

In Touch Newsletter

June 2023

David Veness recognised for service to people with Parkinson's disease.

David Veness, long-time participant of the Bathurst Parkinson's Support Group and former Board Member, has been awarded the Medal of the Order of Australia (OAM) for service to people living with Parkinson's disease.

The Order of Australia is the pre-eminent means by which Australia recognises the outstanding and meritorious service of its citizens.

"David has devoted himself to serving the Parkinson's NSW community," said CEO Jo-Anne Reeves.

"He has been a Member, Vice Chair and Chair of our Board of Directors, and also concurrently served as a Board Member of the Parkinson's NSW Trust. Upon retiring from his Board positions, David became our Community Ambassador.

"David has been a tireless advocate for people living with Parkinson's in rural and remote areas – and in particular the need for Parkinson's Specialist Nurses to support these communities. He is a modest man, so it is particularly pleasing to see his service to our community be recognised with such a prestigious award," she said.

Support Groups celebrate National Volunteer Week

It was National Volunteer Week from 15 to 21 May – Australia's largest annual celebration of volunteering.

Support Group Coordinator Stacey Foster hit the road that week to visit Maitland Parkinsons Support Group and lunch with the Leadership Teams of the Port Stephens, Forster, Taree, and Port Macquarie Groups.

While presenting them with Volunteer Week certificates, Stacey spoke of the crucial role of volunteers in our society. She noted that the theme of Volunteer Week this year was *The Change Makers*.

"I just wanted to take some time to visit you in person and celebrate the Change Makers like you who are making a difference in your communities every day.

“So what is a Change Maker? It’s someone who takes action to make the world a better place. Change Makers are the driving force behind social change. They achieve this by turning their passions into purpose and giving their time to make a real difference in our communities,” she said.

“On behalf of myself and Parkinson’s NSW, we thank you for your commitment to your Support Groups. We acknowledge that it can be a lot of work and we think you are all doing a fantastic job.”

Why volunteer?

We asked Support Group leaders and participants to share their thoughts

Phil Webster, Convenor, Forster-Tuncurry, since 2020:

“To provide educational opportunities for Support Group participants to better understand the disease and to lead a more balanced life.”

Mike Peart, President, Maitland, since 2022:

“I have been able to help others with more severe Parkinson’s than I have at this stage.”

Helen Tolhurst, Publicity Officer, Maitland, since 2022:

“There are very few joys in having a Parkinson’s diagnosis, but one of them is the wonderful people you meet who are living with PD and their carers. They include some of the kindest, wisest, bravest and strongest people I have ever met.”

Carol Brazel, Welfare Officer, Port Macquarie, since 2021:

“To be part of a group of people who understand what living with PD means. Also to make a difference in the lives of Parkinson’s families as we take this journey together.”

Kim Dahler, Leader, Port Macquarie, since 2021:

“After 35 years as a self-absorbed capitalist, I thought it was time to do something for a Not For Profit – plus I dig older men with walkers!”

Margaret McDonald, Leader, Armidale, since 2021:

“My husband was diagnosed in 2020 and we joined the Group for him to communicate with like-minded people. During that time the information and support received from the group has been exceptional. I personally gain self-satisfaction from helping members and making sure that they all feel supported.”

Warwick Bisset, Assistant Coordinator, Goulburn, since 2017

“It helps with my Parkinson’s symptoms by keeping the mind and body active and adds to my feeling of self-worth – reducing anxiety and depression. I feel like I am helping others.”

Lorraine Rutledge, Leader, Macarthur, since 2014:

“I have enjoyed my time with the people of Macarthur who have Parkinson’s and view them as a special ‘family’ in my life. Volunteering has enabled me to get to know those who probably would never have crossed my path, and being of help to them as they journey this side of their life”.

Jenny McIntyre, Leader, Eurobodalla, since February 2022:

"I am honoured to participate in the Eurobodalla Parkinson's Support Group. I have found it difficult at times but feel it is worth all the hassle when our members laugh and have a great time together, and support each other when needed."

Sandra Elms, Vice President (2015 – 2018), President (2019 – 2022), Newcastle:

"We all were enriched by the people we met at the Group. I put a lot of time energy and resources into the group and the Choir but would not have it any other way".

Rosemary Beasley, Co-Coordinator (2019 – 2023), Management Committee Member, Lismore, since 2023:

"I am glad to be able to give back to a Group I have gained so much from... friendship, help and support".

Carmel Mahoney, Step Up Committee, Kiama, since 2022:

"As a person living with Parkinson's, I am very happy to help out with the running of our local Support Group in Kiama. Many of those attending are worse off than me & I enjoy assisting them & trying to keep them thinking positively about their condition & not let it get them down.

Betsy Rumble, Co-Leader, Eastern Suburbs YO, since April 2021:

"Volunteering as a support group leader brings me tremendous satisfaction. Every time I see members connect with each other and share knowledge and understanding or when a speaker shares information that really hits with our Group, I know that people's lives are made better and that my time is well spent."

Desley Banks, Companions Group Leader, Lismore, since 2022:

"It is a real pleasure to be involved in the Lismore Parkinsons Support group. The information sharing is vital to our members and their companions/partners. To provide an opportunity for companions/partners to share in private discussions is vital to our group to assist out companions/partners manage PD".

Robyn Lindsay, Leader & treasurer, Manly Mosman, since 2007:

"My satisfaction from these roles is the joy of having a social and happy environment for the people living with Parkinson's and their carers. New friendships are formed and everyone is there for each other".

Rachael Fischer, Co-Leader, Belrose Young Onset Group, since August 2021:

"Co-facilitating the Group is the greatest of privileges. Watching the Support Group find common ground in a safe and explorative space is not just rewarding but so very satisfying".

The benefits of exercising with your pet

We all know exercise is what you need if you have Parkinson's. However, with Parkinson's you also often have trouble mustering the motivation to exercise at all.

If you have a pet, not only you miss out, but your pet also often misses out on quality time with and their exercise. Let's solve the problem by exercising with and for each other.

If you're thinking about going for a run or walk, take your pet with you because both of you will benefit. Regular workouts will help you and your pet maintain a healthy weight.

Exercise will also help prevent other weight-related conditions, such as diabetes and high blood pressure for both of you. Other benefits for you both are reducing the chances of stiff joints, arthritis, or hip dysplasia. And of course, exercise improves the mental health of both humans and animals.

You know how exercise can just put you in a good mood? It does the same for animals. It's been shown that aerobic exercise can increase serotonin production in not only your brain but your dog's brain as well. This helps them feel more relaxed and less aggressive.

One of the best reasons to exercise with your pets is that you get a workout buddy! Having a workout buddy can help keep you motivated even on days you'd rather stay in bed.

Once you get in the habit of exercising with your dog, he or she is going to be waiting excitedly by the door – possibly with leash ready. Your dog will help push you out for a walk or run whether you want to or not. You won't get a more dedicated workout buddy!

One study discovered that dog owners were 34 percent more likely to get at least 150 minutes of exercise per week than those without a dog.

There are loads of options to vary your pet-buddy workout. You could go kayaking, paddleboarding, Nordic walking, walking on the beach, by a lake, or in the park. Take a ball or Frisbee so that you can both play fetch to break up your workout.

Make sure to consider both you and your pet's health and fitness ability. Can your dog keep up with you, or can you keep up with your dog?

Keep both of you safe and drink lots of water, wear sunscreen and both of you take a break when needed. Dogs can dehydrate and overheat just the same as we can. Look out for excessive panting or drooling.

Try and go early in the morning in summer before it gets too hot. This will also stop your dog's feet from burning from hot pavement.

If you can't get out of the house to get in your workout, try a home workout. There are even yoga classes for you and your dog.

Sit ups at home are great for whatever pet you have. A co-operative cat or dog can be held and used as added weight or you can throw a treat each time you raise your head and shoulders and hopefully your pet will return to you for another.

Squats or lunges are great if your pet is obliging. Hold them in your arms and bend your knees up and down. Repeat as many times as your pet allows.

Doing a push-up is very similar to the body language of animals when they want to play. Front paws lower than their rear and a great tail wag. Your push-up can be the same. Or train them to sit on your back to add a challenge to your push-ups

Make sure you end with stretches; your pet will be right there with you. Ensure you and your pet get a check-up from the vet and GP to say you're both good to go.

Do yourself and your best friend a favour and exercise together!

References

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Nurses in Action: Lauren Hogan

Parkinson's Specialist Nurse Lauren Hogan, who is based in Goulburn, began her working life in the financial sector, despite having a childhood ambition in nursing.

"I had always wanted to be a nurse, because my grandmother had been a nurse, but I didn't go straight into it," explains Lauren. "Eventually I decided that nursing was really what I wanted to do."

Lauren travelled back and forth from Goulburn to Canberra University while doing her nursing training, and as a new graduate worked at Goulburn Hospital.

"Basically I've just stayed on," says Lauren, who has now worked from there since 2013. "I've done various medical, surgical and post grad work, becoming a nurse educator and mentoring and teaching."

"When the Parkinson's Specialist Nurse position came up I saw it as a specialty, an offshoot of education I'd been doing. I'd nursed Parkinson's patients but this role was something I could really educate patients and carers about the disease and also work with allied health practitioners."

Lauren's regional area covers Yass, Crookwell and Queanbeyan as well as her Goulburn base.

“The driving doesn’t worry me,” says Lauren. “It’s not that far to each place. My biggest challenge is getting a patient help in a timely manner. Sometimes that can be me taking a patient’s question about medication side effects straight to their neurologist, rather than having them having to wait weeks or more and then travel for an appointment.

“People living with Parkinson’s and their carers in regional areas can find travel to specialists difficult for a variety of reasons. They may no longer have a driver’s licence, or may have financial issues with the cost of travel and possibly accommodation, as well as mobility issues. A big benefit of my role which drew me in was that I can help people find the right services and facilities. Being a local is also really beneficial as I know who to contact to ask all kinds of advice.”

Lauren began her new role in March 2022, but because it was a new position she first had to spend time setting up a brand new service. She has been seeing patients since June last year.

“I attend all local support group meetings, visit all the local allied health-care services to let them know about how I can help, and meet with each patient and carer as they are referred to me,” says Lauren.

“We find a mutually-agreed time and place for a first assessment, which might be their house or my office and it takes about two hours for a really thorough assessment. I ask about what they usually do in daily life, what they enjoy doing and what have they stopped doing. I try to get a really holistic picture and to work with them and their doctors and specialists to create a better regime for each patient.

“The patient and carer can remain in contact with me as often or as little as they like. I particularly try to help them work with the things they are finding really distressing. This might be not being able to get out as much, or no longer able to cook a meal or even trouble physically getting out of bed each day.

“I can organise an OT (occupational therapy) review and give them some tips as well. Little things can go a long way. And sometimes the patient is more likely to take advice from me, as a nurse, than from their carer, even if it’s the same advice.

“Carers can be pivotal with how we coordinate and plan care of a patient and we always consult them as they may have a different perspective on what has actually been happening. They can give really important information and we have to watch for carer burnout. They are supporting the patient but carers also need support and we do have groups just for them.

“I also love being able to go to the Parkinson’s NSW headquarters at Ryde (Sydney) at times and have get-togethers with other Parkinson’s nurses who are really experienced. We also share new medical and research information. I work part-time and currently have 40 patients on my books and it’s continuing to grow. I also have a family and help my husband in his building business part-time.”

In July this year Lauren will be one of the Parkinson’s specialist nurses attending the World Parkinson’s Congress in Barcelona.

“People there are all doctors, nurses and allied health practitioners learning from the best in the business,” Lauren explains. “I feel honoured to be able to learn and give back to my local community. I am really grateful for the local fundraisers who worked so hard for years to have a nurse locally and it’s a privilege to develop the role in our own community.”

Kiama Support Group Walk in the Park

The Kiama Support Group held its Step Up for Parkinson’s fundraiser on Sunday, 4 June.

It was a lively event in a picturesque location – the beach and walking path adjoining Kiama Harbour. It was well-attended by walkers of all abilities, their families and other supporters.

Kiama Rotary was on hand conducting its popular sausage sizzle and there were two warm-up sessions prior to the walk – dance for Parkinson’s and group exercises.

Prior to the walk a Parkinson’s Community Hero Award was presented to exercise physiologist Sarah Clemm who supports the local Group with exercise sessions at its regular meetings.

In addition to sponsorships of walkers, other fundraising initiatives included multiple raffle draws and sales of Parkinson’s NSW branded merchandise.

Support Group Manual to be Updated

Work is underway on updating the Support Group Manual.

It is expected to be released in July, following review by representatives of Support Groups and the Parkinson’s NSW Leadership Team.

The new Manual will reflect the latest changes to laws and regulations in the Not For Profit sector, as well as the basic processes and information required to run a Parkinson’s NSW Support Group.