CONSENT FORM ADULT

UKHR ID Number: UKHR _ _ _ _ _ _ _

Please initial here

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)

1. I confirm that I have read and understood the information sheet version 1.2 dated 19.02.2019 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.	

When completed: 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature