



GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

Information for Children (8 – 16 years)

UNICORNS

Uveitis in childhood prospective national cohort study

You are invited to take part in this research study

1. What is the aim of the study?



We want to collect information about children with uveitis in the UK so that we can better understand the disease.

2. Why is the study being done?



There are still some unanswered questions about why children get uveitis and why some children with uveitis are more severely affected than others. We want to answer those questions.

3. Why are we being asked to take part?

We are asking you to take part because we would like to include all children and young people who develop uveitis.

4. What will happen if we decide to take part?

If you agree to take part, we would like you and your parents to complete the attached consent forms to let us know. You can use the freepost envelopes provided to post the forms back. If we haven't heard from you by 4 weeks from now, we will write to you to remind you about the study.

You will be asked to complete some questionnaires about how you feel. We would like you to do this when you join the study, and then do it again every year that you are part of the study.

We will ask your eye team at {HOSPITAL} to share information with us, and we will collect data about you from any other hospitals which look after you from now on.

All the information provided to us will be treated in strict confidence by the research team. Other than your doctor and the research team, no-one else is allowed to have access to data which could identify you. We may share grouped data with researchers across the world if we think that this will help unlock the secrets of uveitis.

We will also ask you if it is ok to come back to you later on and ask you are able to help us with our other studies about uveitis

Your treatment will not be changed in any way by being involved in the study.

5. Do I have to take part?



No! It is entirely up to you. If you do decide to take part:

- You will be asked to sign a form to say that you agree to take part (an assent form)
- You will be given this information sheet and a copy of your signed form to keep.
- Your parent will be asked to sign a consent form to give us permission to involve you in this study.

You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive whilst in hospital.

6. Will taking part help me?



This study is unlikely to help you right now. However, it will help to provide information about improving treatment which will be valuable to doctors and children undergoing treatment in the future.

7. Will anyone else know I'm doing this?

The people in our research team will know you are taking part. The doctors looking after you while you are in hospital will also know. If you agree we will also tell your family doctor (GP) that you are doing the study.

All information that is collected about you during the research will be kept strictly confidential.

8. What happens when the research study stops?

When the study stops, we will share the results of the study with you, and ask if you have any questions for us.

We will talk about the research with other people. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it.

Once the study is complete, all the information will be kept for 10 years. Then it will be reviewed to decide if it is appropriate to delete it.

9. Who is organising and funding the research?

The study is organised by Lola Solebo, and funded by the National Institute of Health Research.

10. Who has checked the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. It has also been checked by the Research Department at this hospital.

11. What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You and your mum, dad or carer can contact the project co-ordinator, **Lola**:

Dr Lola Solebo (Study Chief Investigator, NIHR Clinician Scientist and Consultant), UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH, Tel: 020 7905 2250, Email: a.solebo@ucl.ac.uk

Thank you for taking the time to read this – please ask any questions if you need to.