

Centre Number:

Study Number:

Patient Identification Number for this trial:

**CONSENT FORM (Parent / Guardian)**

Title of Project: **Rare and Undiagnosed Diseases Study (RUDY)**

Name of Researcher: Dr M K Javaid  
 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 ...; date .....). 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 child's GP/ Clinician being contacted and being asked to share information about my child's medical history and give access to any other medical records as required.	
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 child's donated samples can be used in genetic research aimed at understanding the genetic basis for rare diseases	
8. I agree that any tissue removed in the course of medical care may be used by the researchers..	
9. My child and I consider this tissue a gift and we understand we will not gain any direct personal or commercial benefit from this	
10. I understand that relevant sections of my child's medical notes (if applicable) and data collected during the study may be looked at by authorized individuals from the University of Oxford, from regulatory authorities and NHS trusts where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child's records.	
11. I agree that the anonymized 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.	
12. I agree that the anonymised data that is collected about my child during the study may be looked at 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.	
13. 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.	
14. 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.	

PLEASE INITIAL NEXT TO EITHER A, B OR C TO INDICATE YOUR PREFERENCE		
15. In the event of my child's death, I want: a) all my child's data and tissue samples to be destroyed and made unavailable for any future research b) my child's data to be made available for any future research approved by the Rudy Data Access Committee but any tissues samples be destroyed.  c) all my child's data and tissue samples to be available for any future research approved by the Rudy Data Access Committee		
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 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).		
18 I agree for my child to take part in this study		

Addition:	YES	NO
PLEASE INITIAL IN THE BOX UNDER EITHER YES OR NO		
19. I agree to be approached in order to consider for my child to take part in sub-studies.		
20. I agree to be contacted about ethically approved research studies for which my child may be eligible via letter, telephone, text message, or e-mail (please delete). I understand that agreeing to be contacted does not oblige my child to participate in any further studies		
21. I agree for my child's anonymised samples to be used in future research, here or abroad, which has ethics approval. I understand this research may involve commercial organisations.		

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

\_\_\_\_\_  
 Name of parent / guardian

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

*For completion by person taking consent: (if consent is not completed online)*

\_\_\_\_\_  
 Name of Person

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

Taking consent.

*1 copy for participant; 1 copy for researcher site file; 1 (original) to be kept in medical notes  
(if participant is a patient).*