsnsw.org.au/information-and-fact-sheets/



Parkinson's Community Heroes a hit in second year

This was the second year that Parkinson's NSW promoted the Parkinson's Community Heroes program to both commemorate Parkinson's Awareness Month and provide opportunities for Support Groups to recognise their local supporters – while also raising their Groups' profiles within their communities.

The Heroes program was not designed to recognise Support Group participants, but local community heroes who had assisted them.

Twelve Support Groups took advantage of this opportunity to generate publicity in their communities:

- U Ashfield
- U Chinatown Bilingual
- U Kiama
- U Macarthur
- U Nepean/Blue Mountains
- U Southern Highlands
- U Blacktown
- U Coffs Harbour
- U Lismore
- U Narrabri
- U Port Macquarie
- U Tweed Heads

"Nominations varied widely – including boxing and exercise trainers, politicians, Allied Health practitioners, supportive community organisations, and active fundraisers," said Support Group Coordinator Cassie Morgan.

"It was heartening to see Groups taking advantage of this opportunity to acknowledge their local supporters while driving publicity and hopefully also attracting new participants.

"These Groups also conducted community outreach campaigns with information stands, raffles, picnics and contacts with local media," she said.



Coffs Harbour Support Group awarded Rotary Club of Coffs Harbour



Blacktown Support Group awarded physiotherapists Mobi Healthcare



Blacktown Support Group awarded exercise teacher Brenda



Kiama Support Group awarded physiotherapist Ryan Parker



Lismore Support Group awarded the Lismore community

Eurobodalla Support Group celebrates 30th anniversary

Eurobodalla Support Group was founded in 1992 and attracted 26 people to its first meeting.

From the very beginning, the Group attracted participants from a wide area ranging from Narooma to Bateman's Bay, with Moruya in the centre – which is where the Group was established and still meets today.

One factor behind the longevity of the Eurobodalla Group is the stability and length of service of its Leadership Team (Committee). Stints of up to eight years in leadership positions have been common.

Another outstanding example of longevity was Mrs Betty Byrn and husband Bruce who participated in the Group from 1998 to 2014 in leadership roles and continued attending meetings until 2019.

"In 2015 we had some turnover because the husbands of several Committee members were very ill so they had to stand down. In that year Cindi McQualter took over as President and has been brilliant. She led the Group into a new era," said current Secretary Joy Overs.

When asked about the characteristics of a successful Support Group, Joy replied: "Consistency and continuity. It doesn't matter if you have 10 participants or 25, you must provide the same support, friendship, and confidentiality so people feel safe talking about what are often very intimate topics related to Parkinson's."

Joy also shared the story of a younger woman struggling with Parkinson's when she found the Group. Her husband confided that she had been struggling to accept her diagnosis and symptoms. After meeting with us he stated, "There has been a very positive change in my wife's attitude since attending your meeting. I am so grateful for your support, and we will continue to participate."

"Over the years we have met families of our group members and had social occasions and it's been more like a 'family group'," said Joy.



World Parkinson's Day at Hornsby Hospital



Nepean Blue Mountains Support Group awarded dance teacher Cassandra



Southern Highlands Support Group awarded physiotherapist Matthew Ott & Mittagong RSL staff

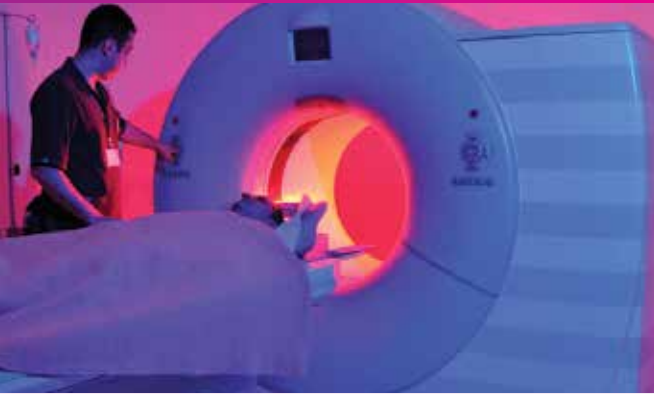


Maitland Support Group awarded Walka Grange Lifestyle Village



Lyn, Pat & Joy from Eurobodalla Support Group

Automated system to diagnose Parkinson's



In an international study, researchers from the US, Germany and Austria have used a non-invasive MRI method to develop an automated system that can diagnose Parkinson's.

Researchers worked with 1,002 patients and used an imaging method that measures how water molecules diffuse in the brain. This helped them to identify where neurodegeneration is occurring.

Parkinson's disease can present a challenge for accurate diagnosis because of shared and overlapping motor and non-motor symptoms.

According to the new study, accuracy of diagnosis in early Parkinson's is about 58 percent – and more than half of misdiagnosed patients actually have multiple system atrophy or progressive supranuclear palsy.

The new results demonstrate the effectiveness of an automated method to provide a differential diagnosis of the various forms of Parkinson's.

"Since these diseases require unique treatment plans and different medications, and clinical trials testing new medications require the correct diagnosis, getting the diagnosis right is important for patient care," said Dr David Vaillancourt, who led the study.

Source: McKnight Brain Institute, University of Florida and The Lancet Digital Health

Introducing the new Parkinson's Passport

One of the biggest contributing factors for people not having their medications on time in Emergency or upon admission to hospital is that people present without their medications or an up-to-date list of them.

