

STANDBYME

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Based at The Brain and Mind Centre of The University of Sydney, Kay is a neurochemist who has been researching Parkinson's for 25 years

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Cover artwork by artist David Carroll

David's artwork was recently shown in the 'Colour my World' exhibition at Grafton Regional Gallery

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IN THIS TOGETHER
parkinson's
NSW

From the CEO

Welcome to the Autumn edition of Stand by Me.

In the Summer 2018 edition of this magazine I wrote to you about the Board elections which took place at the end of last year.

I'm pleased to report that the new Board of Directors line-up has quickly become a strong, focused and high functioning team.

The new Board's strategy is to strengthen our position with additional services and sources of revenue that will benefit people living with Parkinson's, their families and carers.

In line with this strategy, we have applied for registration as an NDIS Provider. Once that process is complete and we have been certified, we plan to register as a provider of services under My Aged Care as well.

This will enable Parkinson's NSW to directly provide services to people living with Parkinson's – as well as to link them with other authorised providers. We can then bill those services to individual support packages funded by the NDIS (for people with Parkinson's up to age 65) and My Aged Care (for people over 65).

On page 4 there is a story about what we have achieved in the first six months of the current financial year. It also talks about the importance of Parkinson's Nurse Specialists, and the team we have established to lead our transition to be an NDIS and My Aged Care service provider.

If you would like to learn more about this new team called PNSW Connect, there is a story on page 7.

If you would like to speak to a member of the Connect team or indeed ask any questions about Parkinson's NSW, please make a free call to our InfoLine on 1800 644 189.

Jo-Anne Reeves
Chief Executive Officer



Diary Dates

27 April: Art for Parkinson's workshop at Mona Vale Pittwater RSL

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

Parkinson's symptoms can be alleviated during the art-making process and this can improve mental and physical wellbeing. Workshops and classes also provide social connections with others in the Parkinson's community.

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

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

Early Bird registrations for the 5th World Parkinson Congress have closed but Standard and Late registrations are still open.

The Standard registration period is 28 February to 20 May. Late registration is available after 20 May and dependent on seats being available. To register and learn more, visit the World Parkinson Congress web site: <https://wpc2019.org/page/RegFees>

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

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

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

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25 August: Unity Walk in the Park

Save the date. More information to follow

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17-18 September: 2019 Parkinson's NSW Support Group Conference

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

To stay up to date, sign up to receive email communications on all seminars and activities. Sign up on our website www.parkinsonsnsw.org.au

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Q&A with Associate Professor Kay Double, Parkinson's researcher

Associate Professor Kay Double is based at The Brain and Mind Centre of The University of Sydney. She is a neurochemist who has been researching Parkinson's for 25 years. Her work focuses on understanding why specific brain cells die in Parkinson's disease so more targeted treatments can be developed.

Q: What is the current focus of your research?

A: We have several projects running in parallel, trying to find ways of diagnosing Parkinson's earlier and exploring the mechanisms that cause the death of dopamine neurones.

If we are going to design a drug to slow or stop Parkinson's, we need to identify a specific target. Our hope is that if we can identify what makes dying cells vulnerable, then we can modify that with treatment.

Q: One area of your research involves studying the restoration of copper in brains affected by Parkinson's. Why is this important?

A: This project involves looking at how individual neurones control both iron and copper levels and how changes in levels of these metals in neurones can make the cells more vulnerable to the disease process.

We're starting to understand the different biochemical steps that happen within dopamine cells that cause damage and eventually cause them to die.

We know iron and copper are essential for the normal functioning of dopamine cells but too much or too little of either in the brain can be dangerous. So, we're studying how drugs can safely correct levels of these metals in the regions of the brain affected by Parkinson's disease, without disturbing metal levels in other areas of the brain, and the result of this for neurone survival.

Importantly, changes in these metals in Parkinson's only occur in the brain. Metal levels in other parts of the body – for example in the blood – are normal. This means we must design drugs to restore these metals in a very targeted manner.

Clinical trials involving people living with Parkinson's are now underway using this approach which hopefully will result in slowing the disease process.

Q: You are also studying another type of motor neurone disease. How does this relate to your work on Parkinson's?

A: This is a new and interesting area we are exploring.

We've identified a link that had not been described before between Parkinson's and Amyotrophic Lateral Sclerosis (ALS) – also known as Motor Neurone Disease or Lou Gehrig's disease.

ALS is a degenerative disorder involving the death of nerve cells resulting in the gradual loss of voluntary muscle control.

While nerve cell death occurs in both Parkinson's and ALS, it was traditionally thought that the reason for the death of these cells was quite different between these two diseases. In ALS the death of motor nerves in the spinal cord and brain results from an abnormal form of protein called SOD1. The abnormal form of SOD1 is toxic to nerve cells.

In Parkinson's it is thought that cell death results from another type of protein that becomes abnormal called alpha-synuclein which forms Lewy bodies – insoluble clumps of protein found in the Parkinson's brain. However, our research found that abnormal SOD1 protein is found in the brain in both Parkinson's and ALS and is only found in areas where cells die.

This is a breakthrough because it reveals that the two diseases actually share a single pathway to cell death. That opens up a whole body of research done by ALS researchers that Parkinson's researchers can tap into.

It has already been shown that therapies targeting the abnormal SOD1 protein in ALS patients result in improvements in movement and survival time.

If we can build on this research to identify why the SOD1 protein is abnormal and then how we can make it stable in people with Parkinson's, it could eventually show us how to save brain cells.

Q: Why did you decide to concentrate on Parkinson's research?

A: My PhD research was on dopamine which led me to study the disorders resulting from dysfunction of the dopamine system, including Parkinson's and various forms of dementia.

I love studying Parkinson's because it is really interesting to understand how the human brain controls movement and how that can go wrong in different diseases. Also, I have met so many brave Parkinson's patients and their families and really want to contribute to finding a cure for this disorder.



Associate Professor Kay Double

Parkinson's NSW by the Numbers

What Parkinson's NSW achieved in the first six months of the 2018-19 financial year.

With a new Board of Directors and a strengthened operations team in place, Parkinson's NSW is tracking well against its business plan for fiscal 2018-19.

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3 community-based Parkinson's Nurse Specialists and more to come

Parkinson's NSW recruited and placed a new Parkinson's Nurse Specialist in Port Macquarie in October 2018 bringing the current state total to three. Several more such roles are under negotiations with Local Health Districts (LHDs) in areas of high need.

The strategy of partnering with LHDs reduces costs for both parties, making the positions more sustainable to respond to the needs of each local Parkinson's community over a longer period.

This approach also has the benefits of providing the Nurse Specialists with access to LHD data and resources, including professional development and peer support – both of which aid in nurse recruitment and retention.

Over the first six months of the fiscal year, our three existing nurses accepted 107 new referrals and conducted more than 500 face-to-face consultations and over 300 telephone consultations.

To give an idea of the scale of work undertaken by community-based Parkinson's Nurse Specialists, in the Shoalhaven area our nurse has more than 600 patients on her books and supports people living with Parkinson's in 52 towns and villages.

When a Parkinson's Nurse Specialist is placed in a community, people experience improved health outcomes as they have access to expert advice at the point of need. Nurses make sense of the technical medical language, assist with complicated treatments and help navigate the medical system for their patients.

A nurse placement also helps to reduce the high rates of depression and anxiety associated for people with Parkinson's and their family members.

Hospitalisation time is reduced, and often avoided, reducing the strain on a stressed health system. When patients residing in residential aged care are supported by a Nurse Specialist, they have access to specialist care that they may otherwise be denied due to their inability to attend outpatient appointments.

Nurses also connect patients to other supports within their community including Support Groups for peer support, Allied Health services to improve general well-being, and specialised exercise programs.

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94 NDIS applicants supported

We created the new role of NDIS Nurse Advocate in mid-2018 and she took up her position full-time in August 2018. Over the following five months she supported 94 people living with Parkinson's through their journey as they applied for funding from the National Disability Insurance Scheme.

By the end of the calendar year, 20 people had been successful and the others were still being supported through the process –including re-applying if rejected the first or second time around, or formally appealing.

The Nurse Advocate also works with Allied Health practitioners, helping them to understand the specialised requirements of the NDIS in terms of patient reports.

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Our specialist InfoLine nurses (L-R): Cathy, Julie and Margi



3,103 calls to InfoLine

In the first six months of the fiscal year, our team of experienced Parkinson's nurses handled 3,103 calls to 1800 644 189. Of these, 75 percent were discussions lasting 15 minutes or less and 25 percent were classed as complex calls – taking up to 1 hour to resolve.

These complex calls required case management, detailed advice on symptoms and medication, and often referrals to Allied Health and counselling services.

10 Education Seminars

Education seminars involved more than 500 participants including people living with Parkinson's and carers, people newly-diagnosed with Parkinson's, aged care support staff and General Practitioners.

The seminars were held in Sydney and as far afield as Tamworth, Kiama, Coffs Harbour, the Southern Highlands and Armidale.

Education Seminars are held over a half day and usually include information sessions delivered by Parkinson's specialists including neurologists, physiotherapists, exercise physiologists, nurses and speech pathologists.

\$300,000 of research grants awarded

In October, Parkinson's NSW research grants valued at \$300,000 were awarded to four researchers.

We prioritise research projects aimed at making an immediate difference in the lives of people with Parkinson's, with a longer-term view of finding a cure.

- **Associate Professor Antony Cooper** of the Garvan Institute of Medical Research was awarded a grant of **\$100,000** for his work on Blood RNA biomarkers to measure the progression of Parkinson's.
- **Dr Natalie Allen** was awarded a **\$100,000** grant for her Integrate: Safe Mobility in PD program. Dr Allen is a lecturer in Neurological Physiotherapy at the University of Sydney.
- **Dr Michal Lubomski**, a PhD candidate at the University of Sydney, was awarded a seed grant of **\$50,000** for his research into gut microbiome changes in Parkinson's disease.
- **Dr Teri Furlong** was awarded a **\$50,000** seed grant for her research looking at improvements to the current treatments of Parkinson's. Dr Furlong is a Senior Postdoctoral Research Fellow at NeuRa.



Colour my World

An accomplished artist recently showed his work in an exhibition called Colour my World at Grafton Regional Gallery.

His name is David Carroll and he is living with Parkinson's.

David – now in his early seventies – was diagnosed with Parkinson's two years ago but he recognised some symptoms as long as a decade ago, including tiredness and lethargy.

Regardless of his symptoms, David says art has always been his clearest form of expression.

After a long career as an electrician, David enrolled in university as a full-time student to formally study art. He graduated with a Bachelor of Visual Arts (Hons) in 2016. It was during those years of study that he began to recognise issues with his handwriting.

"It's actually hard to tell how much Parkinson's has directly influenced my work because creative development is always a process of change," said David. "However, living with Parkinson's changes lots of things; my choice of media and the way that I physically approach painting, and inevitably the subject matter.

Nowadays he tends to work with acrylic paints combined with other media such as charcoal and inks.

"Acrylic is a medium you can put down and come back to, whereas oils take a very long time to dry. That's important to me now because I experience 'freezing of gait' and can no longer stand for long periods," he said.

For David, Colour my World was much more than a creative outlet; he wanted the exhibition to raise awareness of Parkinson's.

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World first for early Parkinson's detection

A student at Charles Sturt University has discovered a new technique for accurately detecting early Parkinson's disease in patients.

Warwick Adams is a PhD research student of the School of Computing and Mathematics. His research found a method of analysing the patterns of a person's finger movements as they type on a computer.



Artwork by David Carroll

He also considers that his art has developed into a form of practice-led research: "As I age and my Parkinson's progresses, I feel there is still so much I have to say. I am very conscious of the time factor."

David credits his membership of a Parkinson's NSW Support Group and participation in a PD Warrior exercise class as helping him stay physically and mentally strong.

"The beauty of being in a support group is that you don't have to explain yourself because everyone is in the same boat. Everyone understands and shares, and we're all focused on doing the best we can," he said.

