UK Histiocytosis Registry

Personal Consultee Declaration Form

Version 1.0 11th January 2022

For staff use only:

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

**PERSONAL 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 Personal 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 my relative/friend 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 my relative/friend’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 my relative/friend’s biopsy samples already stored in pathology archives to be used for research. |  |
| 5. I give permission for my relative/friend’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 my relative/friend’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 my relative/friend’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 my relative/friend’s samples for the purpose of research on histiocytosis. |  |
| 9. I give permission for cells taken from my relative/friend’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 my relative/friend’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 my relative/friend’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 my friend/relative 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 my relative/friend taking part in the above study. |  |

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Name of participant

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Full name of Consultee Date Signature

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Name of Person taking consent Date Signature