Parent/Guardian Information sheet
CHOIR – Childhood Ocular Inflammatory Disease Research tissue biobank
Name of PI: Ameenat Lola Solebo

Introduction.

You and your child are being invited to donate their samples to the CHOIR (Childhood Ocular Inflammatory Disease Research tissue biobank) because your child has an inflammatory eye disease.

Before you decide whether to take part, it is important that you understand why the samples are being collected, a

Benefits of taking part

There may be no immediate benefit to your child from donating samples, but our research will help us and doctors to understand more about eye inflammation which will help the development of new treatments and help more children with this condition in the future. We are not able to feedback any information from any tests taken as part of this research to individual participants.

Potential disadvantages and risks of taking part

No significant physical risk can be foreseen. Any samples will be taken at the same time as routine clinical tests. The discomfort of having samples taken will be no more than that incurred by having tests for medical care.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and granted a favourable opinion by London-City & East Research Ethics Committee

Some people are worried about being identified as being part of research. The chance is very small and we will do everything we can to prevent this happening by anonymising samples in the study.

Who will have access to my chi hi h

Will information from the genetic testing be returned to us?

The importance or implications of those research findings may not be known for some time. It is very important to realize that those results are research findings and not a clinical test.

Your child’s data may be stored in an open access database.
Samples may be sent to external laboratories for analysis. Only approved laboratories and researchers will analyse your samples. Samples may be kept as there may be new ways to of doing testing in the future and the results will be held in a secure database.

When this testing occurs coded data may be placed in international archives of data from people with different types of inflammatory disease. This data will be completely unconnected to your child’s name or other identifiable data and stored for an indefinite period of time. Access to this anonymised information will only be given to bona fide researchers around the world who will use the information for good scientific reasons and if you agree. Access to the anonymised information stored in this archive will only be accepted via applications from appropriately qualified researchers who sign a legally-binding Data Access Agreement in which they commit to:

a) Use the data only for research purposes;
b) Protect the data confidentiality;
c) Provide appropriate data security;
d) Not attempt to identify individual participants from whom data were obtained;
e) Not redistribute the data or any subset or derivative that could be used to identify the research participant.

For the anonymous genetic information data to be useful to the research community, some information about your child and their medical problem/treatment such as age, sex, medical condition will be linked to this. There is a remote possibility that your child could be identified by looking at genetic information, but only if this information is matched to other genetic data held in databases which also store personal, identifiable data. We regard this event as extremely unlikely,

Are there any arrangements for compensation?
No special compensation arrangements have been made for this project.

In the event of any harm occurring to you due to participation in the study, normal University Clinical Trials Liability compensation arrangements apply.

Will we be contacted again?
If you agree to take part on behalf of your child, when they are old enough and able to give consent themselves we will be asking them to agree on their own behalf for permission to collect samples. At that time they will make their own decision.
In the future we may contact you or your child to take part in future research. It is up to you and child if wish to take part in these studies. We may also contact you to update you on the results of research from their samples

What if we have questions or worries?
If you or your child have a concern about any aspect of sample.s:1 Tf(3)-(e)14(se/.a)4(c)-5(ted)7(a)18

We and the research sponsor, UCL, will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your child’s name or contact details. Your data will have a code number instead. Some of your child’s