



APGS NEWS

AUSTRALIAN PARKINSON'S GENETICS STUDY

Issue 2 March 2024

Welcome to the second edition of the APGS News!

Thank you for participating in the Australian Parkinson's Genetics Study (APGS). Every completed questionnaire and saliva sample returned to our lab brings us closer to significant scientific breakthroughs. As an expression of our gratitude, we want to update you on our progress and share some exciting news.

Here's a summary of the latest developments in this newsletter:

- We are very close to achieving our recruitment target of 10,000 Australian participants diagnosed with Parkinson's disease (PD).
- Three **new substudies are being launched**, focusing on (1) **familial PD**, (2) **cognitive symptoms**, and (3) **speech-related symptoms**.
- We are actively **seeking 10,000 volunteers without PD** to participate in our study as part of the 'control' group.
- Preliminary results about **chronic pain** among people with PD in Australia.

We sincerely appreciate your patience and continued commitment to the APGS. Scientific research is a meticulous process that requires time and collaboration. Together, we are making significant progress in unravelling the genetic mysteries of PD. Thank you for being an indispensable part of this journey.

About the APGS

More than 100,000 Australians live with Parkinson's disease, making it the second most common neurological condition in the country. Still, it remains one of the least understood in terms of its cause. Scientists have proven that genetics plays a vital role in determining who develops PD – particularly, but not exclusively, in families where several people have the diagnosis.

Our team of researchers in Brisbane and scientific collaborators around Australia and overseas are

working to understand how different genes can affect the chances of developing Parkinson's and why its symptoms can differ in different people. It's like solving a puzzle where each gene is a piece that helps us see the bigger picture. We are looking for the missing pieces because a better understanding of how our genes are implicated in disease processes can help us advance knowledge about the disease's causes, treatment, prevention, and progression and develop more effective and personalised treatments.

Recruitment progress so far in Australia

- **12,165 people** have completed the online/paper questionnaire, including **9,389 participants** who have a diagnosis of PD and **2,776 participants** who do not have a PD diagnosis.
- A total of **11,264 saliva samples** have been received in our lab and are being processed – **8,898 participants with PD** and **2,366 without PD**.

If you still need to return your saliva kit to us, you can still join the 96.8% of participants who have. If you have misplaced your kit, please get in touch with us, and we will send a replacement. If you did not complete the online questionnaire or had technical challenges, you can contact us and get a paper questionnaire sent to your home. Email pd.genetics@qimrberghofer.edu.au or call us on 1800 257 179.

Every kit gets us closer to our goal. Send yours today and contribute to this critical study.



GP2 worldwide recruitment update

APGS is part of the **Global Parkinson's Genetics Program (GP2)**, the most important study on PD genetics ever undertaken.

The current target for GP2 is to collect **179,139 DNA samples** from **59 countries**. To date, **44,831 samples** have been processed, and teams of scientists are already analysing their genetic information. This includes **1,440 samples from Australian participants**. This number will continue to grow each quarter.



A renewed commitment

The APGS is possible thanks to the **Shake It Up Australia Foundation** and **The Michael J. Fox Foundation for Parkinson's Research**. Although funding for the first part of the study ended in November 2023, we are pleased to share that these foundations have extended their funding to support our study until November 2024. That will allow us to continue our recruitment efforts and perform planned analyses of your questionnaire responses and saliva samples.



The Shake It Up Australia Foundation and its partner - The Michael J. Fox Foundation for Parkinson's Research - are the largest non-government funders of Parkinson's research across multiple institutes in Australia. Only through medical research and international collaboration will we find a cure for Parkinson's. For more information, visit www.shakeitup.org.au



An update on the Services Australia invitation letters

Many of you became aware of the study through approach letters sent by *Services Australia* (formerly the Australian Government Department of Human Services) on behalf of our research team. Services Australia dispatched over 150,000 approach letters to persons who, based on their Medicare and PBS records, had been prescribed medications commonly used to treat Parkinson's symptoms within the past two calendar years.

You might have received the invitation letter after signing up for the study or even received it twice, for which we sincerely apologise. Services Australia distributed these letters to a randomised sample of users, strictly adhering to their privacy and confidentiality policies, thus withholding any personal information from us. As a result, we lack knowledge of the recipients or the timing of the invitations. It is entirely up to the recipients to decide whether to take action, and visit the website to learn more about the study and sign up.

If you received the invitation twice or after participating, please be assured that your original participation has been confirmed, and there is no need to complete the questionnaire again.

Parkinson's Plus conditions

Parkinson's Plus conditions are a group of neurological diseases featuring the classical motor features of Parkinson's disease (tremor, rigidity, slow movement, and postural instability), with additional features that distinguish them from PD.

Parkinson's Plus conditions are often difficult to differentiate from PD and each other.

They include:

- Multiple system atrophy (MSA),
- Progressive supranuclear palsy (PSP),
- Corticobasal degeneration (CBD),
- Pick's disease,
- Olivopontocerebellar atrophy.

Since they are challenging to diagnose and relatively rare, there is little research into these conditions. As part of a larger worldwide effort within the GP2 consortium, **we are expanding the scope of our study to include people with any Parkinson's Plus conditions.** So, if your diagnosis changes or you know someone who did not participate in the study because they have some of these diagnoses, please let us know.

We can make a difference, advance science, and get closer to new cures for these conditions, too.



“

When we find a cure for Parkinson's — and we will — it won't be because of any single person. It will be because of all of us, working together.

Michael J. Fox

”

MonoPDAus: New sub-study on familial Parkinson's

Through the Medical Research Future Fund, the **Australian government has awarded >2.95 million dollars** to a team of Australian researchers **to facilitate research into the genetic causes of familial Parkinson's disease.**

The study is co-led by Associate Professor Miguel Renteria from the QIMR Berghofer Medical Research Institute in Brisbane and Associate Professor Kishore Kumar, a physician-scientist at the Garvan Institute of Medical Research and Concord Repatriation Hospital in Sydney. Eligible APGS participants who reported a family history of Parkinson's disease and/or early age of onset will be approached in the upcoming months to be invited to participate. Participants will have the option to receive genetic counselling and know their genetic test results as part of the study. This may be relevant because new PD therapies target specific genes, which may specifically benefit people who are carriers of specific mutations.

Preliminary results about chronic pain in PD

Pain is also a lesser-known but significant aspect of PD that affects many. One of the modules in the APGS questionnaire asked about your experience with chronic pain, and we have some preliminary results derived from your answers.

So far, in this preliminary study, 75.8% of participants reported experiencing long-term physical pain, while 24.2% reported no chronic pain. The back and neck are the most predominant pain sites. Female PD patients report more physical pain than males, suggesting the presence of gender-related effects on pain. Notably, only 2.4% of participants reported having pain at the onset of PD motor symptoms. In addition, the presence of physical pain in PD was associated with several comorbidities, with depressive symptoms being the most significant.

If you've experienced pain as part of your Parkinson's journey, your story is important. Stay tuned for more information on how you can contribute to this vital research.

Two exciting new research initiatives

1. Cognition and Parkinson's disease

While tremors are a common symptom, Parkinson's can also affect the mind, leading to challenges in thinking and memory. Our new study aims to fill the gap in research about differences in cognitive function among APGS participants and how genetic differences influence cognitive functions such as short-term memory, planning, mental flexibility or inhibition.

2. Speech and Parkinson's

In collaboration with Professor Adam Vogel, Head of The Department of Audiology and Speech Pathology at the University of Melbourne, we are also launching a sub-study to investigate dysarthria and other speech-related symptoms in PD and the role of genetics.

If you indicated interest in participating in other studies related to APGS, you may receive an invitation to join these new substudies. **Your participation is highly valued and could lead to important discoveries!**

We are seeking 10,000 volunteers without PD to help us crack the genetic code of Parkinson's.

Our study employs a case-control study design, which means that we will be making statistical comparisons between the genetic information of two groups of participants, one group with PD diagnosis and the other without PD.

Now that we are very close to reaching the recruitment target of 10,000 volunteers with PD from all over Australia, we will be ramping up recruitment of volunteers without PD, and you can help us make this happen!

In the coming weeks, you'll receive an email inviting you to forward an invitation to a non-blood relative (such as a neighbour, spouse, spouse's relatives, coworker, etc.) to join the study as part of the 'control' group. Your invitation extends beyond a mere gesture; it is crucial in bringing us closer to groundbreaking scientific discoveries.



Other Announcements

POWER FOR PARKINSON'S

Power for Parkinson's is a non-profit organisation that began in 2013. It offers FREE, FUN, symptom-focused exercise, dance, and singing classes to people with PD and their caregivers. In addition to the physical benefits of exercise, they foster values like connection and community. Their approach addresses social and emotional needs through live, in-class community engagement.

Some of their classes include:

- Strength & Balance
- Move & Shout
- Brain & Body
- Parkinson's Dance Exercise
- Vocal Exercise
- Standing Series
- Relax & Reset
- Young Onset Circuit Training

For more information: www.powerforparkinsons.org



NEW PARKINSON'S DISEASE CENTRE OF EXCELLENCE IN SYDNEY

Our collaborator, Professor Carolyn Sue, recently launched a new Parkinson's Disease Centre of Excellence at **Neuroscience Research Australia (NeuRA)** in Sydney, NSW. Her team plans to run clinical trials, including:

- Natural history of Parkinson's disease
- Genetic contributions to Parkinson's disease (including the Global Program for Genetics in Parkinson's disease or GP2)
- Microbiome studies in Parkinson's disease
- Exercise therapy in Parkinson's disease
- Markers of Disease progression in Parkinson's disease
- New therapeutic clinical trials (soon to include a prebiotic treatment for Parkinson's)



For more information about this Centre, please see the following website links:

neura.edu.au/researchers/professor-carolyn-sue

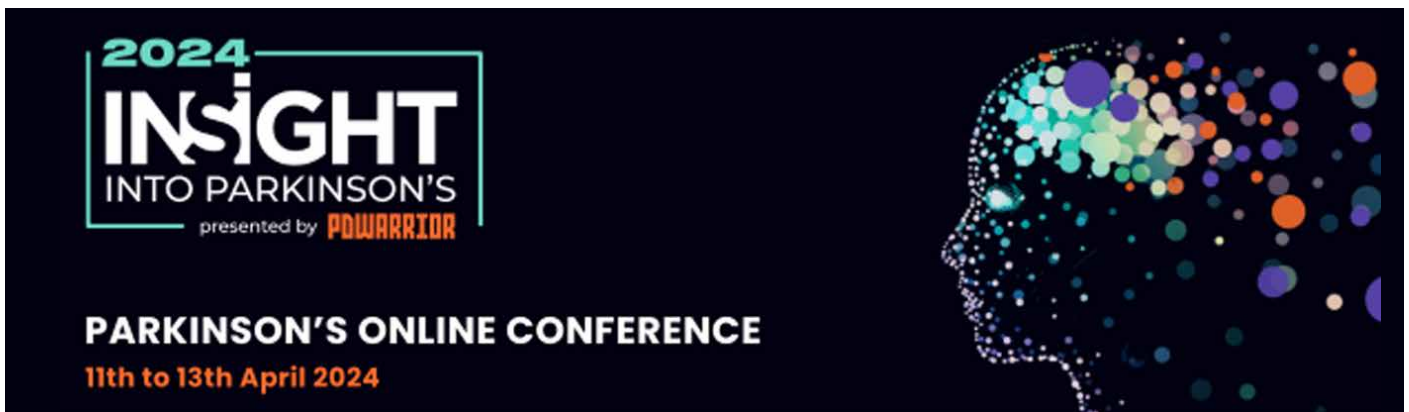
neura.edu.au/research/research-expertise/parkinsons-disease

If you are interested in participating in clinical trials run by Professor Sue and her team, you can register your interest:

by emailing PDclinicaltrials@neura.edu.au

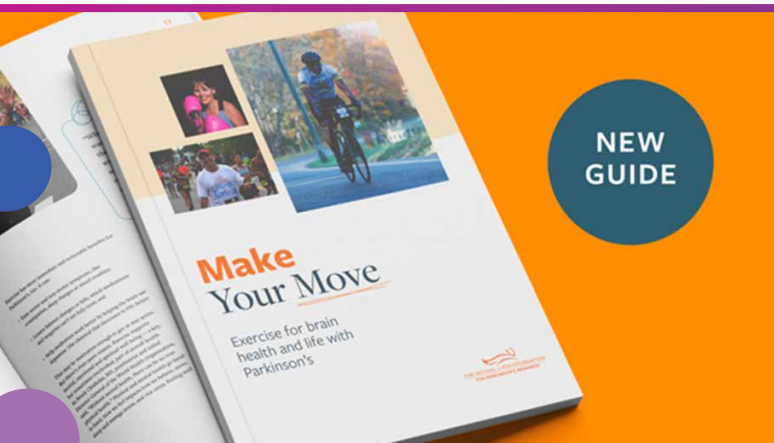
or calling (02) 9399 1805

Please mention that you are an apps participant.



INSIGHT 2024 - PARKINSON'S ONLINE CONFERENCE (11-12 APRIL)

PD Warrior is a support network, education channel, enabler, confidence giver and motivational coach for people with Parkinson's. PD Warrior has been running the INSIGHT conferences since 2018, curating and providing a virtual forum for anyone impacted by Parkinson's to attend and obtain the latest information and insights across the industry. You can learn more about this year's conference by visiting pdwarrior.com/insight/



NEW GUIDE: EXERCISE, BRAIN HEALTH AND PARKINSON'S

Whether you live with Parkinson's, care about someone who does, worry about the possibility of PD, or simply want to care for your brain as best you can — the newly released guide from The Michael J. Fox Foundation for Parkinson's Research has something for you.

Available at www.michaeljfox.org/form/2024-exercise-guide

Stay Connected

Your insights, experiences, and feedback are invaluable to us. Together, we're not just studying Parkinson's; we're setting the stage for a revolution in understanding and treating PD.

Thank you for your support and participation. Your contribution is invaluable, and together, we will continue to crack the genetic code of PD and build a future with more hope.

Sincerely,

Associate Professor Miguel Renteria & Professor Nick Martin,
on behalf of the APGS Research Team





Get in touch

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<https://www.qimrberghofer.edu.au/apgs>



<https://www.facebook.com/AusPGS/>



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