



## CONSENT FORM PARENT OR GUARDIAN

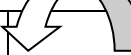
UKHR ID Number: UKHR \_ \_ \_ \_ \_

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

**The parent/guardian 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 dated version 1.2 dated 19.02.19 and have had the opportunity consider the information and to ask questions.	
2. I understand that my child's participation is voluntary and that they are free to withdraw 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 child's medical records for the collection of medical information about my child	
4. I give permission for my child to have additional blood and biopsy samples taken, stored and used for research and for their samples already stored in pathology archives to be used for research.	
5. I give permission to the UKHR to keep my child's medical information and samples for as for use in future research approved by the Access Committee of the UKHR, without my additional consent.	
6. I give permission for my child'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.	
7. I give permission to the UKHR to sequence DNA and RNA from my child's samples, including whole genome sequencing, for 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 child's samples for research on histiocytosis.	
9. I give permission for cells taken from my child'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 child'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 child'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 am willing to be contacted in the future for my child to be invited to participate in further research or clinical trials in histiocytosis	
14. I agree that my child can take part in the above project.	

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



\_\_\_\_\_  
Name of Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature