STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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Message from the CEO

Welcome to the Winter edition of *Stand by Me.* In my message for the Autumn edition I commented that it was a particularly busy time for Parkinson's NSW.

Well, Winter is even more so because it encompasses two major celebrations on the Parkinson's calendar – World Parkinson's Month (April) including World Parkinson's Day on 11 April, and International Nurses Day on 12 May.

And speaking of May, it is also the month of our major online fundraiser Step Up for Parkinson's. You can learn more about it and participate by visiting our website.

Step Up for Parkinson's is a choose-your-own fitness challenge open to everyone. You can do any form of exercise you like – just set yourself a daily target and ask others to sponsor you.

We are working toward a target of $130,000, together as a community – so let's maintain the momentum and Step Up for Parkinson's.

Our momentum hasn't slowed in advocacy either. Gradually we are gaining more meetings with the new Government Ministers as they settle into their new roles and refurbished offices.

Meanwhile, in this issue of Stand by Me, I recommend articles on our Parkinson's Specialist Nurses about their sources of job satisfaction and major challenges (in acknowledgment of International Nurses Day), and in research, the discovery of a new tool that can detect the major pathological protein in Parkinson's.

Enjoy your reading... and do keep your eye on our Step Up for Parkinsons web page to follow who is fundraising, how they are doing it, and what progress they are making.

Jo-Anne Reeves
Chief Executive
Officer

Just six minutes of daily exercise can boost brain health

Just six minutes of intense exercise every day can boost the brain's lifespan and delay the onset of neurological conditions like Parkinson's, according to a new study.

The research, published in The Journal of Physiology, found that a short but intense bout of cycling can increase the production of a special brain protein linked to brain formation, learning, and memory.

Scientists, including those from the University of Otago in New Zealand, say the special protein named brain-derived neurotrophic factor (BDNF) can protect the brain from age-related cognitive decline.

Previous studies have shown that increasing the availability of BDNF in the brain encourages the formation and storage of memories, enhances learning, and also boosts cognitive performance overall.

"BDNF has shown great promise in animal models, but pharmaceutical interventions have thus far failed to safely harness the protective power of BDNF in humans," said study lead author Dr Travis Gibbons from the University of Otago.

> *"We saw the need to explore non-pharmacological approaches that can preserve the brain's capacity which humans can use to naturally increase BDNF to help with healthy aging," Dr Gibbons said.*

In the new study, researchers analysed the influence of fasting and exercise on BDNF production in 12 physically active participants – six males and six females aged between 18 and 56 years.

They assessed the contributing role played on this protein's production by factors such as fasting for 20 hours, light exercise, a six-minute bout of high-intensity vigorous cycling, and the combined effects of fasting and exercise.

Scientists found that brief, but vigorous, exercise was the best way to increase BDNF compared to one day of fasting with or without a lengthy session of light exercise.

Sources
Original story by Sarah McGrath in Parkinson's Life
Study published in The Journal of Physiology

Read more by visiting the **Parkinson's NSW** website
www.parkinsonsnsw.org.au

Parkinson's NSW HealthLine statistics

6,184 *calls handled in 2022*

258 *calls per month from people with Parkinson's*

135 *calls per month from carers*

80 *calls per month from Allied Health professionals*

Parkinson's Specialist Nurses Statistics

Travelled average of **2,750** *km per month*

Performed average of **545** *patient consultations per month*

Supported **76** *device-assisted therapies per month*

Nurse Cathy Melton

What I find most rewarding as a Parkinson's Nurse

"I find it rewarding when I can provide information about Parkinson's and can empathise with people affected by the condition. There are 'light bulb' moments for people when they understand why and how the Parkinson's is impacting on them and their family members."

What I would most like to achieve through my work as a Parkinsons Nurse

"I would love to improve everyone's knowledge about Parkinson's – especially GPs. If there is more understanding of the widespread impact of the condition then there will be more money provided for education, services, support, and research which can then improve quality of life for all."

Rachael Mackinnon, Clinical Lead

What I find most rewarding as a Parkinson's Nurse

"There is always an ongoing learning curve about Parkinson's – things are never the same. I find being a Parkinsons' nurse also very rewarding in taking a very extensive patient history and assessments and offering strategies to help manage the symptoms of Parkinson's.

"I love listening and engaging with people and their significant others about their version of this disease – particularly around the non-motor symptoms – and how much I learn about this very complicated and multifactorial neurodegenerative disease. Often, I learn so much from them and really have a sense of being in it together .

"I know that the people with Parkinsons' and their families also appreciate our good understanding too and how this contributes to great rapport and trust. I know how amazing it has been to do nursing consults aboard a yacht; in a milking shed or a coffee shop, or the privilege of being in someone's home too."

Lauren Hogan, Parkinson's Specialist Nurse, Southern NSW Local Health District

What I find most rewarding as a Parkinson's Nurse

"I love the interaction with my patients, and the privilege of getting to know everyone's story. It gives me a great sense of job satisfaction when we can make small changes to a person's life, that in turn make a huge impact in their day-to-day life.

"I am always learning in this role, and constantly responding to the ever-changing and unique environment that we are in. Parkinson's is so unique to each individual, it is like solving a puzzle each time I assess someone new – finding what can we tweak or change to make life that little bit easier for them."

My greatest challenge as a Parkinson's Nurse

"Being new to this role, the challenge for me has been to ensure I had an excellent knowledge base before I started the service. That way, my patients would benefit from this expertise from the get-go.

"Being in a regional area, and not having any access to a Movement Disorder Specialist other than via telehealth, phone or email is certainly challenging. However, I have found ways we can make this work well for my patients – which is the real reason we exist! To ensure quality, specialist care for people living with Parkinson's in regional areas."

Vince Carroll, Parkinson's Specialist Nurse, Mid North Coast Local Health District

What is most rewarding about being a Parkinson's Nurse?

"I have a great job. I am really well supported by my local manager, the CE and team at Parkinson's NSW, as well as the Parkinson's community.
We have introduced many innovations and new services over the last 8 years which have made a difference.

"Some of these include:

- *Clinical Guideline for the care and management of people with Parkinson's admitted to hospitals on the Mid North Coast*
- *Nursing research providing evidence the Parkinson's specialist nurse are improving the quality of life and reducing length of stay in hospital*
- *The commencement of the Movement Disorders Service on 28 April 2023 after six years of planning. This service closes the gap on services delivered in rural and regional areas as 93 percent of specialist services are in metropolitan areas. The service is a partnership between Mid North Coast Local Health District, Western Sydney Local Health District Movement Disorders Unit and Parkinson's NSW.*

"The clinical director of the service will be Associate Professor Dr Victor Fung, Director of the Movement Disorders Unit and Head of the Neurology Department at Westmead Hospital."

What I would most like to achieve through my work as a Parkinson's Nurse.

"I would like to continue research in the Parkinson's space and translating the research into practice.

"We also need to see more nurses and movement disorder services introduced in rural and regional areas across NSW to support people living with movement disorders, plus a succession plan for Parkinson's Specialist Nurses."

READ MORE
www.parkinsonsnsw.org.au

Support Groups Celebrate World Parkinson's Day

April was Parkinson's Awareness Month & 11 April was World Parkinson's Day.

The Day marks the birth anniversary of Dr James Parkinson, who identified Parkinson's as a medical condition and published an article *An Essay on the Shaking Palsy* in 1817.

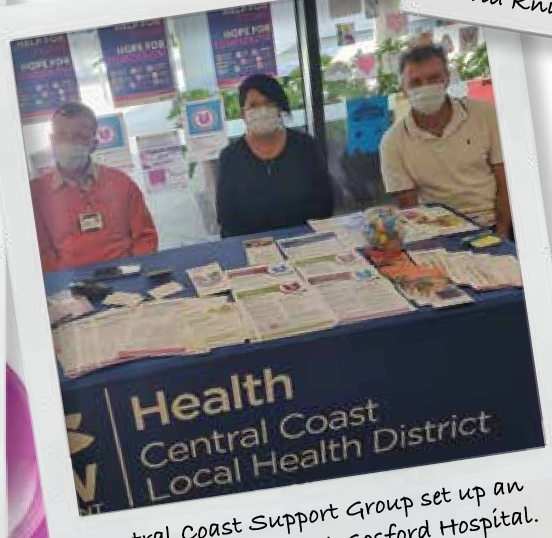
Parkinson's NSW Support Groups and hospitals observed the Day and Month across NSW with a variety of events.


Nepean Blue Mountains Support Group set up an information and awareness stand in the foyer of Nepean Hospital.


Port Macquarie Support Group held a high tea at Bago winery


Lismore Support Group Parkinson's Community Hero presentation to David Knight


Coffs Harbour Support Groups joined forces to hold a morning tea and present their Parkinson's Community Hero


Central Coast Support Group set up an information stand at Gosford Hospital.

Tumut Support Group went all out with three information stands at two locations on three different days – two at Coles and one at Woolworths.

Chinatown Support Group Parkinson's Community Hero presentation to 'Way in Network'

St George hospital information and awareness stand

Maitland Support Group staged an art exhibition.

Forresters Beach retirement village was treated to a performance by Geoff Grundy

Goulburn Support Group staged its annual Shakin' Cocktail Party – a major event to raise funds to continue the work of local Parkinson's Specialist Nurse Lauren Hogan, pictured above.

Forresters Beach retirement village held a Parkinson's awareness morning tea with raffles and donations serving all food that start with the letter 'p'. Organised by Sue and Geoff Grundy and Jenny Pullen

HarbisonCare morning tea

HarbisonCare organised a morning tea and information session for their residents. Attended and presented by Parkinson's NSW Education Manager Christine McGee

Finally, some good news about Parkinson's disease

By Dr Victor Dieriks

In a significant advancement in understanding Parkinson's disease, researchers have discovered a new tool that can detect abnormal α-synuclein, the major pathological protein in Parkinson's disease.

The breakthrough, announced in The Lancet Neurology May issue, opens up new possibilities for research and treatment. People with Parkinson's can expect faster care and improved treatments, and newly diagnosed individuals may never advance to full-blown symptoms.

These prospects cannot come soon enough. From 1990 to 2015, the number of people with Parkinson's disease more than doubled from 2.6 million to 6.3 million.

Currently, 10 million people are estimated to have Parkinson's disease, with numbers steadily rising year-on-year. The old-school thinking that Parkinson's disease only affects older people is no longer accurate, with many now being diagnosed in their 30s and 40s. Even teenagers, although rare, get diagnosed with Parkinson's.

Researchers have developed a new ground-breaking test to detect abnormal α-synuclein in brain and body cells. This protein is normally found in the nervous system, but in Parkinson's disease, it misfolds and clumps, damaging neurons. Up to now, it was only possible to confirm the presence of these clumps through post-mortem analysis.

The α-synuclein seed amplification assay (ASA) investigated by the researchers in The Lancet Neurology paper marks a significant milestone in finding better treatments and a potential cure for Parkinson's disease – and establishes an entirely new chapter of research.

This newly validated test can accurately detect pathology in spinal fluid not only in people diagnosed with Parkinson's disease but also in individuals who have not yet been diagnosed or shown clinical symptoms of the disease but are at a high risk of developing it.

With this novel, early diagnostic capability, it is possible that individuals may never advance to full-blown symptoms, and everyone living with Parkinson's can in the long run expect earlier care and improved treatments.

We already know that early intervention has a massive impact on patient outcomes, so starting treatment, particularly therapeutic interventions, years before the typical tremor, shaking, and changes in mood and balance start would be an absolute game changer.

The α-synuclein seeding amplification assay test exploits an inherent characteristic of α-synuclein, whereby existing clumps recruit nearby normal – 'unclumped' – α-synuclein to misfold, triggering a snowball effect.

For the assay, spinal fluid samples are prepared with a fluorescing dye that only lights up if α-synuclein clumps form, thereby permitting the selective detection of pathological α-synuclein. If no abnormal α-synuclein is present, the dye doesn't fluoresce.

After previously being tested in small, independent studies, the assay was validated in the large, well-characterised cohort of the Parkinson's Progression Markers Initiative (PPMI). The validation was executed by an international coalition of scientists led by the Michael J. Fox Foundation.

The study published in Lancet Neurology tested 1,123 samples of spinal fluid contributed by PPMI participants over the years.

The assay returned data with amazingly high accuracy, with 93 percent of participants with Parkinson's having an abnormal test. Very few tests for neurological disorders are over 90 percent sensitive.

Further development of the α-synuclein seeding amplification assay test will accelerate its widespread and standard use. The test currently elicits a yes/no result — showing that abnormal synuclein is either present or not, but there is tremendous promise in optimising it.

Further developments will allow measuring the amount of α-synuclein present and enable diagnosis of multiple system atrophy (MSA), a condition often misdiagnosed as Parkinson's disease. Getting the diagnosis right from the start would mean that patients get the correct therapy from the beginning.

My group at the University of Auckland is researching how to use this test widely without needing spinal fluid; extracting spinal fluid still involves an invasive technique. Instead, future assays would enable us to detect abnormal α-synuclein in blood, nasal swabs and urine samples — a simple sample that could be collected in any GP's office.

With this discovery, Parkinson's disease is moving from a disease primarily diagnosed when the motor symptoms become visible and measured through subjective clinical assessments to an objectively biologically defined disease.

This brings earlier diagnosis, targeted treatments, and faster and cheaper drug development much closer. There's an exciting future ahead. The prospects of cracking down on Parkinson's disease have never looked better.

