We would like to ask for your help with our project.
We know that you have a rare disease or you have someone in your family who has a rare disease.

Very few children have one of these rare conditions.
We want to learn more about what life is like for you.

Then we will be able to help other children who have it.
We would like to ask you and your mummy and daddy some questions on the computer.

If you don't want to do this - just say no thank you!

If you have any questions you can ask your Mum, Dad or the person who looks after you or one of the people taking care of you at the hospital.

Thank you for reading this.