

STANDBYME

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From the CEO

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

As I write, the Parkinson's NSW annual report is being prepared. It will highlight the continued high demand for our InfoLine staffed by Registered Parkinson's Nurses, as well as growth in education seminars to reach more than 850 people.

Meanwhile, our community-based Parkinson's Specialist Nurses performed more than 2,350 consultations. Our counsellor conducted 217 telephone consultations and 296 face-to-face sessions with individuals, couples and family members dealing with the impact of living with Parkinson's.

The 2017-18 financial year was one of planning and reviews of our sustainability, preparing for investment in services in 2018-19. Accordingly, we posted a surplus of \$2.4 million in the previous year and expect to report a deficit for 2018-19. This is in line with our current five-year strategic plan.

This edition of *Stand by Me* includes articles on the value of multidisciplinary healthcare teams for supporting people living with Parkinson's, the announcement of our registration as a National Disability Insurance Scheme (NDIS) Service Provider, and the benefits of pole walking as fun and safe exercise.

Importantly, there is an announcement about alternatives to Sinemet during the current shortage. Also read about the potential of telehealth services for people living in regional and rural areas and the latest Parkinson's research.

As always, if you have any feedback on this publication or ideas on how we can improve our services please contact us by telephone, our web site or Facebook page. Information on all these channels appear below.

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

Education

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

17 October: Port Macquarie

28 October: Ashfield (carers seminar)

30 October: Blacktown

14 November: Coffs Harbour

TBC: Wollongong

Dance

Free Dance for Parkinson's 'taster' class running from noon to 1.15pm. For more information phone Cathie 0414 067 045 or email: dance@dancepdau.org

13 November: Tramshed Arts and Community Centre, 1395a Pittwater Road, Narrabeen

Art

Art for Parkinson's is an innovative, effective art program designed specially for people living with Parkinson's.

18 October & 25 November: Ingleburn

4 & 29 November: Sans Souci

World Parkinson's Day 2020

Note: this day falls on Easter Saturday

11 April 2020

Want to stay up to date with upcoming events & education?

Subscribe to the Parkinson's NSW newsletter

parkinsonsnsw.org.au/subscribe

Macquarie Hospital Building 17
51 Wicks Road
North Ryde NSW 2113
1800 644 189

pnswn@parkinsonsnsw.org.au
www.parkinsonsnsw.org.au
www.facebook.com/parkinsonsnsw
www.instagram.com/parkinsonsnsw

ABN 93 023 603 545
ACN 622 455 985

Parkinson's NSW services now available under NDIS

Parkinson's NSW is now a Registered National Disability Insurance Scheme (NDIS) Service Provider.

During the application process to become a Registered Service Provider, our management system was certified to ISO 9001 earning us the right to display the 'five ticks' logo.

ISO 9001 certification is focused on an organisation's ability to meet customer expectations and deliver customer satisfaction.

Being appointed as an NDIS Registered Service Provider enables us to deliver services billable to the approved NDIS Plans of eligible people under the age of 65.

A newly-formed team called PNSW Connect Team will deliver these services.

If you are under 65 and have not yet applied for the NDIS, the Connect Team can help with that too. An experienced Parkinson's Registered Nurse on the team provides free information advocacy and advice throughout the application process.

She can also assist with reapplications if the NDIS decision does not go your way the first time around.

Other services the PNSW Connect Team delivers include:

- ✓ Tools to help you plan and prepare for your conversations with NDIS Planners.
- ✓ Stories of people who are already NDIS participants, so you know what to expect.
- ✓ Answers to your questions.
- ✓ Services under your approved NDIS Plan



For evidence-based help, information and advocacy, make a free call to the PNSW Connect Team on 1800 644 189.

For more information about the NDIS, and the difference between the NDIS and Aged Care services, see our web site:

www.parkinsonsnsw.org.au/services/ndis

Alternatives to Sinemet during shortage

There has been a shortage of Sinemet® since August 2018 and this is expected to continue until the end of December this year. Only emergency supplies of these products are available.

