



Participant Consent Form

Version 1.1
04/10/2017

Study: Systems Medicine of Mitochondrial and biochemical Parkinson's Disease and other related movement disorders (SysMedPD)

Principle Investigators: Professor Tony Schapira and Professor Huw Morris

Funded by an EU Horizon 2020 grant

Contact: Dr Philip Campbell (Research Fellow). **Tel:** 0207 7940500 x36834

Email: p.campbell@ucl.ac.uk

Principal Investigators: Professor Tony Schapira and Prof Huw Morris

Participant Name:

Address:

Date of Birth:

Email:

Phone number (Home):

Phone number (Mobile):

GP:

GP Clinic:

Main hospital consultant:

Hospital:

Hospital Number:

NHS Number:

Please review the study information sheets carefully. You are free to withdraw from the study at any point without giving a reason. Your present or future care will not be affected should you decide not to participate or to withdraw from the study at any point

Please
initial boxes
if you agree

1. **I have read and understood Version 1.1 (04/10/2017) of the SysMedPD patient information sheet project** and been given a copy to keep. I have had the opportunity to ask questions about the project 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 urine for research in the above project.** These samples will be used to study inherited material (DNA and its related product RNA) and chemistry (blood cells/serum/plasma/urine).

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 agree to have a neurological examination and to complete questionnaires, if possible for this study.
5. **I understand that I will not benefit financially** if this research leads to the development of new treatments or tests.
6. **I agree that the DNA, RNA, blood samples and other samples that I have given can be looked after and stored confidentially** for use in current and future projects by Prof Schapira, Prof Morris and collaborators, as described in the information sheet. If I have had a lumbar puncture test I agree that surplus Cerebro-Spinal-Fluid can be used for future research.
7. I agree that my personal clinical details can be stored in a clinical research database and understand that a separate anonymized research database will be used to store research results. The anonymized DNA, RNA, biochemical and clinical information may be made publicly available to enable large scale collaborative analysis. These data can be used if I lose the capacity to understand or communicate about the project.
8. I understand that information **held and managed by NHS digital (a body of the Department of Health which is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care) 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 and date of birth will be shared with NHS Digital.
9. 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.
10. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
11. I agree to take part in this study.

- | | | Please indicate
yes or no |
|---|--|--------------------------------------|
| 12. | I am happy to be contacted by telephone or letter to obtain more information or about future research projects | YES/NO |
| 13. | I agree to have a videotape examination, in which I am personally identifiable, to be securely stored as part of my clinical assessment and to be reviewed confidentially by another member of the research team. | YES/NO |
| 14. | 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 |
| 15. | 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 |
| 16. | If possible, I would like to be contacted if the results generated from this study (either genetic or biochemical) indicate that I would be eligible for future research studies about Parkinson's and related disorders. | YES/NO |
| 17. | If possible, I would like to be contacted if the results generated from this study (either genetic or biochemical) indicate that I would be eligible/suitable for a treatment related to my condition. | YES/NO |
| 18. | 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 |
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ADDITIONAL OPTIONAL PROCEDURES | | |
| 19. | I agree to donate a skin biopsy for research into neurological diseases. I agree that the skin and fat samples can be looked after and stored for use in current and future projects by Prof Schapira, Prof Morris and collaborators, as described in the information sheet. | YES/NO |
| 20. | I agree that cell lines generated from my skin biopsy can be shared in an anonymously with the StemBANCC biobank. | YES/NO |
| 21. | I agree to have a lumbar puncture test , to provide a spinal fluid sample for neurological disease research | YES/NO |

Participant Name: _____ Participant Signature: _____ Date: _____

Researcher Name: _____ Researcher Signature: _____ Date: _____