

PARENT/GUARDIAN CONSENT FOR CHILD
BioResource for Rare Diseases (Part of NIHR BioResource)

Version 2 17/09/2012

Please initial boxes

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 understood the information leaflet dated 27/4/12 (version 1) for the BioResource for Rare Diseases. I have had the opportunity to consider the information, ask questions and have had these 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. I give my consent to the use of my child's blood, and components from it, for genetic and medical research and for details about him/her and any samples he/she provides to be kept on a secure database.

6. Samples donated by my child and the information provided can be stored for use in future medical research studies aimed at identifying the interactions between genes, the environment and disease.

7. Research may include the participation of commercial companies and that neither I nor my child will benefit financially if this research leads to new treatments or medical tests.

8. In the unlikely event that an abnormality is picked up from tests carried out on my child's sample, I agree to be informed and with my consent his/her clinical care team / GP being notified.

9. I agree for my child to be contacted and invited to participate in medical research studies based on the results obtained from his/her samples and the information provided. Both I and my child will be provided with age appropriate information about these studies, when and if we are contacted. I understand that I am free to decide whether or not my child will take part in these studies.

Optional feedback of genetic test results

10. I give consent for the research team to feedback the results of genetic tests that may be linked to the cause of my child's disease to my extended clinical care team. I agree that the clinical care team can feedback this information to me.

First name and surname of parent (PRINT) Date Signature

Name of Child (BLOCK CAPITALS) Date of Birth Date Signature

Researcher Date Signature