David is gifted with words as well as visual art. He publishes a monthly newsletter that talks about both his art and his daily experiences while living with Parkinson's.

David's plain-spoken musings and anecdotes about living with Parkinson's in a small regional community have attracted subscribers from as far afield as several Australian states, the UK and America – including people with Parkinson's and their friends and family members, as well as healthcare workers.

If you are interested in subscribing to David's free personal e-newsletter, please contact him at: dcarroll1066@gmail.com

Until now, diagnosis of Parkinson's has relied on a doctor's observations of a person's movement where the initial signs can be quite subtle.

The new test is a world first in Parkinson's diagnosis and has a 97 percent accuracy rate, which significantly outperforms general practitioners.

Parkinson's NSW has a close relationship with Charles Sturt University. Its School of Nursing, Midwifery and Indigenous Health is currently conducting research to support advocacy for the placement of Parkinson's nurses in regional communities of NSW.

Margi will be

Parkinson's NSW to become NDIS Provider

The application process for Parkinson's NSW to become a Registered National Disability Insurance Scheme (NDIS) Provider is underway and expected to be complete before mid-year.

Once this process is complete, we plan to register as a provider of services under My Aged Care as well.

This will enable Parkinson's NSW to directly provide services to people living with Parkinson's – as well as to link them with other authorised providers. We can then bill those services to individual support packages funded by the NDIS (for people with Parkinson's up to age 65) and My Aged Care (for people over 65).

New team

A new team called PNSW Connect has been established to spearhead this development of new services.

NDIS Nurse Advocate Margi Edmondson guides and supports people living with Parkinson's who are undertaking the sometimes-frustrating process of applying for the NDIS. She is a nurse and nurse educator with more than 35 years of experience.

Margi is currently working with more than 100 people, accompanying and advocating for them on their NDIS journey. She also liaises with primary and allied health practitioners to ensure the appropriate documents and reports are assembled to support each application.



to navigate the NDIS

Once people are approved for an NDIS support package, experienced Social Worker Melanie Browning steps up to help.

Support Coordination available

Melanie's role is to provide Support Coordination. She supports and informs approved NDIS applicants so that they can confidently negotiate the supports they need, then implement their NDIS plans for maximum benefit.

Melanie will also assist approved applicants who are going to their first NDIS Planning meeting, helping them to self-advocate for the supports they need to live the life of their choice.

Information gathered at the first Planning meeting is used by the NDIS to determine the extent of reasonable supports and the amount of funding the person needs to purchase the services they require.

Once a plan is approved Melanie can connect the person with services and supports – either from Parkinson's NSW or others in the community – according to the individual requirements and choice.

She can also arrange training for carers, families and Support Groups – such as in planning and plan management.

"The NDIS states that your supports must be reasonable and necessary," said Melanie. "However, there is a wide variety of support categories available including personal care, equipment, community inclusion, therapies, mobility assistance, respite for carers, and specialist employment services.



Melanie supports and informs approved NDIS applicants

"It's a long list, but Parkinson's NSW has more than 40 years of experience in helping people to live well with Parkinson's – and we have well-established community networks. We are very well-placed to connect people with the services they need while the search for a cure continues."

For more information on the NDIS and PNSW Connect services, make a free call to the Parkinson's NSW InfoLine: 1800 644 189.



Artwork by David Carroll

Can we find preventions and a cure for Parkinson's?

Yes, we can. We just need to continue doing the research.

Research like that being done by Dr Kay Double, Associate Professor in Biomedical Sciences at The University of Sydney. With her team, she has received several Parkinson's NSW Research Grants.

Dr Double's work is focused on learning what in Parkinson's makes certain brain cells die while others don't. Understanding this is a crucial step towards discovering how the process can be disrupted and stopped.

Lack of funding can't be allowed to stand in the way of important research like this. We must find ways of supporting talented researchers like Dr Double and her team.

Please give today if you would like to be part of the effort to drive Parkinson's breakthroughs in 2019.

Your gift of any size can help to keep vital research moving forward.



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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 _____

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