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Study of Blood Diseases

Young donor information sheet (aged 11 to 15)

We are asking you whether you would like to take part in a research project to see whether we can find out how and why young people like yourself become ill because of problems with their blood.

The study is organised by the doctors and scientists in the blood department here at Addenbrooke's Hospital in Cambridge. Before you decide, it is important for you to understand why the research is being done and what it will involve for you. Please consider this leaflet carefully and talk about it with family, friends, nurses or doctors if you want to. Please ask us if there is anything that you don't understand.

Why are we doing this research?

We are studying the causes of illness and disease in the blood and bone marrow. This will hopefully allow us to make better tests for the diseases as well as better treatments in the future. You have been offered an invitation to take part as you have one of these blood diseases.

Deciding whether to take part in the study

It is up to you and your parents / guardians to decide if you want to join the study. If you do decide to take part you will be given this information sheet to keep. Your parents / guardians will be given their own sheets to read, and they will be asked to sign a form giving us permission to continue with the study. If you decide to take part you can still stop the study at any time and without giving a reason. If you do or don't go in the study it will not effect your treatment in any way.

What you will be asked to do?

Children who enter our study will be asked to give us a small amount of blood, hair and mouth-swab. We would take the blood when you are normally giving some as part of your normal treatment, so we wouldn't need extra samples. Taking a tiny piece of hair and mouth swabs is very quick and doesn't hurt. We would also like to use any of your blood that is left over in the laboratory after your normal tests have been done. This would normally be thrown in the bin, but for us it is useful to do research with.

You would not have any other extra tests with this study, and the study will not effect your medicines and treatment in any way.

Will anyone else know I'm doing this study?

We will keep your information in confidence. This means that we will only tell those people who have a right or need to know. We make sure that we take your name and address off any samples and replace them with a code. This means we can look at the code and work out who the samples came from, but other people could not.

Study organisers

Professor A.R. Green is the Lead Researcher for this study. All samples and information will be sent to Professor Green's group. Professor Green would be happy to explain anything concerning the research. He can be contacted by telephone on 01223-596279

Thank you for reading this information sheet.