



PPMS STUDY

STATEMENT OF INFORMED CONSENT

1. I have read and understood the information sheet about the Primary Progressive Multiple Sclerosis (PPMS) Study, or it has been read to me in full. I understand the purpose of the study, and understand that I am under no obligation to participate in it.
2. The nature of the study has been explained to me. Any questions I have asked have been answered to my satisfaction.
3. I understand that the study has two phases, and that Phase 2 will extend into future years. I understand that I can choose to participate in both Phase 1 and Phase 2, or in Phase 1 only, and that I can withdraw from the study at any time by contacting the Study Officer.
4. Should I develop a problem which I suspect may have resulted from my participation in this project I am aware that I may contact the chief investigator A/Prof Ingrid van der Mei, at the Menzies Institute for Medical Research in Tasmania on (03) 6226 7710.
5. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact: The Secretary, Tasmania Research Ethics Committee, HREC (Tasmania) Network Executive Officer (03) 62267479, human.ethics@utas.edu.au
6. I am willing to complete the study questionnaires.
7. I understand that a person authorised by me (e.g. partner, carer, family member) may assist me in completing the questionnaires and in the phone interview.
8. I am willing to visit a local pathology service to have a venous blood sample (40ml) taken by a medically qualified person, which involves negligible risk beyond that of routine venipuncture. Possible adverse effects of taking blood include bruising, redness or swelling at the site.
9. I understand that my blood sample will be stored and will not, without my consent, be released for uses other than examining markers that may be associated with the onset or progression of MS.
10. I understand that DNA will be extracted from part of my blood sample, and will not, without my consent, be released for uses other than to identify genetic markers that may be associated with the onset and progression of MS.
11. I understand that this study does not have the potential to detect non-paternity or paternity.
12. I understand that all information given by me will be treated as confidential, stored with a numerical identity code and not my name, in a secure location and no identifying information will be released or published.
13. No information will be provided to any third party, including my family members, unless I consent.
14. Participation in this project will not result in any medical costs to me.
15. I agree that research data gathered for the study may be published, provided that I can not be identified as a participant.
16. I understand that, if I wish, the researchers will provide me with a published medical journal article of the research findings.

17. I believe I have been part of a genetic study from the Australian and New Zealand Multiple Sclerosis Genetics Consortium (ANZgene)

- No
- Yes
- Unsure

If **Yes or Unsure**: I give permission to use my genetic data from ANZgene for the PPMS Study

- No
- Yes

18. I agree for the PPMS study to contact my treating neurologist/physician to confirm my diagnosis of PPMS, to provide the estimated date of onset of the disease, the date of diagnosis, and his/her assessment of my disability. The name and contact details for my neurologist/physician are:

Neurologist/Physician name:.....

Neurologist/Physician address:.....

Neurologist/Physician phone number:.....

19. My date of birth is ____/____/____ (dd/mm/yyyy)

After returning this form, we will telephone you to confirm your statement of consent and discuss the study further. Please provide the following contact details:

My preferred phone contact number is: _____

My preferred week day to be contacted:

- No preference
- Mon
- Tue
- Wed
- Other: please specify _____

My preferred time of day to be contacted is: Morning Afternoon Evening

My Name (printed)

My Signature Date/...../.....

Office Use Only

Declaration by PPMS Study Officer: I have given a verbal explanation of the research project, its procedures and risks and I believe that the consent is informed and that the participant has understood the implications of participation.

PPMS Study Officer's Name (printed)

Signature Date/...../.....