



Participant Information Leaflet to be read with children 6 - 10 years

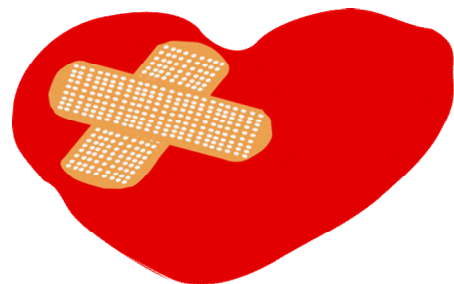
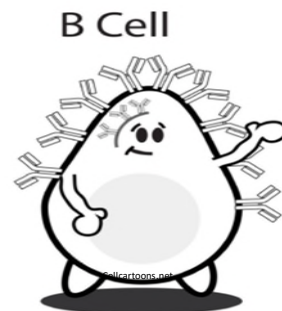
**What is a research study?**

A research study is the way we try to find out answers to questions.



**Why is this study being done?**

After a transplant, some children can become poorly with an illness called post-transplant lymphoproliferative disease (PTLD). This happens when cells in the blood called "B" cells become infected with a bug called Epstein-Barr Virus (EBV). This only happens in a tiny number of children with transplants but is more likely to happen in those who have a new heart. We want to look at how well the cells in the blood of young children with a transplant are able to fight off EBV infection. We also want to look at how well these cells can either protect children from getting PTLD or make them more likely to get it.



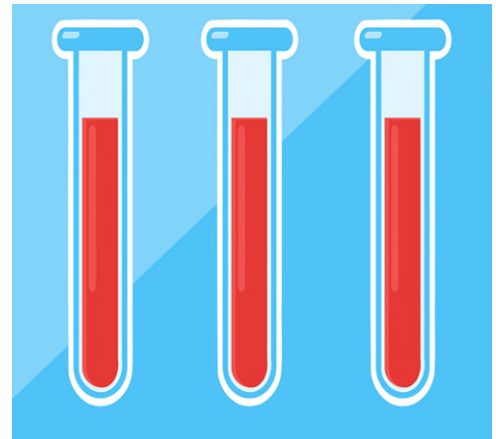
### Why me?

We are asking children around the country, who like you, have recently had or are about to have a transplant. We would like to include 40 children with transplants in the study.



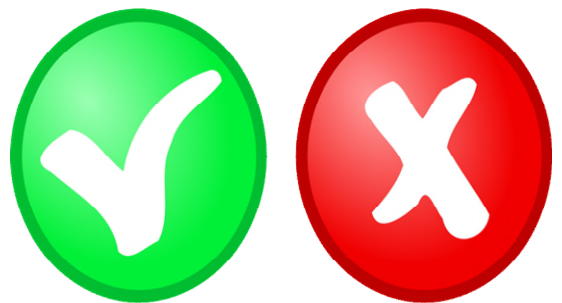
### What will happen to me if I join the study?

We would like to take a small amount of extra blood samples during your other blood tests. We would like to do this just before your transplant and at some of your visits to see the doctors and nurses in clinic with your mum/dad/carer. We will also collect some information about you from your doctors and nurses while you are in the study.



### Do I have to say yes?

No, not at all. It is up to you!  
Just say no if you don't want to join. Nobody will mind. If you join but then change your mind later, that's ok as well. It won't change the way the doctors and nurses will look after you.



### Will taking part in the study help me?

No, it won't help you right now. But it will help us learn more about PTLT and how to prevent other children from getting it in the future.



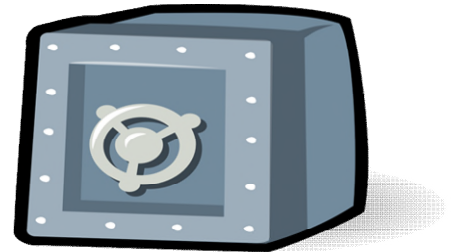
**Will anyone else know that I am taking part in the study?**

We will keep anything we find out about you private. We will only tell your parents and the doctors looking after you. The people who are responsible for checking that the study is done properly may also ask to look at information about you. You will be given a special study number so that we don't have to use your name in the study.



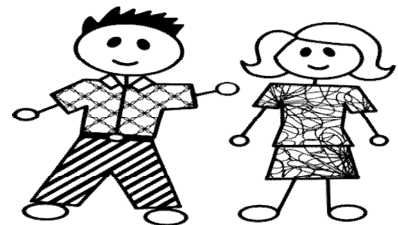
**What will happen to the blood samples I give?**

We will do some extra tests on the blood samples you give us. If you agree, we will store any of your leftover blood in a safe place so that we can use this for other research in the future.



**What if something goes wrong?**

Just in case there is a problem, we will work with you and your parents to help make it better.



If you have any questions or would like to know more about this study, you can contact us at any time.

Email Dr Simon Bomken and Dr Ugo Offor at [nuth.ithaca@nhs.net](mailto:nuth.ithaca@nhs.net) or call +44 (0) 191 2824068.



**THANK YOU** for taking the time to read this information sheet!