

(To be printed on institutional headed paper)

**Children's Cancer and Leukaemia Group
Tissue Bank (2008 BS 01)
Storing and using blood, bone marrow and tumour samples for
research**

INFORMATION SHEET FOR CHILDREN AGED 8 - 12 YEARS

(Version 3.0, 6th April 2011)

1. Introduction

We would like to ask you if we can keep small samples of your blood, bone marrow and tumour lump (if you have one) to store in a Tissue or Leukaemia Bank, to help with research. It's important that you understand and are happy to let us store and use your samples. You can say no if you want to. If you have any worries or would like to ask any questions, you can ask your doctor or nurse.

2. What is research?

Research is done in order to find out more about something. Your teacher might ask you to do research for a school project. This usually means looking things up in books or on the internet. Medical research on illnesses such as cancer and leukaemia means doing special tests in a laboratory on blood and tumour samples to find out new things.

3. Why is the Tissue and Leukaemia Bank needed?

Doctors and scientists need to do research on small samples from lots of children who have had cancer or leukaemia in the past. This will help us to understand why children like yourself become ill in the first place and help find ways to improve treatment. To make sure we have enough samples to do the research, children and young people with tumour lumps or leukaemia are being asked to consent (give permission) for small samples of their blood, bone marrow/or tumour lump to be kept for research. These samples could be stored for many years and may be used in research done either here at **(local centre name)** or at other hospitals.

4. What will happen if I say 'Yes'?

We are asking you to say 'Yes' or 'No' to the question:

"Can we keep some of your blood and bone marrow/or tumour lump (if you have one) for scientists to do research?"

The samples will mostly be little pieces of tissue left over from when you have operations or biopsies, when the doctors looking after you have finished with them. The only time we would need something extra is when we need an extra blood sample but this sample would be taken at the same time as your treatment so you would not have to have an extra needle or anything else.

5. Do I have to say 'Yes'?

No you don't. It's up to you to decide if you want to give some of your blood, bone marrow and/or tumour lump for research. If you say yes now but change your mind when you're older, just tell your mum or dad or your doctor. Any samples left will be disposed of, usually by burning them. (If you're still under 18 years old at that time, your parents will need to agree).

6. Will it do some good if I say 'Yes'?

We hope the research that can be done using your samples will help us improve treatments for children like yourself in the future.

7. What will happen if I say 'No'?

If you decide to say no, nobody will mind and your treatment will still be the same.

8. What shall I do now?

Take some time to think about whether or not you want to give your samples for research. It would be a good idea to talk with your mum or dad or anyone else you would like to ask, before you decide. Your doctors and nurses would be happy to answer any questions you may have. If you do decide to say 'Yes', you'll be asked to sign a special form. Your mum or dad will also need to sign this form.

My Doctor is:

Telephone Number:

My Nurse is:

Telephone Number: