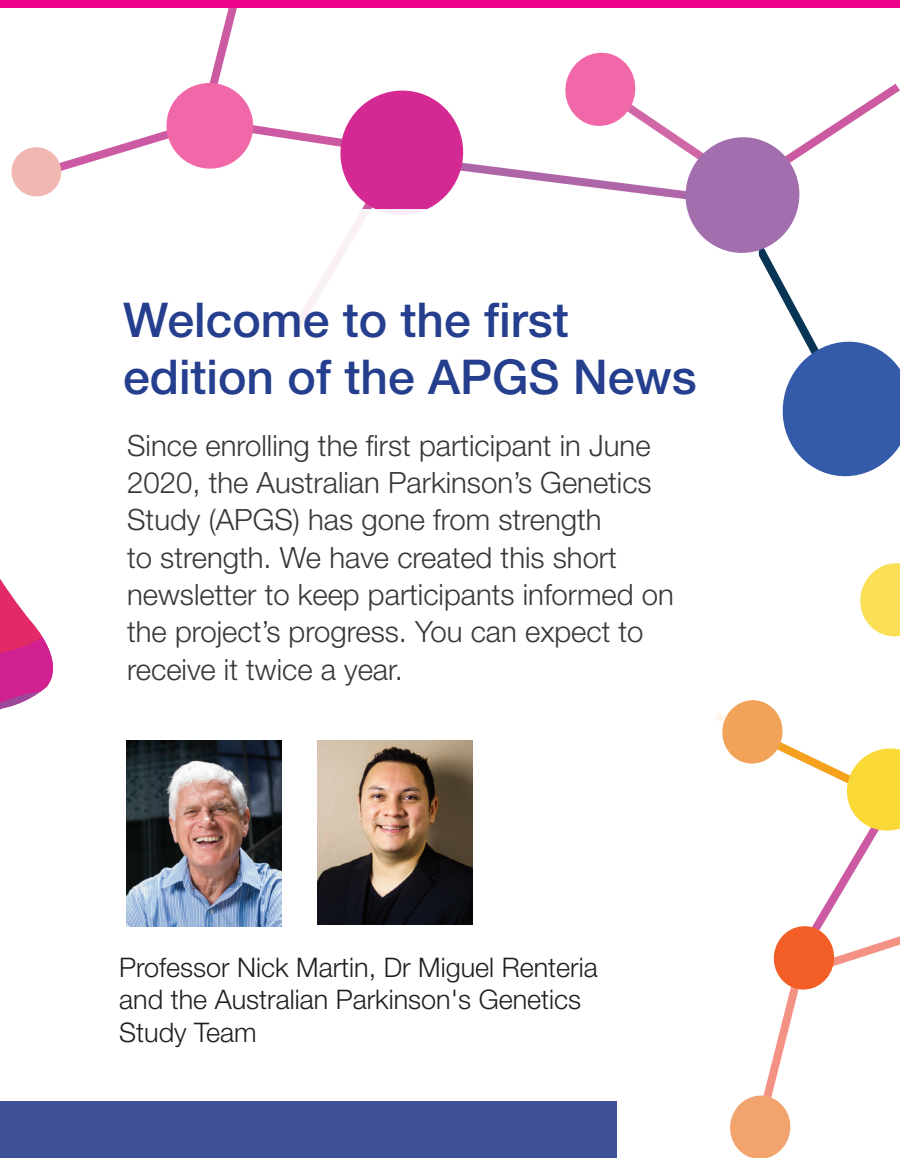




# APGS News

AUSTRALIAN PARKINSON'S  
GENETICS STUDY

Issue 1 Winter 2022



## Welcome to the first edition of the APGS News

Since enrolling the first participant in June 2020, the Australian Parkinson's Genetics Study (APGS) has gone from strength to strength. We have created this short newsletter to keep participants informed on the project's progress. You can expect to receive it twice a year.



Professor Nick Martin, Dr Miguel Renteria and the Australian Parkinson's Genetics Study Team

## About the APGS

More than 100,000 Australians live with Parkinson's Disease (PD), making it the second most common neurological condition in the country, but 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 with several members affected. The APGS researchers aim to crack the genetic code of Parkinson's by helping to identify the hundreds of genetic variants that influence a person's risk of developing the condition and its various symptoms. A better understanding of how genes are implicated in the disease process can provide insights and revolutionise future research into the causes, treatment, and prevention of the disease and its progression and enable the development of more effective and more personalised treatments.



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# Recruitment milestone

To date, nearly 3,000 participants from across Australia have voluntarily signed up to participate in APGS. That is a fantastic result that puts us on the right track to making meaningful scientific discoveries from our work over the coming months and years.

Internationally, the Global Parkinson's Genetics Program (GP2) has completed the analysis of 8,644 samples out of 159,576 expected from 52 locations worldwide by 2024.



## Processing of saliva samples

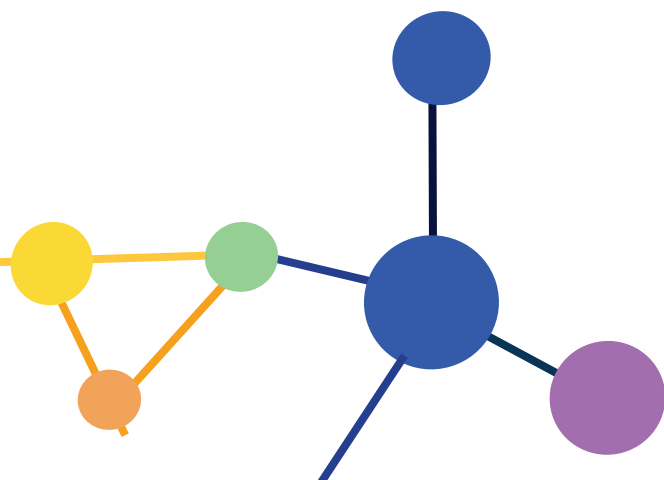
One thousand four hundred eighty saliva samples donated by participants in the pilot have been processed and DNA extracted.

This genetic material is now being analysed using the latest technology. It will take approximately six months before the first results of this analysis are available.

## Funding

We are pleased to report that funding for APGS has been secured from an equal partnership between The Michael J. Fox Foundation and the Shake It Up Australia Foundation. This will allow the project to progress for the following year. Subject to meeting milestones, we expect to be able to continue gathering data until the end of 2023. This will provide a solid statistical basis for future research.

The Shake It Up Australia Foundation, together with their partners - The Michael J. Fox Foundation, are the largest non-government funders of Parkinson's research across multiple institutes in Australia. Only through international collaboration will we find a cure for Parkinson's. For more information, visit [www.shakeitup.org.au](http://www.shakeitup.org.au)



## Pilot cohort profile publication

If you filled in the questionnaire in 2020, you were part of our 'pilot' study. In February, we published an article in the scientific journal BMJ Open, describing the general characteristics of the cohort of participants who joined the study pilot in 2020. A few insights into the cohort are listed below:

- 93% of participants completed the online questionnaire, and 7% the paper questionnaire.
- 65% of participants were men, and the mean age of the cohort was 64 years
- A previous traumatic brain injury was reported by 16% of participants and was correlated with a younger age of symptom onset.
- At the time of the questionnaire, constipation (36% of participants), depression (34%), anxiety (17%), melanoma (16%) and diabetes (10%) were the most reported comorbid conditions.
- More than two-thirds of participants (71%) currently drink an average of 8 standard alcoholic drinks per week.
- For current smokers, there was a significant negative relationship between the number of cigarettes/ cigars/pipes smoked daily and the age at onset of the first symptom of PD (Pearson correlation coefficient,  $r=-0.2$ ,  $p=0.03$ ).
- Tremor was the most common first symptom reported by participants, with 54% endorsing it, followed by bradykinesia and muscle rigidity (20%) and gait disorder (10%)



The study publication can be accessed online: <https://bmjopen.bmj.com/content/12/2/e052032>

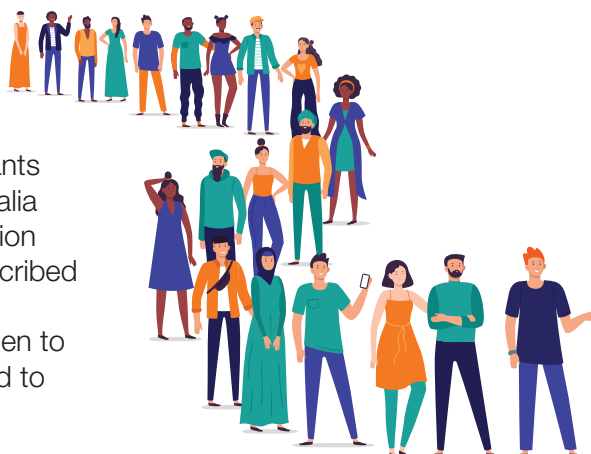


## APGS in the news

With the help of the Shake It Up Australia Foundation, we have undertaken a significant communications campaign to make the Parkinson's community aware of our study. The study has been featured in regional and national news, including Channel 10, 7 News, and 9 News. Thank you to those who volunteered to talk about your experience with the media.

## Ramping up recruitment

Our ultimate recruitment goal for the study is 10,000 participants with a Parkinson's diagnosis. Later in the year, Services Australia will conduct an assisted mailout on our behalf, sending invitation letters to a large sample of people who might have been prescribed medications typically used to treat symptoms of Parkinson's disease. If you are already a participant in the study and happen to receive another invitation, please disregard it. There is no need to complete the questionnaire twice.



## Next steps

We plan to launch a follow-up questionnaire (online and paper-based) later this year. You will receive an invitation and information on how to take part. Your participation in the follow-up is voluntary but extremely valuable. Whether you decide to participate or not in the follow-up does not affect your contribution to the baseline questionnaire.

Many thanks for your participation in the study so far. We look forward to keeping you informed about our work and the results of our research over the coming months.

Sincerely,

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



## Get in touch

You can contact us by email, phone, or mail:



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