Sinemet® (levodopa/carbidopa) is a medication commonly used in the treatment of Parkinson's disease as well as other neurological disorders.

The Australasian Neuroscience Nurses Association (Movement Disorder Chapter) and The Movement

Disorder Society of Australia and New Zealand have issued a joint statement providing information about optional substitute medications for Sinemet® during this period of shortage:

Note: These listed medication conversions are provided for guidance only, are not intended as personal medical advice. Any such changes should be discussed with your doctor.

Sinemet® (Levodopa/Carbidopa)	Recommended substitute brand and dosage with closest Levodopa dose equivalence
Sinemet® 100/25 tablet (Immediate release)	<ul style="list-style-type: none"> ✓ Kinson® (Levodopa/Carbidopa) 100/25 tablet ✓ Madopar® (Levodopa/Benserazide) 100/25 tablet ✓ Madopar® (Levodopa/Benserazide) 100/25 capsule
Sinemet® 250/25 tablets (Immediate release)	<ul style="list-style-type: none"> ✓ Kinson® (Levodopa/Carbidopa) 100/25 (x2½) tablets ✓ Madopar® (Levodopa/Benserazide) 100/25 (x2½) tablets ✓ Madopar® (Levodopa/Benserazide) 200/50 (x1¼) tablets
Sinemet® CR 200/50 Controlled Release tablets	<ul style="list-style-type: none"> ✓ Stalevo® (Levodopa/Carbidopa/Entacapone) 150/37.5/200 tablet ✓ Madopar® HBS (Levodopa/Benserazide) slow release 100/25 (x2) tablets ✓ (HBS - hydrodynamically balanced system)

Reference: Tomlinson, C, Stowe, R, Patel, S, Rick, C, Gray, R & Clarke, C 2010, 'Systematic review of levodopa dose equivalency reporting in Parkinson's disease' Movement Disorders, vol. 25, no. 15, p. 2649-2653

Pole walking for Parkinson's

Pole walking is a form of fitness walking using two poles for support. It requires a little effort to learn the technique, but it delivers big payoffs in terms of fitness.

It increases your cardiovascular fitness and uses 90% of your body's muscles. It is low impact walking that can be done by anyone, anywhere, at any time and it is affordable.

Pole walking is perfectly suited to our beautiful Australian climate and can be performed on any surface – from sandy beaches, parks, trails and grassy fields to footpaths.

Pole walking is a good choice for people who:

- U Have difficulty walking.
- U Do not have an active lifestyle and feel uncomfortable with quick movements.
- U Have developed poor posture or stiffness.

Walking improves circulation and digestion, decreases risk of heart disease and lung disease, improves how you feel and reduces stress. By adding poles and doing what is often called Nordic walking, you can get some great results.

Some of the pole walking benefits you can expect to experience include:

- U Poles supporting your body and stabilising your standing posture.
- U Improved arm swing – bigger, stronger arm movements.



- U Increased stamina – people can walk 3 to 5 times longer with less fatigue due to extra support from the poles.
- U Boost in confidence – no longer afraid of catching a toe, tripping or having a leg give out (which minimises falls).
- U Eliminates shuffling – helps re-train the brain to take consistent, purposeful long strides.

If you have any problems with balance, stamina or shuffling, please don't head out on your own. Make sure you have someone with you. They can offer encouragement, companionship and help you improve your techniques and posture as you go along.

For first-hand information about the value of pole walking, view this Parkinson's NSW video on YouTube: <https://youtu.be/mz7v79AezPg>

See also our *Living Well* leaflet on pole walking available on the Parkinson's NSW web site here: parkinsonsnsw.org.au/living-well-with-parkinsons

If you want to find a Nordic Walking group, visit this site: www.nordicacademy.com.au

Reference: Effects of an intensive Nordic walking intervention on the balance function and walking ability of individuals with Parkinson's disease: a randomized controlled pilot trial. Dae-Hyook Bang & Won-Seob Shin, 31 October 2016

Benefits of a Home Medicines Review

Clinical Pharmacist Ben Basger has some advice for people living with Parkinson's: request a Home Medicines Review every 12 months.

