Parent/Guardian Information Leaflet
For the post mortem collection and storage of tissue for research

www.cclg.org.uk/tissue-bank

We are very sorry to hear that your child has died and offer you our condolences. We understand that you have consented to a post mortem examination on your child, and have also expressed an interest in research. We would be very grateful if you could take the time to read the following information and decide whether you would like to consent for your child’s tissue to be stored in the Children’s Cancer and Leukaemia Group (CCLG) Tissue Bank.

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 cancer in children and young people. The purpose of this leaflet is to invite you to consider donating some of your child’s tissue samples for research.

Why do we need your help?
A lot of research into understanding and treating cancer uses cancer 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 small pieces of tissue samples from your child for future research. This may include the genetic analysis/study of tissue for research.

Do I have to consent to use of tissue samples?
No. Donating tissue is entirely voluntary, we are very grateful to families who give consent for us to store and use samples.
What will happen if I say yes?
A member of your child’s medical team will ask you to sign a post mortem 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 and treatment, 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?
We hope that the results that researchers obtain from the tissue samples will help improve the diagnosis and treatment of children with a similar condition in the future. On rare occasions research may suggest an inherited abnormality that could affect other family members. In this unlikely event, the CCLG will pass the results onto your child’s doctor. Samples from the Tissue Bank may also be used to invent new treatments or tests for cancer which could be patented. However you will not be able to receive any money from these discoveries.

What happens if I change my mind?
You can change your mind at any time. Any tissue samples that remain will be lawfully and respectfully 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 do change your mind please let your doctor know or contact the CCLG. If you have any questions or concerns about the information in this leaflet or anything else please speak to a member of the local medical team or contact the CCLG Tissue Bank at: www.cclg.org.uk/tissue-bank or email: cclgtissuebank@le.ac.uk

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