Oxford University Hospitals NHS
NHS Foundation Trust

RUDY
Uniting Patients and Researchers to Investigate Rare Diseases

UNIVERSITY OF OXFORD

Centre Number:

Study Number:

Patient Identification Number for this trial:

ADULT CONSENT FORM

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 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 participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3.	I agree to my GP/ Clinician being contacted and being asked to share information about my medical history and give access to any other medical records as required.	
4.	I agree to provide information about my events and their consequences using my secure personal profile on the RUDY website and for this information to be made available to the RUDY research team.	
5.	I agree that my NHS records and or social care records can be made available to researchers	
6.	I agree that my donated samples can be used in genetic research aimed at understanding the genetic basis for rare diseases.	
7.	I give permission for my GP/ clinician to be informed via the Rudy Data Oversight Committee if I am found to be affected / or have carrier status.	
8.	I agree that any tissue removed in the course of medical care may be used by the researchers.	
9.	I consider this tissue a gift and I understand I will not gain any direct personal or commercial benefit from this.	
10.	I understand that relevant sections of my medical notes (if applicable) and data collected during the study may be looked at by individuals from University of Oxford, from regulatory authorities and NHS Trusts, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
11.	I agree that the anonymised data that is collected about me 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 research records.	
12.	I agree that the anonymised data that is collected about me 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 Rudy. I permit these individuals access to my research records.	
13.	I agree for my data to be linked with the data from other research studies by using my NHS	

number, date of birth, surname and forename.	
14. I agree for my data to be linked to my relations whom I have indicated on my 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 death, I want: a) all my data and tissue samples to be destroyed and made unavailable for any future research b) my 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 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 to take part in this study	

Addition: PLEASE INITIAL IN THE BOX UNDER EITHER YES OR NO	YES	NO
19. I agree to be approached to take part in sub-studies.		
20. I agree to be contacted about ethically approved research studies that I may be eligible for by letter, telephone, text message, or e-mail (please delete). I understand that agreeing to be contacted does not oblige me to participate in any further studies		
21. I agree for my 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	Date	Signature

If not consenting online the person taking consent should complete the following:

Name of Person Taking consent.	Date	Signature

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