Ben's full title is Clinical Pharmacist – Medication Management and he is based at Wolper Jewish Hospital in Sydney. His role is to evaluate patient's medications – both prescribed and self-administered – in order to identify, manage and prevent any drug-related problems.

"Anyone taking five medications or more should request regular reviews by a third party," said Ben. "This involves an independent pharmacist taking an overview of the whole patient, including their medical history, test results, how they are feeling, what they know about their condition and medications, and what they believe.

"What the health system often lacks is time for individual attention. However, a Home Medicines Review will give you that attention and take the time required to assess your needs on an individual basis."

Any General Practitioner can write a referral for a Home Medicines Review. These Reviews are available under Medicare (Item 900 with 100 percent benefit paid).

They will cover what your medicine is for, how the medicine will help you, how long you need to take it, and any special instructions for taking the medicine.

Ben explained that people living with Parkinson's have particularly complex needs because they face multiple challenges including their evolving symptoms, ageing, and complex medication regimes which can sometimes have adverse effects.

"With complex conditions like Parkinson's, there is a potential for polypharmacy or over-medicating," he said. "That means more potential for side effects of medication, additional cost and burden on the patients.

"What we need is patient-centred care where the pharmacist conducting the review can listen and explain medications to people in ways meaningful to them, and on their own terms."

For more information on the Home Medicines Review Program, visit this Department of Health web page:

https://www1.health.gov.au/internet/main/publishing.nsf/Content/medication_management_reviews.htm

Diabetes linked with Parkinson's

Research published in the journal *Neurology* indicates that people who have type 2 diabetes are almost a third more likely to develop Parkinson's than people without the illness.

The risk increases if patients aged 25 to 44 years are diagnosed with diabetes.

This research was conducted by a team drawn from University College London, Queen Mary University London and Oxford University. The study followed more than two million people diagnosed with type 2 diabetes between 1999 and 2011 and compared them with more than 6 million people without diabetes.

After allowing for variables such as age, gender and location, the research team concluded that people with type 2 diabetes are 32 per cent more likely to have a subsequent diagnosis of Parkinson's.

Alastair Noyce, a co-author of the study, said that findings could help to develop further treatments for Parkinson's. Research conducted last year also indicated that a diabetes drug may relieve Parkinson's symptoms.

Telehealth for Parkinson's pilot delivers promising results

Parkinson's NSW is participating in a pilot telehealth program on the Mid-North Coast of NSW involving the delivery of neurology consultations online to patients using computers or smart devices such as phones or tablets.

The pilot grew from a St Vincent's Health Network telehealth project enabling cancer specialists to provide remote consultations for individuals living in rural areas. Since 2018, the service has grown rapidly to provide a number of virtual telehealth clinics – including other specialities such as the Body Movement Clinic.

There are currently no permanent residential neurologists who specialise in Body Movement disorders based in the Hastings Macleay Clinical Network, so people living with Parkinson's in that region must travel to metropolitan areas or wait for the services provided by fly-in/fly-out clinics in Port Macquarie or Kempsey.

Many other Parkinson's patients are managed by local Geriatricians and GP's. They provide excellent care however their services are stretched.

Specialist Parkinson's Nurse Rachael Mackinnon is based in the region with co-funding from Parkinson's NSW and the Mid North Coast Local Health District. In her previous role in Sydney, she became aware of the promising results being delivered by the St Vincent's Telehealth Project.

Rachael and the St Vincent's Telehealth Project Manager Majid Shahi joined forces to investigate the feasibility of providing remote consultations for people living with Parkinson's who had been unable to access a neurologist in a timely manner.

