Frequently Asked Questions

WHO CAN PARTICIPATE?

Who can participate in the study?

Volunteers must be:

- Male or female
- Any age
- Have been diagnosed with and treated for Parkinson’s disease **OR** do not have Parkinson’s disease and no family history of Parkinson’s disease
- Residing in Australia at the time of participation

Why should I participate?

The ‘Australian Parkinson’s Genetics Study’ is a scientific undertaking aimed at identifying the genetic variants that not only predispose people to Parkinson’s disease (PD), but also determine its symptoms and progression. This knowledge is fundamental step to develop new treatments to slow down or stop the progression, and ultimately find a cure for PD.

Can I participate if I am living overseas?

Unfortunately, at this stage, we are unable to collect DNA samples from people living outside of Australia. However, we are currently looking into options for people living outside Australia who would like to participate further in the research. Alternatively, if you are returning to or visiting Australia in the next 12 months or so, you are welcome to undertake the survey then and we can forward a saliva collection kit to your Australian contact address – just contact us 3-4 weeks before you arrive, and we can see what we can arrange.

Will I get paid for participating?

Participants in the ‘Australian Parkinson’s Genetics Study’ will not be paid. However, Australians who choose to volunteer will be contributing to a national effort to unravel the genetics of Parkinson’s disease and may eventually learn more about their own potential genetic make-up with regard to Parkinson’s.

Your participation is important to enable scientists to understand the molecular mechanisms of the disease, and to eventually develop new treatments.

What is in it for me?

While this study is unlikely to be of any immediate and specific benefit to you, extensive research is required to find answers to the questions we are investigating. Future medical or scientific discoveries may come from the research in which you participate, and, in turn, help improve the available treatments and outcomes for all people with PD. Many participants value the unique contribution that they can make to research.

Due to the specific sample design of the study, we will not be able to provide any individualised analytical feedback to participants about their health condition, biological sample, or DNA. However, researchers will be providing everyone who participates with a newsletter. In this newsletter, we will give you information about the progress and outcomes of this study, as well as that of several other relevant studies. Our research team values the time and effort that you give to research.

HOW TO PARTICIPATE?

Can I read the Participant Information Sheet before I agree to take part?

Yes. A copy of the participant information sheet can be found here: link

What does participation involve?

Volunteers will be asked to:

- Read and understanding an online study information sheet.
- Provide contact information; and
- Indicate their consent for collection of data for current and future study purposes.
- Complete a 25-minute online survey about medical history and your experience living with Parkinson's disease.
- If eligible, provide a saliva sample via traditional post at no cost to them.

What is the content of the questionnaire?

The online questionnaire covers information about diagnosis, symptoms, medical history, family history, lifestyle, and environmental factors. This information will help the researchers understand how genetic information is associated with clinical features in groups of participants.

Can a caregiver or support person assist me answering the questionnaire?

Yes. A caregiver or support person may help you complete the questionnaire if you prefer or feel you are not able.

Can I answer a paper-based questionnaire instead of the online version?

Yes. You can contact us to have a paper questionnaire sent to you by traditional mail. You can request this by calling 1800 257 179, writing an email to pd.genetics@qimrberghofer.edu.au or sending a letter to the following address:

Kerrie McAloney - APGS Project Coordinator
Locked Bag 2000
Royal Brisbane Hospital
Herston, QLD, 4029
AUSTRALIA

Are there any risks?

Researchers acknowledge that being invited into this research study may be a sensitive issue for you and may, therefore, cause you some discomfort. We would like to restate that we currently do not have any information about you.

You may feel that some of the questions we ask in the questionnaire are stressful or upsetting. If you do not wish to answer a question, you can skip it and go to the next question, or you may stop immediately.
If you have any questions or concerns about this research study, you may telephone the Project Coordinator, Kerrie McAloney on 07-3362-0192. You may also use our free call number: 1800-257-179 or email us at pd.genetics@qimrberghofer.edu.au. If you have any concerns or complaints regarding the conduct of this study, you may contact the Chairperson of the QIMR Berghofer Medical Research Institute Human Research Ethics Committee (QIMRB HREC) via the Secretary on Tel: 07-3362-0117 and quote reference number P3711.

What happens after I take the questionnaire?

After completing the study, participants may be asked to donate a saliva sample, from which researchers can extract their DNA to identify specific genes associated with Parkinson's disease, its progression and treatment response. Researchers will send a saliva collection kit together with a pre-paid return envelope to selected participants. QIMR Berghofer will biobank DNA from saliva samples for immediate and future genetic analysis.

