What is CCLG?

The Children’s Cancer and Leukaemia Group (CCLG) is a group based in Leicester which is working to improve prevention, diagnosis, and treatment of tumours in children and young people.

The purpose of this leaflet is to invite you to consider giving tissue samples that may be left over following some of the procedures you have had to diagnose and treat your tumour.

www.cclg.org.uk/tissue-bank
Why do we need your help?
A lot of research into understanding and treating tumours uses tumour cells as well as normal tissue (such as bone marrow and blood). To help this type of research the CCLG works with a team based in Newcastle who store and release samples for research. (The Bank is funded by Cancer Research UK.) We are asking for your permission to store a small tissue sample (e.g. grape size amount of tumour or 1-2 teaspoons of blood and/or bone marrow) to use in future research.

Will I need extra tests?
No. During procedures to help with your diagnosis and treatment you will have tissue samples taken. Only samples ‘left over’ after these tests, which the doctors no longer need, will be stored with your consent, in the Tissue Bank. Blood samples can be taken, with your permission during routine blood tests. DNA (genetic material) will be separated from blood samples and stored for research only, which may include genetic tests.

Do I have to take part?
No. Donating tissue is entirely up to you, we are very grateful to patients who give their consent for us to store and use their samples. Giving or refusing consent for the collection and storage of tissue for future research will not affect the care or treatment you receive in any way.

What will happen if I say yes?
One of your doctors or nurses will ask you to sign a consent form. You may want your Mum or Dad to help you with this, or if you prefer they can sign it for you.
Your tissue samples will be transferred and stored in the CCLG Tissue Bank in Newcastle. All researchers wanting to use these samples must apply to a special committee. No tissue samples will be released to them without permission from one of these committees. Research may be carried out at your hospital, at another hospital or university in this county or another country, or by private scientific companies.

**What information is stored and used?**
We give your tissue samples a unique identifying code and we store the information given in very safe databases at CCLG and in Newcastle. We also collect facts relating to your medical records, i.e. diagnosis, treatment and progress, and we would obtain facts that are held by other sources like Disease Registries. Researchers usually need this information to make best use of the samples. However, we always ensure that they do not know your name or personal details.

**What are the advantages of taking part?**
The research will not help you directly. Your doctor would be told if any information that may affect your future treatment and care is found as a result of the research. We hope that the results that researchers get from the tissue samples will help improve the diagnosis and treatment of patients with a similar tumour to you in the future.

**What happens if I change my mind?**
You can change your mind at any time in the future. Any tissue samples that remain will be removed and destroyed, and details about you will be removed from the database. It will not be possible to erase data from research that has already used the tissue samples, however, this data cannot be associated with a particular person. If you do change your mind please let your doctor know or contact the CCLG via the details at the end of this leaflet.
If you have any questions or worries about the information in this leaflet or anything else please speak to one of your nurses or doctors, or contact the CCLG Tissue Bank at:
www.cclg.org.uk/tissue-bank or email: cclgtissuebank@le.ac.uk

Thank you for reading this leaflet