With the support of Dr Stephen Tisch, Head of Department of Neurology at St Vincent's Hospital Sydney, Consultant Neurologist Dr Sam Bolitho has provided Telehealth consultations to ten patients with a diagnosis of Parkinson's within the Hastings Macleay region since December 2018.

St Vincent's was able to overcome technology barriers such as hardware and software availability, compatibility and expense. Now requirements are simple; a personal computer or smart device – such as a phone, iPad or tablet – equipped with built-in camera and microphone and running Google Chrome software.

One of these patients had not received any neurologist input in more than two years and was concerned by the progression of his Parkinson's. The Telehealth appointment was conducted from his home.

Adjustments were subsequently made to anti-Parkinson's medication which resulted in improvements to his wellbeing and quality of life.

Another participant in the trial had been diagnosed with Parkinson's in 2017 during a trip to Sydney for an investigation of another neurological disease: Multiple Sclerosis. She had not seen a neurologist for over 18 months as she found it difficult to travel to Sydney or Newcastle.

She had been experiencing increased dystonia and slowness and suffered from nausea and chronic constipation. Following her Telehealth consultation, she started on new medications and reports that she is feeling much better both physically and mentally knowing that she has easy access to excellent specialist care.



My World Parkinson Congress experience

By Alison Irving

Ever since my husband Malcolm had raved about the last World Parkinson Congress in Portland, USA, I'd wanted to attend the one in Kyoto.

It was with some excitement that we boarded the plane. We were looking forward to staying for two days near the centre of Kyoto for sightseeing, before transferring to another hotel within walking distance of the Congress venue.

Kyoto is an interesting mix of old and new. There were plenty of temples and shrines, a castle and a palace to visit. We found the Manga museum and purchased a T-shirt for my son-in-law. When we had enough of history, the market was fascinating, and the botanic gardens were well worth exploring.

One of the easy day trips was a short train ride to the old capital of Nara, where tame deer roam the grounds of the temples and school groups doing surveys come up to practice their English on tourists. A few of them left clutching clip-on koalas and kangaroos that we'd brought with us.

My areas of interest at this Congress involved sleep problems and also diet issues. Fortunately, there were plenty of options for attending different lectures and talks.

One of the great innovations for this Congress was the use of 'round tables' in which a researcher or expert in his or her field, sat down with twelve people and discussed their findings.

I had intended to attend the one on nutrition, but it was fully subscribed so I booked onto the one on gut biome instead. This was fortunate as a number of speakers later in the conference discussed the role of the gut. The round table gave me a better understanding of their talks.

The leader of this particular round table was Haydeh Payami who has a PhD in Genetics and is the founder of the NeuroGenetics Research Consortium. Dr Payami was a fascinating speaker. I was surprised by the mention

of links to H. Pylori and intrigued by the ten studies mentioned that discussed probiotics. H. Pylori interferes with the absorption of levodopa, which was interesting as at least four out of the twelve attendees of that round table had been diagnosed with H. Pylori.

I had not realised that two key components of over-the-counter probiotics are already at very high levels in the gut of people with Parkinson's. Dr Payami suggested avoiding bottled probiotics for this reason and recommended a diet of varied fibre.

One of the critical features of a successful round table is that the leader must be allowed to lead it, and the participants must let them lead. One or two of the attendees were keen 'would-be' leaders, so I was impressed that our facilitator was tactful in not allowing them to take over. As a result, the discussion varied widely, covering constipation, faecal transplants, fermented food, probiotics, diet and herbicides.

I felt that the round tables were an excellent idea to enable people with Parkinson's, their carers and the professionals to come together to discuss new research in an approachable and easily digestible manner. For me, these roundtables were the highlight of the conference.

I also attended lectures on sleep. These provided plenty of facts, but few answers to our issues at present. With trepidation, I went to the talk on intimacy, and found that it was great. The speakers were encouraging and down-to-earth. As far as I could tell, no one felt embarrassed about the subject matter and we all left with some confidence for the future.

