

STANDBYME

Parkinson's NSW Limited | Issue 138 Autumn 2020
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April is Parkinson's Awareness Month

with World Parkinson's Day
recognised on 11 April
each year

Find out how you can get involved on page 2

IN THIS TOGETHER
parkinson's
NSW



From the CEO

Welcome to the Autumn 2020 edition of *Stand by Me*.

As you will see from the contents of this edition, the past few months have been a very busy and constructive time for Parkinson's NSW.

We have appointed four new Board Members who come from a variety of backgrounds including fundraising, Not for Profit operations management and governance.

This is in addition to our existing three Board Members – including two who are living with Parkinson's and one with family experience as a carer.

We have also seen significant growth in the Parkinson's NSW Support Group network.

To our base of over 70 existing Support Groups we have added more than 15 new Groups that are at various stages of the registration process.

We are continuing to identify gaps in regional and metropolitan areas where new Support Groups may be required. We are also facilitating more direct contact between Groups – especially in neighbouring areas – to expand peer support and information sharing opportunities.

Speaking of support and opportunities, don't forget to mark a very important date in your diaries: April 11 is World Parkinson's Day. This year it falls in the Easter holiday period, so many Support Groups are planning community outreach activities for later in the month.

Do try to join in and raise awareness of Parkinson's in your community.

Jo-Anne Reeves
Chief Executive Officer



Raising Awareness of Parkinson's

Parkinson's impacts more than a person's movement and speech. In fact most Parkinson's symptoms are invisible and referred to as non-motor symptoms. Being unseen they are misunderstood and hard to talk about – yet they can have a greater effect on relationships, friendships and overall quality of life.

During the month of April, Parkinson's NSW along with its Support Groups and the NSW Parkinson's community, will expose the myths and realities of Parkinson's while raising awareness of the disease and its impact on individuals and society.

Join in

You too can join in by supporting a Parkinson's NSW Support Group activity in your local area or by helping distribute conversation cards. Call us on 1800 644 189 for more information and say, "I want to expose Parkinson's".



World Parkinson's Day is on April 11.

Follow us on our social channels and get involved in the conversation and help raise awareness of Parkinson's

@ParkinsonsNSW



Want to stay up to date?

Subscribe to the Parkinson's NSW newsletter
parkinsonsnsw.org.au/subscribe

Multidisciplinary teams improve health outcomes

Since Parkinson's is a complex disease involving both motor and non-motor symptoms, there is strong research interest in the effectiveness of multidisciplinary teams in delivering Parkinson's therapies and support.

Multidisciplinary teams involve experts in various Primary and Allied Health fields working together as a team, consulting one another and above all communicating effectively to improve outcomes for Parkinson's patients – and their carers and families.

There are several models of multidisciplinary teamwork currently being evaluated:

- The parallel model where independent healthcare practitioners share a clinic, so patients can meet different experts in a single location.
- The consultative model (common in Australia) which involves exchanges of advice between experts – usually through a formal letter about each patient. This model works on an ad hoc and case-by-case basis.
- The collaborative model where independent healthcare workers interact and share information on a particular patient on an ad hoc and informal basis. This is different from the consultative model in which the information is usually sent in one direction.
- The coordinated model that requires a formal administrative structure and a case coordinator (or case manager) who facilitates communication and sharing of patient records among a team of healthcare workers.
- The interdisciplinary team approach that that requires Primary and Allied Health team members working to a consensus model and making decisions through regular face-to-face meetings.

Two countries are leading in the development and evaluation of these models – Israel, with its Movement Disorders Unit at the Tel Aviv Medical Centre and The Netherlands with its ParkinsonNet initiative. Both were established in 2004.

Movement Disorders Unit, Tel Aviv Medical Centre

The Movement Disorders Unit at the Tel Aviv Medical Centre takes an interdisciplinary team approach.

The team consists of neurologists, gerontologists, a psychiatrist, nurses, a social worker, a speech therapist, a sexologist, physiotherapists, an occupational therapist, a dietitian, a neuropsychologist, research assistants, genetic counsellors and secretaries.

Resources

- B. Gray, D. Sarnak, M. Tanke 2016 ParkinsonNet: An Innovative Dutch Approach to Patient-Centered Care for a Degenerative Disease
N. Giladi 2011 Multidisciplinary Team Work Can Improve the Care of Families With Parkinson's Disease
D. Wade, H. Gage, C. Owen, P. Trend, C. Crossmith, J. Kaye 2003 Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study
M.van der Marck, H. Kalf, I. Sturkenboom, M. Nijkrake, M. Munneke, B. Bloem 2009 Multidisciplinary Care for Patients with Parkinson's Disease

The centre has clinics for Parkinson's, atypical parkinsonism focusing on multiple system atrophy, an autonomic laboratory, sexual counselling service, a gait and falls prevention clinic, a special clinic for dementia and psychosis patients and a genetic counselling clinic. In addition, a clinic for prevention of Parkinson's was recently opened for populations at risk.

The centre also provides individual counselling to carers in a dedicated clinic, as well as a wide variety of group therapy programs for patients, carers and family members.

The Movement Disorders Unit treats people living with Parkinson's over the long term (many years).

ParkinsonNet, The Netherlands

ParkinsonNet was created by a neurologist and physiotherapist at Radboud University Medical Center after their research concluded that the lack of Parkinson's- specific knowledge among allied health professionals – along with an absence of practice guidelines – was producing "...unacceptable variations in the quality of care, with sub-optimal health outcomes and high costs as a result."

It consists of geographically based, multidisciplinary networks of Allied Health professionals who are committed to providing services to Parkinson's patients using evidence-based practice guidelines.

ParkinsonNet includes 69 regional networks involving more than 3,000 Allied Health professionals, including nurses and physical, occupational, and speech therapists.

Outcomes of ParkinsonNet			
Patients	Providers	Cost	Payment structure in the Netherlands
<ul style="list-style-type: none"> • Lower rates of hip fractures and hospitalizations • Improved patient-reported outcomes on quality of life, motor scores, depression, and psychosocial measures • Improved self-perceived daily function 	<ul style="list-style-type: none"> • Pride in expertise • Better knowledge of Parkinson's disease and care • Higher caseloads of Parkinson's patients • High overall satisfaction • Increase in self-reported physiotherapist adherence to evidence-based guidelines 	<ul style="list-style-type: none"> • Most studies show lower cost of care in PN regions • Use of rehabilitation centers for day care treatment was lower in PN regions, perhaps reflecting improved care in or close to patients' homes 	<ul style="list-style-type: none"> • Insurers provide higher payment levels to, or even contract exclusively with, PN allied health professionals • PN is exploring new payment arrangements with insurance companies

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Bushfire assistance and information

Parkinson's NSW is compiling information, tools and resources to assist people living with Parkinson's who may have been directly or indirectly affected by the recent bush fires.

Visit this page of the Parkinson's NSW web site for more information:

parkinsonsnsw.org.au/bushfire-assistance-reference

Information on this page will be regularly updated.

Protect yourself

Some people with Parkinson's experience shortness of breath as one of their symptoms. There is no clear cause for respiratory dysfunction in Parkinson's, its frequency or the effect that medications have on respiration.

However, exposure to smoke and poor air quality will obviously exacerbate shortness of breath so avoid vigorous activity and remain indoors – preferably in air conditioning – when possible.

Wear a mask if you do need to venture outdoors. P2 or N95 masks are required to protect you from smoke. They are available from pharmacies.

Exposure to heat is another hazard for people living with Parkinson's.

Up to 64 percent of Parkinson's patients report thermoregulation. This includes symptoms of heat and cold intolerance as well as excessive sweating.

People living with Parkinson's have problems with their autonomic nervous system, which controls sweating. While perspiration helps regulate the body's temperature, too much or too little perspiration can result in overheating.

If you are experiencing any of these symptoms you need to get out of the heat:

- Excessive sweating
- Not sweating enough in the heat
- Exhaustion and fatigue
- Nausea, vomiting, or dizziness in response to heat
- Changes in mood when too hot

Parkinson's NSW granted Vice Regal Patronage

Her Excellency the Honourable Margaret Beazley AO QC Governor of New South Wales and Mr Dennis Wilson have graciously agreed to grant Parkinson's NSW Vice Regal Patronage.

Her excellency is the 39th Governor of New South Wales and began her five-year tenure in May 2019.

Prior to her appointment as Governor, Her Excellency enjoyed a long and distinguished law career spanning 43 years, during which time she served as a role model for women in law at both the State and national level.

Appointed Queen's Counsel in 1989, in 1993 she was made a judge of the Federal Court of Australia, the first woman to sit exclusively in that Court.

In 1996, she achieved the distinction of being the first woman appointed to the New South Wales Court of Appeal and, subsequently, as the first woman to be appointed as its President.



Janina Jancu

Janina Jancu graduated and practised law before following a 12-year corporate career path that included roles up to the level of General Manager.

She has also held other key positions outside of the corporate sphere including Chief of Staff to the Lord Mayor of Sydney and Manager – Scholarships for the University of NSW.

Her most recent roles have been in the not-for-profit sector – as Chief Operating Officer and Company Secretary of the Victor Chang Institute and Director of Operations and Company Secretary of ReachOut Australia.

Nicole Schleicher

Nicole Schleicher has more than 20 years of experience in key roles within the not-for-profit sector.

Her experience includes managing service delivery and systems, quality, strategic projects, research and evaluation, and administration.



New Directors join Board of Parkinson's NSW

Following a talent search by an external consultant and skills assessments by an independent panel, Parkinson's NSW has appointed three new Board Members.

This is in addition to an existing three Board Members – including two who are living with Parkinson's and one with family experience as a carer.

Nambucca Support Group participant awarded OAM

John Mills – a stalwart of the Nambucca Valley Parkinson's Support Group – has been awarded a Medal of the Order of Australia for his contributions to the local community.

John had a long career as a pharmacist. Twelve years ago, he was invited to speak at the Nambucca Valley Group to speak on medications available for Parkinson's.

He offered his ongoing assistance which was enthusiastically accepted, and he has been part of the Group ever since – including serving as Chairman for six years.

John has also an enthusiastic member of his local Lions Club for 40 years, a patron of the Nambucca Valley branch of the Red Cross, and a representative of the Mid North Coast Local Health District Advisory Committee.

His past community contributions have included 26 years as Chairman of the Nambucca River Salvation Army Red Shield Appeal, and membership of the Macksville Hospital Board for 12 years.



Nicole has held program development, operational and policy management roles with The Smith Family, Baptist Community Services NSW, Wesley Mission, and The Benevolent Society.

She is currently General Manager of National Services for RedKite

Margaret Scott

Margaret Scott has more than 30 years of experience in senior fundraising roles for a variety of health and disability related not-for-profit organisations. In addition, she has operated her own business as a fundraising consultant since 2013.

Margaret was on the Board of the Fundraising Institute of Australia from 1998 to 2008. She held a number of key roles on that Board over the years including Chair, Vice Chair, and Chair of multiple Committees.

She was also on the Bloom Asia Board from 2017 to 2019.



Parkinson's NSW Support Group network grows

Already more than 70 Support Groups strong, the Parkinson's NSW network is experiencing a growth spurt with more than 15 new Groups at various stages of the formal registration process.

Ashfield, Tumbarumba, and Albury Young Onset have commenced in the last year, and Maitland has just been approved. Broken Hill is coming soon.

There are also five Carers Groups in the process of formalising their status in various areas across the State.

These Carers Groups have previously been operating on an informal basis and are now completing the Parkinson's NSW registration process.

We are also assisting another five existing Support Groups to start up Carers Groups and will be working with other Groups as the need arises.

Requests to establish Support Groups have also been received from Henty and Inverell, and Parkinson's NSW is sizing up Blacktown and Five Dock as potential new areas for development following successful local information sessions last year.

Want to know more or enquire about starting a Support Group or Carers Group in your area? Contact Support Group Coordinator Felicity Jones.

Phone: 02 8051 1900
Email: felicity.jones@parkinsonsnsw.org.au

Australian Government recognises Parkinson's NSW with grant

The Australian Government has recognised the expertise and leadership of Parkinson's NSW by awarding it a significant grant.

The purpose of the funding is to develop a program to support other organisations as they undertake the complex process of applying to become a Registered NDIS Service Provider.

Parkinson's NSW successfully achieved registration as an NDIS Service Provider in 2019. The process was challenging and time-consuming and required significant resources.

Understanding what to do and how to do it was often unclear and presented barriers to reaching well-informed business decisions on managing risk, compliance, financial sustainability and quality considerations.

Under the grant, the Parkinson's NSW Support for NDIS Providers project will develop resources and educational materials to help governance bodies and executives understand how they need to develop their business systems to comply with the NDIS Quality and Safeguards Commission Rules.

Two target audiences will benefit from this project – Boards of Governance and senior management teams of service providers that wish to maintain their existing NDIS Registration, or organisations which may be thinking of registering to become an NDIS Approved Provider.

The Parkinson's NSW project team is conducting consultations and seeking input from a variety of stakeholders about what information or assistance they require as they move along the NDIS Registration journey.