The Parkinson's Passport addresses this issue. It is a single page A4 document that folds down to a convenient pocket size – yet holds all the information you may need to communicate to medical staff.

If you present at hospital with your Parkinson's Passport and your Webster-pak® (including the list of medications that comes tucked into the back of the box), it will ensure that you receive your correct medications on time, every time.

The Parkinson's Passport can be downloaded from the Parkinson's NSW web site here www.parkinsonsnsw.org.au

Just write in the required information for you:

- U Medical practitioner contacts
- U Emergency contact
- U Enduring Guardian contact and location of form OR location of Advance Care Directive form

This information, plus the guidance already printed on the Passport for medical staff and the information in your Webster-pak® will be all you need.

We suggest you keep your completed Parkinson's Passport under a magnet on your fridge door, so you won't forget it on the way out.



Our next Pitch in for Parkinson's Raffle is now open.
For your chance to drive away in a brand-new Suzuki Swift call the dedicated Raffle Hotline to purchase your tickets 1800 806 277



Purchase your tickets by 17 June 2022 (Permit Number NSW GOCAU/2362)

Hornsby Parkinson's clinic celebrates first anniversary



Hornsby Ku-ring-gai Hospital Neurological Parkinson's Clinic has just marked its first year of service to the Parkinson's community of northern Sydney.

The clinic is located in the Outpatients Department of the hospital and staffed by Parkinson's Specialist Nurse Suliana Manuofetoa and a rota of four neurologists led by Dr Omar Ahmad, Head of Neurology.

A second Parkinson's clinic also operates at the hospital, staffed by a multidisciplinary Allied Health team with a focus on rehabilitation.

"The benefits of the Neurological Parkinson's Clinic are that there is no waiting list, we operate under the public health system so it is free, we are able to refer directly to Allied Health, provide access to community services, and we can start patients on advanced therapies immediately when they are required," said Suliana.

Wait times for neurology appointments at some other northern Sydney hospitals are measured in years, so the

Clinic also attracts some out-of-area patients who require more immediate treatment.

Patients attending for an initial consultation have 40 minutes with a neurologist, followed by a 20-minute appointment with Suliana. Follow-up patients have a 20-minute appointment with the neurologist and a 20-minute appointment with the nurse.

In its first year of operation, the once-a-fortnight Clinic saw 50 new patients, and performed 68 neurologist follow ups, 89 nurse follow ups, and three patients commenced on advanced therapies. In addition, Nurse Suliana has undertaken 92 nurse in-patient consultations during the past year.

"Feedback from patients has been very gratifying," said Suliana. "We have received many positive comments on the quality of service and our focus on patient-centred care."

Martin Pryor and the tales of his dog, Bungee

Writing a children's book about a dog named Bungee – in fact, a series of books about this dog – was never on Martin Pryor's to-do list.

"It was an accident," laughs Martin, 68, who is living with Parkinson's and has so far released Bungee, A Doggy Tale, and Bungee's Buddies.

"Bungee is our dog, and he was a rescue dog. The books follow his life and adventures and are written to make reading enjoyable for primary school children. Once the publishing costs are covered a percentage of the profits will go to Parkinson's NSW. It's the least I can do to thank them for all they do for people living with Parkinson's." Martin was diagnosed with Parkinson's in 2016

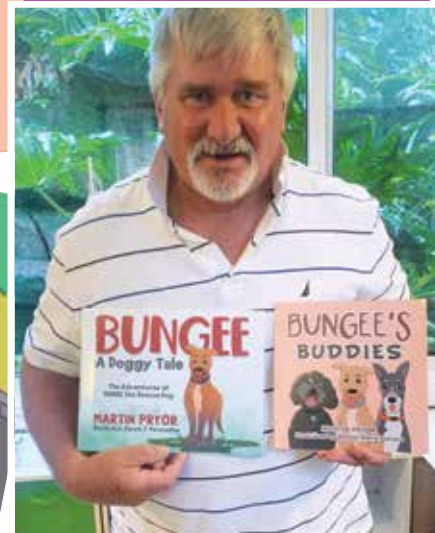
"It was fun to write the books and as a teacher I have a good understanding of what helps children to read," says Martin.

Just recently I've signed with a book outlet in Britain called Featherbed Tales (<https://featherbedtales.com/>). My book is their first outside author on their website.

This site allows people to record themselves reading the books there so that their child or grandchild can log in and hear the book being read to them as they follow the pages, which is great for families who can't see each other easily."



If you'd like to buy copies of Martin's books, you can purchase them on Amazon, Barnes & Noble, Xlibris and Booktopia. Martin also has a number of personally signed books available through Thebungeebooks@gmail.com





You can help fund life-enhancing Parkinson's Nurses



A person's Parkinson's journey often starts with the shock of diagnosis as they step into the unknown.

Parkinson's is a progressive disease that is different for everyone, so there is a question mark over tomorrow.

There is a new vocabulary, information about medications, and challenging symptoms – so much to take in at once, and so many questions needing answers. And is extra challenging if you happen to live in a rural area.

This is where Parkinson's Specialist Nurses apply their skills, knowledge, and compassion.

They answer the questions, connect people with the services they require, and support both patient and carer as they step through their Parkinson's journey.

You can help them do this important work. You can help them enhance the lives of people living with the challenges of Parkinson's.

Donations from generous people like you mean we can help fund more Parkinson's Specialist Nurses in rural NSW. Please give now.

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

