



National Institute for Health Research

PARTICIPANT CONSENT FORM (Parent, adult sibling or other adult relative of patient with Rare Disease)

NIHR BIORESOURCE - RARE DISEASES

Version 1.1 22/09/2014

Please initial boxes

- 1. I confirm that I have read and understood the information leaflet dated ___/___/___ (version_) for NIHR BioResource - Rare Diseases. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.
3. I agree to join the BioResource - Rare Diseases.
4. I agree to give a sample of blood and/or saliva for medical research and for details about me and any samples I provide to be kept on a secure database.
5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from NIHR BioResource -Rare Diseases or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records
6. I agree that the samples I have donated and the information gathered about me can be stored for use in future medical research studies aimed at identifying the interactions between genes, the environment and disease.
7. I understand that this research may include the participation of commercial companies and that I will not benefit financially if this research leads to new treatments or medical tests.
8. In the event that an abnormality is picked up from tests carried out on my sample, I agree that my clinical care team or GP can be notified.
9. I agree that I can be contacted and invited to participate in medical research studies based on the results obtained with the samples and information from me which has been retrieved from databases. I will be provided with full information about these studies, when and if I am contacted. I understand that I am free to decide whether or not to take part in these studies.

Optional Feedback of results

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

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

Name of Researcher (BLOCK CAPITALS) Date Signature

Original to be kept by researcher and copy to be given to participant