Dr Victor Dieriks, is Group leader of the Synuclein Group at the University of Auckland. His Group is part of the global effort to further develop and optimise this α-synuclein seeding amplification assay test. Find out more at Dierikslab.com.

Application for voice games may aid at-home speech therapy

Researchers have proposed a set of voice exercise games to help speech quality in people with Parkinson's disease, which licensed speech therapists found to be a generally feasible, promising approach.

If adopted in speech therapy routines, the games could motivate patients to practice more often at home so that their voice better retains volume and clarity, the researchers suggested.

The proposed approach, *The BioVisualSpeech Serious Game with Voice Exercises for People with Parkinson's Disease with Hypokinetic Dysarthria,* was published in Studies in Health Technology and Informatics.

Speech changes, including dysarthria or difficulty speaking, are common in Parkinson's, affecting about 89 percent of those with the condition. Often, patients have hypokinetic dysarthria, characterised by a reduced voice intensity, problems articulating words, a hoarse voice, and a monotonous pitch.

While these speech changes can affect a person's social and professional life, only 3 to 4 percent of those with such alterations take part in speech therapy to improve their ability to communicate, the researchers reported.

Additionally, the success of such therapies requires intensive training and participants' willingness to practice regularly at home, for which the essential motivation can be challenging.

A pair of researchers in Portugal proposed a game-based way of practicing voice exercises for Parkinson's patients with hypokinetic dysarthria, designed to make and keep them motivated.

> *"Our proposal is to combine therapy, technology, feedback, and fun to motivate patients to practice the voice exercises regularly and at home, and to give them the appropriate feedback that allows them to understand their performance," the researchers wrote.*

Accessed as an app on a computer or mobile device and controlled by the user's voice, the game involves three exercises commonly used in speech therapy and selected on the advice of speech therapists. Each has a particular focus on helping a person increase their vocal intensity, or ability to speak more loudly.

With intensity first determined for each participant by a speech therapist, players are asked to sustain a vowel sound at a stable intensity, to sustain the same vowel sound while adding pitch variations, and to practice the use of functional phrases common to daily life routines.

Each game's goal is to get an onscreen character to move in a straight line toward a box holding a surprise, picking it up once reached.

The character's movement is controlled by the player's voice, and it moves forward only if the voice is within the intensity range – and pitch, when relevant to the exercise – chosen by the therapist. Reaching the box unlocks new game features.

Characters stop moving when vocal intensity is inadequate, and a player then has a few seconds to correct their voice before the game ends in failure.

> *"In this way, the character's movement provides intuitive visual feedback on the player's vocal intensity," the researchers wrote.*

Exercises can be adapted to meet an individual's particular needs and abilities, and therapists can alter the game's difficulty as a person improves.

Additional features to help with motivation, the researchers noted, include a push notification reminder if the app has not been opened for more than a day. Points awarded when vocal intensity is maintained within the set range also allow players to accrue coins that can be used to unlock new characters or scenarios.

Researchers asked six speech therapists, with between three and 37 years of experience working with Parkinson's patients, to evaluate the game. Generally, the therapists found it to be a useful tool for keeping patients motivated both during therapy sessions and at the home.

> *"The game can be a good option for patients to train without the presence of a [speech therapist], every day or consistently, however it has some features that may depend on the [therapist], such as microphone calibration and customisation," the researchers wrote. "Thus, it would be required that the game is parameterised at a therapy session prior to being used at home."*

The six therapists largely thought the game was appropriate for people with Parkinson's and had potential to improve voice quality.

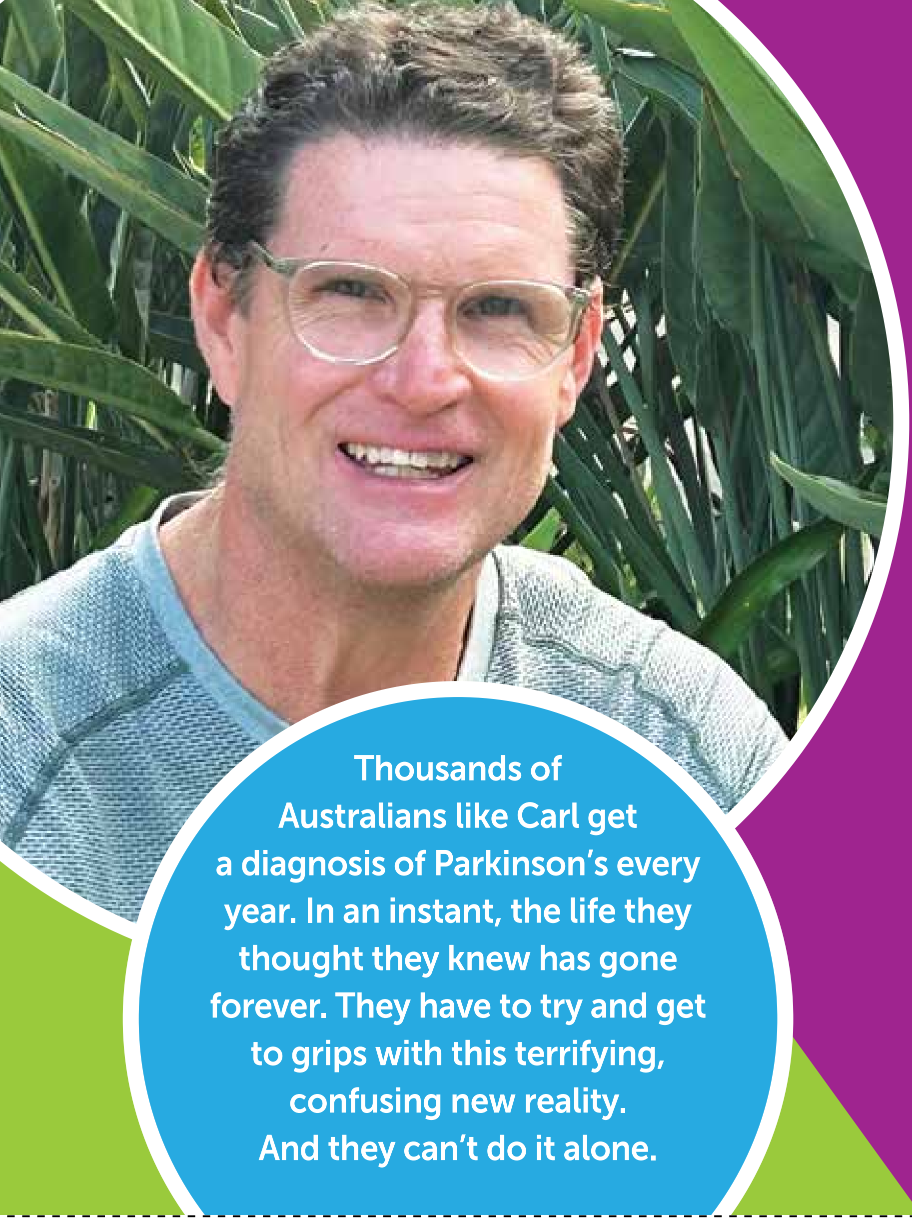
According to the researchers, "the game fulfills its main objectives: (1) it motivates training, (2) it is suitable for home training provided there is an initially in-person session for customisation, (3) it gives intuitive visual feedback on the player's voice performance and (4) it has potential to help improve voice performance."

Voice training that can be done at the home also offers an alternative to the face-to-face appointments that can be difficult, the team added.

Sources:

Original story by Lindsey Shapiro, PhD

Published by Parkinson's News Today



Thousands of Australians like Carl get a diagnosis of Parkinson's every year. In an instant, the life they thought they knew has gone forever. They have to try and get to grips with this terrifying, confusing new reality. And they can't do it alone.

Help us support people like Carl facing the challenges of Parkinson's

At 39, Carl had big plans for his future. He had a job he enjoyed and four children to raise.

But a diagnosis of Parkinson's changed his life forever.

Carl hadn't recognised any problems apart from a sore left arm. His wife convinced him to see a GP, who immediately booked him in to see a neurologist.

The resulting diagnosis of Parkinson's shattered his world, his family, and his dreams.

Your donation will help Parkinson's NSW ensure people like Carl don't have to face such a challenging future alone.

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☑ 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** ____________

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☐ **I have already included Parkinson's NSW in my will**

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Spotlight on Parkinson's

Parkinson's medications must be taken **on time every time**

1 in5 people living with Parkinson's are of working age

Parkinson's is **more common** than most cancers including breast and lung cancer

Loss of smell and **sleep disturbances** are early signs of Parkinson's

More than **200,000 people** in Australia are affected by Parkinson's*

37 people will be diagnosed with Parkinson's every day

Some symptoms may present **5 to 10** years before diagnosis

The cause of Parkinson's is unknown.

There is no test to diagnose Parkinson's.

There is no cure.

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Ayton, D., Ayton, S., Barker, AL., Bush, AI and Warren, N. (2018). Parkinson's disease prevalence and the association with rurality and agricultural determinants. Parkinsonism & Related Disorders

Find out more
www.parkinsonsnsw.org.au