What is CCLG?

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

The purpose of this leaflet is to invite you to consider donating tissue that may be left over following surgical procedures used to diagnose and treat your child’s 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 coordinates a national Tissue Bank (based in Newcastle) for storage and release of samples for research. (The Bank is funded by Cancer Research UK.) We are asking for your permission to store and use tissue samples from your child in future research. These samples are no larger than a small grape size for tumour and 1-2 teaspoons of blood and/or bone marrow.

Will my child need extra tests?
No. During procedures to help establish your child’s diagnosis and treatment they will have tissue samples taken. Only samples ‘left over’ after these tests, which the doctors no longer require will be stored, with your consent, in the Tissue Bank in Newcastle. 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 purposes only, which may include genetic tests.

Does my child have to take part?
No. Donating tissue is entirely voluntary, we are very grateful to families who give 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 your child receives in any way.

What will happen if I say yes?
A member of your child’s medical team will ask you to sign a consent form. Your child’s tissue samples (surplus to local requirement) will be transferred and stored in the CCLG Tissue Bank in Newcastle. All researchers requesting samples must have their research subjected to scientific approval by a special independent committee, or local ethical approval. No access to tissue samples will be allowed without permission from one of these committees. Research may be carried out locally, in the UK or abroad, by universities or commercial organisations.
What information is stored and used?
We allocate your child’s tissue a unique identifying code and we store this information within secure databases at CCLG and in Newcastle. We also collect data relating to your child’s medical records, i.e. diagnosis, treatment and progress, and information held by other sources such as Disease Registries. Researchers usually need this information to make best use of the samples. However, we always ensure that they have no access to your child’s name or personal details.

What are the advantages of taking part?
While it is unlikely that the research will help your child directly, your doctor would be notified if any information that may affect your child’s future treatment and care becomes available as a result of the research. We hope that the results which researchers obtain from the tissue samples will help improve the diagnosis and treatment of patients with a similar condition in the future. On rare occasions research may suggest that further tests will help with your clinical care. In this unlikely event, CCLG will discuss the result with the doctor in charge of your treatment. Samples from the Tissue Bank may also be used to invent new treatments or tests for tumours which could be patented. However you and your child will not be able to receive any money from these discoveries.

Consent
It is important that you discuss this with your child and if they are able to understand, they too can give consent for tissue samples to be stored and used for research. If your child is too young to consent at the moment, then you must inform them, when they are old enough to understand, that you have consented to this on their behalf.

What happens if you change your mind?
You, or your child can change your mind at any time. Any tissue samples that remain will be disposed of, and details about your child will be deleted from the database. It will not be possible to erase data generated by studies that have already used the tissue samples, however this data cannot be associated with a particular person. If you, or your child 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