



Consent form

Cohort Research On Wilson's Disease: Genetic determinants and biomarker discovery for neurological involvement – The CROWD Study

Chief investigator: Professor Thomas Warner

Please initial in each box and then sign at the bottom of the second page. A witness will need to provide their signature below yours.

1. I confirm that I have read and understood the participant information sheet dated 1/8/2018 (version 1.0) for the CROWD study. If I had any questions, I was able to discuss these with the study team and the questions were answered.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.

3. I understand that the study team may access medical records held by my GP and/or specialist and will inform them of my participation in the study.

4. I understand that information collected about me will be held by University College London and that identifiable information will be destroyed ten years after the study has ended and non-identifiable information will be retained for analysis in future studies.

5. I understand that my saliva sample will be given to the CROWD study as an absolute and non-returnable gift, meaning without conditions and without receiving payment, and will be stored for future studies.

6. I agree to take part in the CROWD study

7. I give permission for non-identifiable information about me or my sample to be shared with other researchers in the UK or abroad. ***If you do not want these to be shared with other researchers, please leave this box empty.***

8. I give permission for my NHS number and the name of my specialist to be shared with the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). ***If you do not want these to be shared with NCARDRS, please leave this box empty.***

9. I give permission for the study team to inform me, through my specialist, if I am accidentally found to have a genetic abnormality known to cause a disease AND for which there are specific treatments or preventative measures. ***If you do not want to be informed about such findings, please leave this box empty.***

10. I give permission to be contacted about participating in other research studies in the future. ***If you do not want to be contacted about other research studies please leave this box empty.***

Name of Participant

Signature

Date

Name of Witness

Signature

Date