The Botnar Research Centre
Oxford NIHR Musculoskeletal Biomedical Research Unit
The University of Oxford
Nuffield Orthopaedic Centre, Headington, Oxford, OX3 7LD, United Kingdom
Study telephone number: 07775541615

Information for Children: To be read and discussed with children aged 11-15 years

Rare diseases of the bone, joint and vessels Study (RUDY)

The RUDY study received a favourable ethical opinion from the South Central – Berkshire B REC

We would like to ask you to take part in a research study. Before you decide, it is important for you to understand what the study is about and what will happen to you if you take part. Please read this leaflet carefully and ask us about anything that you do not understand.

What is the study for?

This study is trying to improve the understanding of rare diseases affecting the bones, joints or blood vessels. We are working with doctors and researchers from all over the United Kingdom who are helping us gather information and samples from their patients who have these conditions and their blood relatives. The results of all this work may help us to understand these rare diseases and give better tests and treatments to children with these diseases in future.

Why have I been chosen to take part?

You are under 16 years old, you have a rare disease of the bones, joints and/or blood vessels or are a relative of someone who has.

What will happen to my data?

The information we collect about you will be labelled only with your study number. Your name will be stored separately and safely. Only the nurse and doctor will know who you are.

What will happen if I take part?

We will ask you to tell us how you feel by asking you to fill out some questionnaires and an online diary. You can do this on the RUDY website. We will also ask your doctors what treatments you have had and, if you agree, we would like to link your data with that of any of your relatives who have registered to take part. Your relatives will not be able to see your information and you will not be able to see theirs. With your permission we would also like to link your data to any other studies you have agreed to take part in

Do I have to take part? You do not have to take part if you do not want to.
The research may not help you, but we hope the information learned from the study will help other children with rare diseases in the future. You can change your mind about taking part at any time without saying why. If you withdraw from the study it will not affect any treatment you might need in the future.

What happens afterwards?
The study results will be made available for you to read on the RUDY internet website. We will send you a newsletter update every year.
We would also like your permission to ask you to take part in future studies.

If you have any questions, you can contact us at any time. Email Dr. MK Javaid at Kassim.javaid@ndorms.ox.ac.uk or call 01865 07775541615.

Thank you for reading this information leaflet.