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Rare and Undiagnosed Diseases Study (RUDY)

To be read and discussed with children aged 6-10 years

We would like to invite you to take part in a research study called RUDY.

The RUDY study is trying to improve the understanding of rare diseases.

Why Me?

You have been chosen because you have a rare disease or because you have a family member who has a rare disease. We want to understand how your condition has affected you or your family member. Your information could help us treat children who have similar conditions to you or your family member.

What will happen if I take part?

We will ask you to tell us how you feel. We will ask you and your parent or the person who looks after you to answer questions and keep a diary of what life is like for you. We will also ask your doctors what treatments you have had, if you have had any. We will put your medical information in a database.

What happens to what the researchers find out?

Any information about you which leaves the hospital or database will not have your name in it.

We will send you a newsletter every year to tell you what we have found.

How do I join?

You should talk to your parents or the person who looks after you about the project. It's your choice if you want to join and you can change your mind whenever you like. You must have permission from your parents or the person who looks after you if you want to take part.

What else happens?

If we start a new study we might ask you if you want to take part in it.

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

Thank you for reading this information leaflet.