**CONSENT FORM ADULT**

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

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

**The participant 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

|  |  |
| --- | --- |
| 1. I confirm that I have read and understood the information sheet version 2.0 dated 04.03.22 and have had the opportunity consider the information and to ask questions. |  |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without this affecting my medical care or legal rights. |  |
| 3. I give permission for responsible individuals conducting the research to have access to my medical records for the collection of medical information about me. |  |
| 4. I give permission for additional blood and biopsy samples to be taken, stored and used for research and for my samples already stored in pathology archives to be used for research  |  |
| 5. I give permission for my 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 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 samples, including whole genome sequencing, for the research on histiocytosis. |  |
| 8. I give permission to the UKHR to make ‘stem’ cells and cell lines that can grow by themselves in the laboratory from my samples for research on histiocytosis. |  |
| 9. I give permission for cells taken from my 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 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 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 am willing to be contacted in the future to be invited to participate in further research or clinical trials in histiocytosis |  |
| 14. I agree to take part in the above project. |  |

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Name of Participant Date Signature

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Name of Person taking consent Date Signature