



Centre Number:

Participant Identification Number:

CONSENT FORM (Parent / Guardian)

Title of Project: **Rare diseases of the bone, joint and vessels Study (RUDY)**

Name of Researchers: Dr M K Javaid and Professor R Luqmani
 RUDY Study, Botnar Research Centre, Old Road, Oxford, OX3 7LD

If you agree, please insert the version number and date of the information sheet you have reviewed and please initial each box

1. I confirm that I have read and understand the information sheet for this study. (Version 6; date 16/11/2015). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without their medical care or legal rights being affected.	
3. I agree to my GP being informed of my child's participation in the study	
4. I agree to have my child's routine NHS records made available to researchers as these are relevant for this study.	
5. I agree to have my child's routine social care records made available to researchers as these are relevant for this study.	
6. I agree to provide information on behalf of my child about their events and consequences using my secure personal profile on the RUDY website and for this information to be made available to the RUDY research team.	
7. I agree that my donated samples can be used in genetic research aimed at understanding the genetic basis for rare diseases and that any results that are clinically important as judged by the RUDY Data Oversight Committee will be sent to the clinical team caring for me.	
8. I agree that any tissue removed in the course of medical care related to my child's condition may be used by the researchers. My child and I consider this tissue a gift and we understand we will not gain any direct personal or commercial benefit from this.	
9. I understand that data collected during the study may be looked at by authorized individuals from the University of Oxford, OUH NHS Trust, funding agencies, research governance monitors (where it is relevant to my child taking part in this research) and also by both national and international academic researchers approved by the RUDY Data Access Committee that contribute to the aims and objectives of RUDY.. I permit these individuals access to my child's research records.	
10. I agree that the data that is collected about my child during the study may be looked at by both national and international industry researchers approved by the RUDY Data Access Committee that contribute to the aims and objectives of the study. I permit these individuals access to my child's data.	
13. I agree that my child's anonymised samples / data can be deposited in research tissue banks where they can be used by other researchers, in both public and private sectors in the UK and internationally.	
14. I agree for my child's data to be linked with the data from other research studies I have consented to using my child's NHS number, date of birth, surname and forename.	
15. I agree for my child's data to be linked to their relations whom I have indicated on their family history map using forename, surname and date of birth.	

16. I agree to be sent reminders about completing questionnaires and providing follow up information by letter, telephone, text message, or e-mail. (please delete)	
17. I agree to be contacted about future ethically approved research studies for which my child may be eligible via letter, telephone, text message or email (please delete. I understand that agreeing to be contacted does not oblige my child to participate in any further studies.	
18. I would like to be sent updates on the progress of the study via the website, email, letter (please delete), whenever available, monthly, quarterly, annually (please delete).	

Name of participant

Name of parent / guardian

Date

Signature

For completion by person taking consent:

Name of Person
Taking consent.

Date

Signature