

(To be printed on institutional headed paper)

**The Children's Cancer and Leukaemia Group
Tissue Bank (2008 BS 01)**
**Summary information sheet for patients on consenting to storage
and use of tissue samples for research**
(Version 1.0, 6th April 2011)

The Children's Cancer and Leukaemia Group (CCLG) is an organisation where doctors, nurses, researchers and patients in the UK and Ireland work together to improve the treatment of children with cancer and leukaemia.

In order to improve diagnosis, treatment, and prevention of childhood cancer and leukaemia, researchers need to be able to study cancer cells in small samples of tumour, bone marrow and blood. The CCLG runs a national Tissue Bank where samples of children's cancers and leukaemias are stored for research.

We are asking you to help with this vital research by giving permission for samples from your tumour or leukaemia to be stored in the bank and used for research, both now and in the future. Samples stored in the bank are small, usually no bigger than a sugar lump for pieces of tumour, or a teaspoon or two of blood or bone marrow.

The CCLG Tissue and Leukaemia Bank does not obtain any samples of tumour or leukaemia just for research. Any samples that are stored in the Bank are those that are "left over" from operations, biopsies or other procedures, after the doctors caring for you have done everything they need to do with the samples. This means you will not have anything extra done to you on top of your normal treatment unless we ask you separately about this.

Under the Human Tissue Act 2004, children and young people who are "competent" may consent to storage and use of tissue for research, regardless of their age. A parent may give consent if this is what the child prefers or if there is doubt about whether the child understands enough to give consent. In most cases we will ask parents of children below the age of 18 to consent as well as asking children and young people themselves (if "competent") to consent.

1. If you sign the consent form, you are agreeing that the tissue samples can be stored and used in research projects. Samples will only be used in scientifically and ethically approved studies.
2. You are under no obligation to consent for storage and use of tissue samples in the CCLG Tissue and Leukaemia Bank. If you prefer not to consent, this will not affect the care given to you in any way. Whether or not you decide to give consent, you will still receive the best available treatment.
3. You can withdraw consent at any time without having to give a reason. Your samples will then be removed from the Bank. Withdrawing consent will not affect the care given to you in any way.

4. Doctors are not asked to obtain extra material for the CCLG Tissue and Leukaemia Bank when they are carrying out procedures. Most tissue samples stored in the Bank are those “left over” after procedures carried out to diagnose or treat your illness, when there is no further need for the samples for clinical purposes. If extra samples are requested, you would be asked to consent for that separately. Consenting to banking covers storage and use of the samples only.
5. Tissue samples may be stored either at the hospital where you are being treated or at a national storage centre. The samples are stored securely.
6. To maintain anonymity, the samples are given a code. Researchers who use the samples will not know your name or any other identifiable details. Information such as your diagnosis and treatment is kept so it can be matched up with the tissue, but only in anonymised form. The link between this code and information about your diagnosis and treatment is kept secret, in accordance with the Data Protection Act.
7. In line with normal practice, individual results of research on your samples will not be given to you or your doctors. However, general results of research on tissue samples will be published regularly in CCLG newsletters and/or elsewhere.
8. Your samples could be used in more than one research project, but you will be asked to consent once only for storage and use of the samples for research.
9. Although samples are mostly used by university-based researchers, it is possible that the samples might be used in research by commercial organisations or in commercially-sponsored research, subject to scientific and ethical approval.
10. You would not receive money from any discoveries made from research on your tissue samples.

We hope that research using samples from the CCLG Tissue and Leukaemia Bank will help to improve treatment for children with cancer in the future.

Thank you for taking the time to read this sheet.