UK Histiocytosis Registry

Personal Consultee Declaration Form

Version 1.2 1st March 2022

For staff use only:

|  |  |
| --- | --- |
| **Name of Participant:** |  |
| **Date of Consultation:** |  |
| **Name of Consultee:** |  |
| **Relationship to Participant:** |  |

**NOMINATED CONSULTEE DECLARATION**

**UKHR ID Number:** UKHR \_ \_ \_ \_ \_ \_ \_

**Title of Project:** United Kingdom Histiocytosis Registry (UKHR)

**The consultee should complete the whole of this sheet him or herself.**

(Please write your initials in the following boxes if you agree with the statement)

Please initial here

**CONSULTEE DECLARATION**

|  |  |
| --- | --- |
| 1. I am willing to act as a Nominated Consultee for the proposed participant and I am able to do this because I meet one of the criteria as listed in the Information for Consultees Sheet version 1.1 dated 11.01.22 |  |
| 2. It is my belief that the proposed participant would consent to donating their clinical data and sample(s) to the UK Histiocytosis Registry if they were able. I am not aware of any previously expressed contrary opinion. |  |
| **CONSENT** |  |
| 1. I confirm that I have read and understood the Information for Consultees Sheet and the information sheet for the UK Histiocytosis Registry version 1.2 dated 19.02.19. I have had the opportunity to ask questions and to have these questions answered fully. |  |
| 2. I understand that the inclusion of the patient in the study is voluntary and that I am free to withdraw them at any time, without giving any reason and without this affecting their medical care or legal rights. |  |
| 3. I give permission for responsible individuals conducting the research to have access to the patient’s medical records for the collection of medical information about them. |  |
| 4. I give permission for additional blood and biopsy samples to be taken, stored and used for research and for the patient’s biopsy samples already stored in pathology archives to be used for research. |  |
| 5. I give permission for the patient’s medical information and samples to be sent abroad to International Histiocytosis Registries. This includes digital images of pathology, X-rays, scans and photographs and samples for pathology review. |  |
| 6. I give permission to the UKHR to keep the patient’s medical information and samples for use in future research approved by the Access Committee of the UKHR, without my further consent. |  |
| 7. I give permission to the UKHR to sequence DNA and RNA from the patient’s samples, including whole genome sequencing, for research on histiocytosis. |  |
| 8. I give permission to the UKHR to make ‘stem’ cells and cells that can grow by themselves in the laboratory from the patient’s samples for the purpose of research on histiocytosis. |  |
| 9. I give permission for cells taken from the patient’s samples to be injected into animals for research on histiocytosis. |  |
| 10. I give permission for members of Regulatory Authorities and NHS Trusts to have access to the patient’s medical records for the regulation and audit of research. |  |
| 11. I agree that UKHR may recover the costs of running the registry by charging researchers a fee to access information and samples. |  |
| 12. I agree that the patient’s samples can be used for research in collaboration with a commercial company that has been approved by the Access Committee of the UKHR. |  |
| 13. I understand that the patient will be asked to re-consent to joining UKHR if they regain capacity and may be invited to participate in further research or clinical trials in histiocytosis. |  |
| 14. I agree to the patient taking part in the above study. |  |

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of participant

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Full name of Consultee Date Signature

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Person taking consent Date Signature