Will I be contacted again about this study?

We plan to extend this study and may seek to re-contact some of the participants in the current study.

Choosing to participate in the current study does not mean that you will necessarily be re-contacted. If we do contact you about a follow-up study, you can of course choose not to participate, and it will not affect your participation in the current study in any way.

PROVIDING A SALIVA SAMPLE

Do I have to give a saliva sample?

To participate in this study, you may be asked to provide a saliva sample, as explained in the paragraph above. Providing a sample can be done in your own home.

Where can I get a copy of the saliva sample collection instructions?

Please find instructions on how to provide a saliva sample into the tube here: Link

What if I am having trouble producing a saliva sample?

If you are having trouble producing a sample, please visualise squeezing a half-lemon. Please note that any volume is useful, even with bubbles.
If you are still unable to produce a sample, take a teaspoon of water, vigorously swish it around in your mouth and add that to the tube.

I have provided a saliva sample, but the sample is discoloured

Even if your saliva sample is discoloured in the tube (e.g., lipstick or food scraps or blood), there is still plenty of your DNA in the tube for us to extract and use. Please return it to us and if we need you to provide another sample we will be in contact.

CONFIDENTIALITY AND GENETIC DATA STORAGE

Is the information I give you kept confidential?

Study participation is strictly confidential. All patient information provided will be maintained in accordance with the Commonwealth Privacy Act (1988) and National Health and Medical Research Council (NHMRC) Guidelines.

How will you use the survey, biological and genetic information that I give you?

QIMR Berghofer Medical Research Institute will extract DNA from the saliva samples.
Your personal details, questionnaire data, biological sample and genetic information will all be stored in separate, firewalled password protected databases, and the only link between your personal details and your other data is your participant identification number.
Linking your personal details and the other datasets using this number is restricted to members of the data collection research team. Internal access to these databases and samples are compartmentalized – the data collection team can only access your personal and survey information, analysts can only access your survey information and genetic data,

and laboratory staff can only access your biosample and DNA [the latter two groups only have your ID number]. This compartmentalization protects the confidentiality of participants. When results are published, they are done as aggregated data altogether, so no individual results are included.

Where will my DNA records be stored?

Participant DNA will be stored at QIMR Berghofer Medical Research Institute.

What information will be shared with the GP2 consortium?

Your genetic information and some of your questionnaire information (but not your name or other personal details) will be put into the GP2 international data repository. Information in the database will be available only to researchers from around the world who are approved to study how genes cause Parkinson's disease and a variety of related health conditions. These scientists will not know your name or other personal information we learn about you.

Can I access my genetic data?

This research is not designed to provide any clinical results to participants. The study does not undertake individual analysis of each sample provided, but rather will undertake an overall comparison of genetic markers on all samples provided. If you have a personal interest in obtaining a genetic test on your DNA, we suggest you consider contacting a genetic testing entity which can provide such testing. Your participation is important to enable scientists to understand the molecular mechanisms of the disease, and to eventually develop new treatments.

Will the saliva sample tell you about my ancestry or health?

The analysis we conduct on a participant's saliva sample will not tell us that individual participant's health status, ancestry or predict health outcomes. Researchers are not looking for these particular genes in their analysis; rather they are searching for groups of common genes involved in Parkinson's from a large group of people.

Will I get my results from the study?

We certainly want to feedback as much as possible to participants about the study, so we provide all participants with an update of the project's progress and results via regular newsletters.

Furthermore, when we publish the results from the research, any genes identified in the development, course or treatment of Parkinson's disease will be publicly available in a scientific journal.

Where can I get information/help about living with Parkinson's?

Doctors, Parkinson's Specialist Nurses, Physiotherapists, Occupational Therapists and Speech Pathologists are among those who can provide advice on managing your disease. Many people also benefit from talking to other people who are similarly affected with the disease. Parkinson's Australia's State organisations can put you in contact with other individuals or support groups in your area.

If you are seeking information, resources, or advice on Parkinson's, please contact the Parkinson's organisation in your home State or dial the info line 1800 644 189 and your call will be redirected to your home State office.
For more information, visit: https://www.parkinsons.org.au/find-support

Do I have to disclose my participation to my life insurance company?

In this study you do not need to disclose to Insurers that you have had a genetic test. This is because we are not providing participants any personal or family information from the research. The only results you will receive are those from the scientific papers we publish from the combined genetic analysis of all participants' data. For further information, refer to this summary article discussing insurance and genetic research, as well as Section 10.3 of the Financial Services Council policy on genetic testing and research (fsc.org.au).