Parkinson's NSW is already working with stakeholders seeking information on:

- The implications of NDIS Registration for Board members
- Which governance systems need to be strengthened or implemented in order to comply with NDIS regulatory requirements
- What Risk and Quality Frameworks will support effective operation in the NDIS environment
- What resources are required to register or maintain registration
- What information is available about the NDIS registration process for sharing with Boards and management teams
- What staff competencies need to be developed to comply with NDIS Rules

If your organisation has questions, wants to make comments about your own registration experience, are seeking information or want to contribute to the development of resources, please contact the Parkinson's NSW Project Team.

Telephone 02 8051 1900 and a Project Team member will respond promptly.

You can also follow the progress of the project on Facebook at: facebook.com/groups/NDISprovidersprogram

Personal Trainers improve Parkinson's exercise outcomes

All exercise is good for people living with Parkinson's, however exercise with a Personal Trainer is even better.

A US study of 129 volunteers aged 20 to 65 who undertook 10 weeks of exercise guided by Personal Trainers found that 73 percent of participants (who were not already fit) showed improvement during the trial.

According to the Australian Institute of Fitness, certified Personal Trainers:

- Are trained and able to educate you about effective exercise.
- Demonstrate correct technique so you can perform exercises safely and correctly for optimum results.
- Can meet your unique exercise requirements.
- Help you set realistic goals.
- Hold you accountable and help you to commit and stick to your fitness goals.
- Help you manage your exercise time and routines for maximum results.

- Can advise on nutrition to complement your exercise.
- Help you improve your mental health through exercise which releases endorphins.
- Help you form good habits.
- Fit in with your schedule so you can tailor your exercise times.
- Are flexible in choice of location for your exercise.

Parkinson's NSW has a qualified and Parkinson's-experienced Personal Trainer on staff. She can provide advice over the phone, set up and lead Parkinson's exercise groups and provide individual Personal Training in Sydney.

Want to learn more? Phone the Parkinson's NSW InfoLine: 1800 644 189

Additional Parkinson's Nurse for Coffs Harbour

The role of the Parkinson's Specialist Nurse in Coffs Harbour has been expanded to a full-time position with an additional part-time position created.

Based on the findings of the Parkinson's Specialist Nurse research conducted by Charles Sturt University, the Mid North Coast Local Health District decided to increase the position to full time to maintain services to the local Parkinson's community.

Amanda Buzio has taken up the new part-time role working alongside Vince Carroll.

She has been working with Vince for a number of months in addition to working as the permanent part time Stroke Clinical Nurse Consultant at the Coffs Harbour Health Campus.

Amanda has been working in the neurology specialty for over 25 years and was previously the Community Services Manager at Royal Rehab in Sydney.

She has qualifications in Neuroscience Nursing, Clinical Teaching, Rehabilitation Nursing and Management and brings a wealth of experience and knowledge to the position.



Help us fund new community-based Parkinson's Nurses

Working as a Parkinson's Nurse across the Shoalhaven region in southern NSW, Nina feels honoured to be able to offer her support to people in her community.

"Parkinson's is a debilitating and progressive neurological condition affecting motor and non-motor activity in the body with over 50 symptoms!

My role is to empower people and give them information that's pertinent, that allows them to improve their quality of life and settles their anxiety and depression.

Support, advice and reassurance – these are basic human needs in a time of crisis – helping people feel safer and showing that someone cares.

Your support and donation keeps our wonderful Nurse Team going... and growing! Thanks to generous donors like you



Your generosity has impact

In 2019, our community-based Parkinson's Nurses:

Made more than **2,350** consultations

That included **870** home visits, **1,560** phone consultations and **212** hospital and aged care visits

Covered geographic areas ranging from **1,000** to **4,000 square kilometres** each

Drove up to **2,000 kilometres every month** to support people living with Parkinson's. The equivalent of driving more than one and a half times around Australia each year!

Parkinson's by the numbers

Every hour of every day someone is diagnosed with Parkinson's



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



9,780 people helped each year on our Infoline



1 in 5 people living with Parkinson's are of working age



Access to more than **70** support groups across NSW



Prevalence of Parkinson's is higher than prostate, breast, colorectal and lung cancers combined.



Education delivered to more than **850** people per year



More than **500** counselling sessions delivered per year



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



\$160,000 average lifetime financial cost for someone living with Parkinson's for 12 years.

*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.