For me, these were the highlights of the conference. I would like to thank Parkinson's NSW for everything they did to make our attendance at the Congress such a terrific experience. We learned a lot, met new people and made new friends. We found out information for others and we discovered ways forward for ourselves.

Now I'm looking forward to Barcelona in 2022!

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Potential stem cell therapy for Parkinson's

A team at Kyoto University Hospital in Japan has injected stem cells into the brain of a Parkinson's patient to ease his symptoms.

The procedure used induced pluripotent stem cells (iPS cells) which can turn into any kind of other cells – including neural progenitor cells.

About 2.4 million progenitor cells were injected into the left brain of the 50-year-old patient in a three-hour operation.

The cells are expected to grow into neurons and release dopamine to send signals to other nerve cells. Parkinson's is caused by a shortage of dopamine.

The hospital plans to continue trials of this therapy through to 2022 with a further six patients.

Australian research presented at World Parkinson Congress

Thirty Support Group members and some Parkinson's NSW staff travelled to Kyoto, Japan, early in June to attend the World Parkinson Congress 2019.

The objective of the event (held every three years) is to create a space for cross-fertilization of delegates' ideas, research projects, and collaboration. The hope is that this collaboration will help to expedite the discovery of both the cause and cure for Parkinson's.

Australia was well represented in the 2019 Congress program by local neurologists, counsellors and experts in art, music and exercise for Parkinson's.

Associate Professor Dr. Rachel Rossiter of the School of Nursing, Midwifery and Indigenous Health of Charles Sturt University presented the research she is conducting for Parkinson's NSW on the value of community-based Parkinson's Nurse Specialists.

Parkinson's NSW CEO Jo-Anne Reeves participated in a Leadership Forum at the event, speaking on strategies for supporting people living with Parkinson's in underserved regions of NSW.

Australian researchers were also invited to submit abstracts and posters for the Congress. One set of posters about the Charles Sturt University (CSU) research was jointly submitted by Parkinson's NSW, CSU and the Mid North Coast Local Health District.

Another set of posters was presented by the Shake, Rattle and Roll Parkinson's Choir which is associated with the Newcastle Parkinson's NSW Support Group.

Want to know more about the full range of research projects presented at this year's World Parkinson Congress? See a list and summaries of all abstracts here:

<https://content.iospress.com/download/journal-of-parkinsons-disease/jpd199900?id=journal-of-parkinsons-disease%2Fjpd199900>

Vince Carroll Parkinson's NSW Nurse and Assoc Prof Rachel Rossiter at WPC 2019



Your privacy is important to us

Many readers ask:

"Will Parkinson's NSW sell my contact details to marketing organisations?"

The answer is no, we will not. Your privacy is important to us.

Parkinson's NSW uses your contact details for:

- Two-way communications with you – keeping you informed about our work and responding to your questions, comments, compliments or complaints
- Distributing publications including our Annual Report, newsletters, magazines and email updates.
- Delivery of services.
- Conducting quality assurance activities.

You can view our full Privacy Policy here: www.parkinsonsnsw.org.au/privacy-statement/

If you have questions about your privacy and how your information is used, make a free call to the Parkinson's NSW InfoLine: 1800 644 189.



CEO Jo-Anne Reeves at WPC2019 leadership Forum

More people need a caring expert by their side

We currently support Parkinson's Specialist Nurses in three locations who assist more than 1,240 people.

Our goal is for two more Nurses to be recruited as soon as possible. But a shortfall in funding is stopping us from moving forward.

With neurologists located too far away for some people to ever access them, Parkinson's Specialist Nurses are a local and reliable point of contact for Parkinson's treatment and care. Their practical advice on everything from lifestyle changes to medication adjustments can reduce people's symptoms, so they feel well for longer.

Parkinson's Specialist Nurses have the expert knowledge and networks to work with other health professionals and lead people through the healthcare maze that comes with this chronic condition.

Your donation will help us bring Parkinson's Specialist Nurses to the NSW regions where people need them most



Gregg and Sue enjoying life now, thanks to Rachael

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