

INDEX CASE AND AFFECTED RELATIVES

Informed Consent Form

Version 1.7

22/05/2018

Study: Parkinson's Families Project (PFP)

Chief Investigator: Professor Huw Morris. **Principal Investigator:** Professor Huw Morris

Name:

Address:

DOB:

Hospital:

Hospital Number:

NHS Number:

Phone number (H)

Phone number (M)

Email:

GP:

Main hospital consultant:

Researcher:

Next of kin name:

Relationship to you:

Phone number (H)

Phone number (M)

Please initial boxes if you agree

1. **I have read and understood Version 1.8 (19/10/2018) of the PFP participant information sheet** and been given a copy to keep. I have had the opportunity to ask questions about the project and have had these answered satisfactorily and I understand why the research is being done and any foreseeable risks involved.

2. **I agree to give a sample of blood and/or saliva for research in the above project.** These samples will be used to study inherited material (DNA, RNA).

3. **I give permission for my medical records, including investigations, X-Rays and scans to be looked at confidentially** by members of the medical research team who would not normally be involved with my clinical care.

4. **I understand that I will not benefit financially** if this research leads to the development of new treatments or tests.



5. **I agree that the DNA and blood samples that I have given can be looked after and stored** for use in current and future ethically approved studies by Prof Morris and collaborators, as described in the information sheet.
6. **I agree that my clinical details can be stored in a highly secure clinical research database** and understand that a separate anonymized research database will be used to store research results. **The anonymized DNA and clinical information may be made publicly available both within and outside the European Economic Area, and combined with samples from many other affected and unaffected people to enable large scale analysis.**
7. **I understand that information held and managed by NHS Digital and other central UK NHS bodies** may be used in order to provide information about my health status. To do this, I understand that my name, postcode, date of birth and NHS number will be shared with NHS Digital. I understand that a copy of my consent form and personal details will be held by the main study centre.
8. I consent to the **collection of blood for submission to the European Collection of Cell Cultures (ECACC)**, a British based research resource, to establish an anonymous cell line.
9. I agree to take part in this study. I understand that my participation in research is voluntary and I can withdraw at any time.
- Please indicate
yes or no
YES/NO**
10. **I am happy to be contacted** by telephone or letter by a member of the research team for follow-up of the current research project. YES/NO
11. **I am happy to be contacted** by telephone or letter to obtain more information or about future research projects. YES/NO
12. **I agree that my own doctor (GP and/or hospital)** can be informed of my involvement in this study if they have not already been involved. YES/NO
13. **I agree that my personal data can be shared with NHS Digital** as described above. I understand that if I do not agree to this, my standard NHS care will not be affected. YES/NO
14. **If possible, I would like to be informed of research results** that might indicate that an NHS (or equivalent) test could be developed or used, **related to my condition**, which might help me or my family. YES/NO
15. **If possible, I would like to be contacted** if the genetic results generated from this study indicate that I would be eligible for future research studies about Parkinson's and related disorders. YES/NO
16. **If possible, I would like to be contacted** if the genetic results generated from this study indicate that I would be eligible/suitable for a treatment related to my condition. YES/NO
17. **If possible, I would like to be informed of research results** that might indicate that an NHS (or equivalent) test could be developed or used, **unrelated to my condition**, which might help me or my family. YES/NO

Participant
Name:

Participant
Signature:

Date:

Researcher
Name:

Researcher
Signature:

Date: