Hospital logo

CHILDREN'S CANCER INSTITUTE

MINIMUM RESIDUAL DISEASE TESTING AND BANKING OF SPECIMENS FOR FUTURE RESEARCH

PARENT/GUARDIAN INFORMATION STATEMENT

Your child's doctor or clinical trials centre has requested that Children's Cancer Institute performs some tests to measure minimum residual disease (MRD) for your child. MRD is a research test based on the identification of unique features known as markers that are present in leukaemic or lymphoma cells but that are not usually present in normal cells. Once they have been identified, these markers can be measured in a sample collected from the same patient after treatment. MRD testing is usually done on bone marrow samples but blood and other tissues can also be tested. MRD testing is used mainly to identify patients at higher or lower risk of relapse. **We will not provide any test results to you directly. The results of MRD testing will be sent to your child's doctor and the clinical trials centre if applicable, and your child's doctor has the responsibility for interpreting these results for you.**

We would like your permission to keep any leftover sample (DNA and/or cells) for research. If you agree, the sample(s) will be kept frozen in our Tissue Bank at the Lowy Cancer Research Centre, UNSW, Randwick, NSW, 2031 for an unknown amount of time. Sometimes doctors request additional diagnostic tests for a patient using their stored samples. Stored left over samples may also be used in Human Research Ethics Committee (HREC) approved medical research. Most research will not show results for a considerable period and there will be no direct medical value to your child. The use of your child's sample(s) could however benefit other patients in the future. All research using banked tissue requires approval by an HREC and the Management Committee of the Children's Cancer Institute Tissue bank. The results of the research may be published provided that patients cannot be identified. The choice to let us keep your child's samples for future testing or research is up to you. If you decide to let us keep left over sample(s) (cells and/or DNA), you may change your mind at any time and we will destroy any remaining sample(s).

In the event that incidental/unexpected information relevant or useful to you, your child or your community becomes available, the researchers who have been given your child's sample have agreed to provide the results to the Tumour Bank Management Committee. If information becomes available, you and your child will be informed of this information by your treating doctor or GP who is listed on your medical records charts. You can choose to be notified about these findings by ticking the option on the consent form.

Researchers who use your child's samples in the future may need up-to-date information on your child's health. If you give consent, then Children's Cancer Institute staff from the MRD group or Tissue Bank may request your child's health information from your child's doctor or hospital or clinical trial co-ordinator. Only these staff will have access to your child's name and other personal details. Your child's health information will be coded to preserve your child's privacy. In rare cases, more information may be needed from you about your child for a research project, but this will only happen if you have given specific consent.

Your child's sample(s) will not be sold and will only be used for: 1) tests that your child's doctor requests including MRD testing, 2) quality control purposes or 3) cancer research. Although research conducted using your child's samples may result in the development of new medical products or treatments you will not receive money or other forms of compensation.

If you have questions at any time your child's doctor will be happy to answer them.

If you have specific questions about the Tissue Bank at the Children's Cancer Institute, you may contact Ms Kiri Collins, tbmgmt@ccia.unsw.edu.au; phone 02 9385 2085.

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PARENT/GUARDIAN CONSENT FORM

~ I understand that MRD testing will be performed for my child at the Children's Cancer Institute. I understand that MRD test results will be provided to my child's doctor who is responsible for their interpretation.

I freely consent to MRD testing for my child. **Yes** ☐ **No** ☐

~ I understand that any samples left over after testing will be stored in the CCIA Tissue Bank for future testing if requested by my child's doctor or for future research approved by an ethics committee. This applies to all specimens collected from the date of my child's first admission documented below.

I freely consent to storage of my child's samples and their use in research. **Yes** ☐ **No** ☐

~ I understand that information on aspects of my child's health may be useful for future research; that any information will be kept confidential and may be updated in the future.

I freely consent to the provision of information about my child's health. **Yes** ☐ **No** ☐

I agree to be informed of any new information that may benefit or reduce the risk to my child, my family or my community resulting from research on my child's sample. **Yes** ☐ **No** ☐

I freely consent to being contacted by the medical staff in the future. **Yes** ☐ **No** ☐

Name of Child	**Date of first admission**	
Medical Record Number	**Hospital**	
Signature of Parent/Guardian	**Name of Parent/Guardian**	**Date**
Signature of Witness	**Name of Witness**	**Date**
Signature of Patient (if 14 to 16 years)	**Date signed by patient (if 14 to 16 years)**	
Signature of Interpreter (if needed)	**Name of Interpreter**	**Date**

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REVOCATION OF CONSENT

☐ I hereby WITHDRAW my consent for future research on samples collected from my child. I understand that such withdrawal WILL NOT make any difference to my relationship with the hospital or medical attendants.

Name of Patient: ______________________________

Date of Birth: ______________________________

______________________________ ____________________

Signature of Parent/Guardian ***Date***

The section for Revocation of Consent can be given to your child's doctor for forwarding to
The Scientific Services Manager,
Children's Cancer Institute,
C25 Lowy Cancer Research Centre, UNSW,
PO Box 81, Randwick, NSW 2031, Australia.
Fax 02 9662 6584