

## PARENT/GUARDIAN CONSENT FORM

### Generation of Induced Pluripotent Stem (iPS) Cells and Rare Diseases – from blood - V 1.1 02/03/2015

**Please initial box:**

1. I, the undersigned, am the parent or legal guardian of the child named below, and I have the authority to execute this Consent Form on behalf of the child. ☐
2. I confirm that I have read and understand the information leaflet dated   /  /   (version   ) for the 'Generation of Induced Pluripotent Stem (IPS) Cells and Rare Diseases' study, and have had the opportunity to consider the information, ask questions and had them answered satisfactorily. ☐
3. I agree for my child to take part in the study. ☐  
  
More specifically, I understand and agree that:
  4. My child's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason and without his/her medical care or legal rights being affected. ☐
  5. My child's medical notes may be looked at by responsible individuals from their Clinical Care team, the NIHRBR–RD team or regulatory authorities where it is relevant to my child's taking part in the research. I give permission for these individuals to have access to my child's records. ☐
  6. I agree to my child donating a blood sample for the purpose of generating induced Pluripotent Stem (iPS) cells. ☐
  7. I consent to my child giving a saliva and/or urine/hair sample for the study if required. ☐
  8. I understand that my child's identity will remain confidential to the doctors and nurses in his/her Clinical Care team and to authorised members of the NIHRBR–RD team. No data will be released with participant identification attached. ☐

9. I agree that the samples my child has donated, and the information gathered about my child can be stored and shared with other researchers in the UK and overseas for future research studies. ☐
10. I understand that this research will include the participation of commercial companies and that my child will not benefit financially if this research leads to new treatment or medical tests. ☐
11. I agree that the information produced by studying my child's sample, including their entire DNA sequence, may be placed in an electronic archive with no connection to my child's name or other personal identifier. I understand that this archive will only be accessible to researchers who apply to use my child's samples and/or anonymised data to ensure the results are only used to advance scientific and medical understanding. ☐

\_\_\_\_\_  
**Name of participant**

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
**Name of person taking consent**  
(If different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
**Researcher**

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Staff to complete**

**NHS Number**

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**Pedigree/Family number:**

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