

## World Parkinson's Congress, Barcelona 2023

The World Parkinson Congresses are held every three years in a different country provide an international forum for scientists, clinical researchers, health care professionals, people living with Parkinson's and others to come together under one roof to discuss, learn, and engage in debate around the latest scientific discoveries, medical and comprehensive care practices related to Parkinson's disease.

Unlike other scientific congresses, the World Parkinson Congress (WPC) brings together all members of the Parkinson's community.

As an inclusive event, the WPC was founded on the belief that getting world leaders out of their professional silos and forcing a cross pollination of the scientific, clinical, rehabilitation, and advocacy communities would expedite the discovery of a cure and cultivate best treatment practices for this devastating disease.

Whether this cross pollination takes place in the audience at a scientific lecture, from the stage between the presenters, during poster talks, or at a small round table discussion, the take away is often the same: we need to evolve how we think when it comes to treatment for Parkinson's and how to move forward together as a community to expedite research and get us closer to new treatments and ultimately a cure.

Read about the impact of this cross pollination format in these impactful stories on the [Working Parkinson Connections](#) blog page, written by UK-based neuroscientist Dr. Jon Stamford who is also living with Parkinson's.

**The 6th World Parkinson Congress (WPC 2023) will be held in Barcelona, Spain from July 4 – 7, 2023.** Everyone in the Parkinson's community is welcome to attend.

## Does Parkinson's disease impact your quality of life?

You can help advance research into Parkinson's Disease by participating in a research project which aims to better understand how the communication and swallowing symptoms associated with this disease impact quality of life. Additionally, what barriers impact access to speech pathology services for individuals living in regional Australia.

Participants must live in regional Australia (population less than 100 000) and have been formally diagnosed with Parkinson's disease by a doctor or neurologist.

The survey will remain open until 31 July 2022.

To participate in the survey please click on the link to the electronic survey platform: [https://uoc.syd1.qualtrics.com/jfe/form/SV\\_d05EA615xmmo8dM](https://uoc.syd1.qualtrics.com/jfe/form/SV_d05EA615xmmo8dM)

If you would like more information, please contact the researcher at the University of Canberra: [u3213342@uni.canberra.edu.au](mailto:u3213342@uni.canberra.edu.au)

## **World Parkinson's Congress, Nurses Testimonials**

### **Vince Carroll**

“The World Parkinson's Congress is a unique opportunity to unite as one voice for Parkinson's. Clinicians and people living with Parkinson's share knowledge and stories – and hear about the latest research and innovation from across the world.

“At the last Congress in Japan I had the opportunity to present a research poster with Associate Professor Rachel Rossiter from Charles Sturt University on the progress Parkinson's NSW has made with our Parkinson's Specialist Nurse models in rural and regional areas of NSW.

“This is the world stage where you have the opportunity to influence practice and inform others, as well as learning to nurture and grow your own practice. You network with other clinicians and meet so many beautiful people of different cultures from around the world.”

### **Cathy Melton**

“The World Parkinson's Congress provides the latest updates on treatment for Parkinson's from specialists around the globe. It also re-evaluates and confirms what is already considered best practice.

“The Congress covers much more than medication; it also reviews a range of other options managing symptoms. This event is highly valuable to me as it directly informs my nursing role – supporting people through the Parkinson's NSW InfoLine.”

### **Rachael Mackinnon**

“There are few opportunities available for professional development for health workers supporting people living with Parkinson's in Australia.

“The World Parkinson's Congress brings the international Parkinson's community together – including researchers, people living with Parkinson's, Neurologists, Movement Disorder Specialists, Primary and Allied Health professionals – to share insights and advances in Parkinson's treatments, care strategies and research.

“The Congress was the best conference I have ever attended in terms of increasing my knowledge of Parkinson's. I was surprised that, following the Congress, I had direct access to the presenting researchers and specialists (all leaders in their fields) who were highly collaborative and responsive to follow up communications.

“Following each Congress, we share our findings with peers and patients alike. The information we bring back is also used to further develop content for the Parkinson's NSW Education and training programs.”

## **World Parkinson's Congress, Delegate Testimonials**

### **Robyn Lindsay – Manly-Mosman Support Group**

“Japan was our third congress and the most recent we attended. The first was in Montreal and the second was in Portland.

“Attending the lectures is such a huge learning initiative. There are so many to choose from. Meeting people connected in many ways with Parkinson's was wonderful as they were from all over the world. You never know who you are going to be sitting with at lunchtime for a chat!

“We also loved the travel and joining some of the day tours that were organised. The volunteers from all countries were always there for help.

“Having the companionship of people from Parkinson's NSW was great as well and we had a lot of fun. World Parkinson's Congress is a fun-filled learning experience.”

### **Sandra Elms – Deputy Leader, Newcastle Support Group**

“The World Parkinson's Congress – usually held every three years – involves specialist clinicians, nurses, therapists, those providing support and activities for Parkinson's people but most important people who are actually living with Parkinson's.

“Everything is totally inclusive; you can attend any lecture, discussion, or activity that you wish. You will be able to discuss with renowned professors what you have always wanted to discuss. You have the disease and can openly discuss it and give your thoughts and feelings.

“This Congress offers you a schedule which is diverse, interesting, comprehensive and which can at times be fun and adventurous. There is simply no other forum quite like it.

“As well as all the medical knowledge you can hear about you have the opportunity to meet people living with Parkinson's from all over the world. What are the latest developments in the UK? How do they cope with freezing of gait in Norway? What foods are they promoting in Japan? How do they dance in Spain? The opportunities to learn so much and forge friendships with people living with Parkinson's in other countries are there for you to share.

“You can also enter the competition for posters after you send an abstract of what you might be doing for people with Parkinson's or a research program. if your

abstract is chosen you make a poster outlining your work which is displayed in the Poster Room. There is also the possibility of obtaining a small travel grant if your work is displayed.

“I have attended two Congresses: Portland, USA and Kyoto, Japan. At both I had my abstract *Living with PD* chosen and posters displayed. I am hoping to be able to go to Barcelona.

“I believe these Congresses are extremely worthwhile – despite the cost – as they provide a truly unique experience and give one hope and encouragement to face this disease.

## Parkinson's NSW advocacy update

Advocacy is the process of seeking support for a cause or policy.

In this case the cause is support for the NSW Parkinson's community and funding for services. However because of its highly targeted and often confidential nature, much of the advocacy done by this organisation goes unseen by the community it serves.

This article is intended to give some insight into the advocacy activities of Parkinson's NSW.

### Political outreach

Thanks advocacy by two prominent State MPs with an interest in our cause, Parkinson's NSW over the past year was twice invited to participate in information evenings at Parliament House.

The receptions were attended by MPs and their advisors from across the political spectrum and featured speeches from the President and CEO of Parkinson's NSW.

***“The latest research tells us that there are already 69,600 people living with Parkinson's in New South Wales. If you add in caregivers and immediate family that brings the total of people affected by Parkinson's in some way to more than 200,000... and most of them are voters!*”**

***“The general population growth rate of Australia is just over one percent. However, the average growth rate in Parkinson's will be 40 percent over the next 20 years. This presents a major public health challenge that can't be ignored.”***

### **Extract from speech to parliamentarians by Parkinson's NSW Chair, Margaret Scott**

Former Deputy Premier of NSW, The Hon. John Watkins AM, who is living with Parkinson's, also spoke movingly about the impact of the disease on his physical and mental wellbeing. He has since been appointed a Board Member of Parkinson's NSW where he is playing an active role in ongoing political advocacy.

Annual mailing campaigns around Budget time have also been conducted. They addressed every MP in NSW along with the State and Federal Health Ministers,

requesting recurrent funding for the delivery of services to the Parkinson's community.

This is a priority because almost 90 percent of funding for Parkinson's NSW activities currently comes from fundraising. This is not sustainable.

***“Parkinson's has become... a hated influence that has invaded my body to deform my abilities and sense of self.”***

***Extract from Sydney Morning Herald opinion article by Parkinson's NSW Board Member, The Hon. John Watkins AO***

### **Co-funded Parkinson's Specialist Nurses**

Research conducted by the Faculty of Nursing, Midwifery and Indigenous Health of Charles Sturt University indicates that the most effective model for Parkinson's Specialist Nurses is:

- To have them jointly funded by Local Health Districts (LHDs) and Parkinson's NSW
- Jointly managed by the two organisations
- Based in the LHD offices in order to provide nurses with access to health records and data, professional development opportunities and peer support.

Therefore advocacy to the management of LHDs across NSW where nurses are not yet placed is ongoing. Our most recent success has been the placement of a co-funded nurse based in Goulburn, within the Southern NSW LHD.

### **Joint advocacy with Parkinson's NSW Support Groups**

Parkinson's NSW encourages all Support Groups to engage in joint advocacy at their local level to raise the profile of Parkinson's in the community and enlist the support of MPs to make submissions to key Ministers.

Pro forma letters and advice on how to engage with MPs are provided by Parkinson's NSW.

A video message from the Chair on World Parkinson's Day goes out to all Support Groups and via social media to raise the profile of the Parkinson's community across NSW.

### **Joint advocacy in the not-for-profit and healthcare sectors**

Parkinson's NSW is working with Fight Parkinson's (formerly known as Parkinson's Victoria) to jointly target the Federal Health Minister, advisers, and other members of the national health bureaucracy. This involves multiple meetings and outreach, backed by a well-researched document supporting our request for funding.

Our organisation also works with others in the healthcare sector. For example, we supported St Vincent's Hospital's bid for increased funding to treat Movement

Disorders and joined the Australasian Neuroscience Nurses Association (ANNA) to lobby the Minister for Health for a rapid resolution of the Sinemet™ shortage. Parkinson's NSW has also made formal written submissions to Government inquiries into:

- The National Disability Insurance Scheme
- Aged Care Quality and Safety
- Regional, Rural and Remote Health

## **Win up to \$5,000 cash this Friday!**

When you purchase tickets in the latest 50-50 raffle you have a 1 in 1000 chance to win up to \$5,000 cash to use how you wish.

Only 1,000 tickets are available at \$10 each giving a maximum 'Pot' value of \$10,000\*! The winner splits the final 'Pot' 50/50 with Parkinson's NSW.

Secure your tickets today: [www.parkinsonsnsw.org.au/50-50-raffle/](http://www.parkinsonsnsw.org.au/50-50-raffle/)