

TISSUE BANKING: INFORMATION

Blood and Cancer Care Service of the Canterbury District Health Board, and Children's Haematology Oncology Centre (CHOC)

Patient Sticker

You are about to undergo a procedure to take a tissue sample from your body. This may be an operation, a biopsy, a bone marrow test, or a blood test. The tissue will be looked at using a microscope and other tests done to establish a diagnosis. This is a routine part of your medical care. In addition we would like to freeze any spare tissue and store it in our tissue bank for future examination and research. This makes no difference to your planned procedure.

Sometimes, more than one tissue specimen is obtained on more than one occasion during the evaluation and treatment of your condition. We seek your consent for the storage of these tissues which may be obtained at different times during the course of your treatment. Your tissue will only be stored if there is enough left over after the routine diagnostic tests have been done. Therefore, we invite you to consent to the donation of any of your spare tissue as an outright gift to be stored for future examination and research.

There are several reasons for storing the tissue

- to help doctors work out why changes occur in the tissue;
- doctors and scientists continue to discover that some tissue changes are related to genetic factors. These factors can be investigated further using preserved samples;
- the detailed study of stored tissues may help develop treatments.

We cannot know now exactly what uses there will be for the stored tissues in the future. We cannot, therefore, be specific about what tests might be done on them. For some research it may be necessary to insert small fragments of your DNA taken from your tissue into bacteria or yeast cells in order to analyse it. We can assure you, however, that any research that is carried out on your tissue sample will be approved by an accredited Ethics Committee, a registered Biological Safety Committee and the Tissue Bank Board.

Some of the tissue is stored in a very low temperature (-80°C) freezer in the Pathology Department, Christchurch Hospital and University of Otago, Christchurch. Some tissue will be stored in paraffin blocks or on glass slides. Your tissue will be stored indefinitely. At some time in the future your tissue may be thawed and further studied. Your tissue and any information relating to it will remain confidential and be identified by a code that only the Tissue Bank will be able to decode. Since the results of any research on your tissue may be of benefit to you or your family in the future we will keep a confidential file of your name and address. Some results may not be just about you but could be about your blood relatives too (hereditary conditions, for example). So you may want to discuss with your family or whanau whether they or your descendants would be agreeable to you donating your spare tissue, especially if you consider that your genetic material (DNA) is collectively owned by your whanau, hapu or iwi. Maori health support contact details are listed below

It is often helpful to be able to link the tissue features with what has happened to the person who donated it. We therefore separately seek your permission to access your medical records (including all those held with the Canterbury District Health Board) in the future to find out what has subsequently happened to you.

Should researchers working on your sample discover something about you that might affect your future health or that of your family or whanau, we will contact you through the appropriate health care team.

Some tissue changes may relate to your ethnicity so we also invite you to record your ethnicity on the consent form.

It is possible that some future research may involve sending tissues out of New Zealand for study in overseas research institutions. This would only occur when New Zealand researchers are working with an overseas group on the same project. The project will be ethically reviewed in New Zealand to ensure there are equivalent ethical, cultural and biological guardianship in place. We separately ask your permission for this on our consent form.

Some research could be carried out by commercial biomedical organizations. This would only occur in collaboration with New Zealand researchers and would also have the same ethical, cultural and biological guardianship in place. We separately ask your permission for this on our consent form.

After your tissue has been used in a research study, any remaining sample (s) is required to be disposed of by standard disposal methods (incineration) under the Healthcare Waste Management Standard NZS 4304:2002. You may choose to have your sample(s) disposed of with an appropriate karakia (blessing).

After studying your tissues the information obtained could lead to discoveries that are of commercial value to the researcher and their institution, but there will be no financial benefit to yourself, your family or whanau, or the tissue bank..

The Upper South Regional Ethics Committees has approved this information and consent form. This is a collaborative project involving many staff and patients at Christchurch Hospital, Christchurch Women's Hospital, University of Otago Christchurch and other Hospitals in Christchurch.

Contact persons:

Dr Bridget Robinson, Director, Cancer Society Tissue Bank,
Oncology Service. Christchurch Hospital
Phone (03) 364 0020

Dr Peter Ganly, Haematology Department. Christchurch Hospital
Phone (03) 364 0300

Dr Rob Corbett, Dr Michael Sullivan or Dr Amanda Lyver
Paediatric Oncologists
Children's Haematology/Oncology Centre
Christchurch Hospital
Phone (03) 364 0740

Your rights:

If you have any queries or concerns about your rights as a Tissue Bank donor, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax: (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)

Email: (NZ wide) advocacy@hdc.org.nz

For Maori health support, or to discuss any concerns or issues regarding this study, please contact the Maori Health Team Leader on (03) 364 0640 ext.88797.

TISSUE BANKING: CONSENT
(Copy of consent to be given to patient)

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Patient Sticker

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Io	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

- I have read the Information Sheet dated version dated 5th November 2009 about Tissue Banking.
- I have been asked to give permission for any of my spare tissue removed to be stored indefinitely in the Tissue Bank at Christchurch Hospital.
- I understand that more than one tissue specimen may be obtained during the course of treatment.
- I understand that this spare tissue will be frozen, stored indefinitely and may be used for future research. This may include other spare tissues in paraffin blocks, on glass slides, or spare blood and body fluids.
- I, or my blood relatives on my behalf, will be able to obtain any results likely to be of benefit to us.
- I understand that I will be contacted if future research discovers something about me that might affect my future health.
- I understand that my tissue can be removed from the bank at any time at my request, by contacting the persons listed in the Contact section. I understand, however, that any information obtained from my tissue before my request for removal will not be able to be claimed by me.
- I have had enough time to consider whether to gift my tissue.
- Any questions I have had about this proposal have been answered to my satisfaction.
- I understand that gifting my tissue for research is voluntary (my choice).

- I understand that if I choose not to give my tissue to the Tissue Bank, or if I request it to be removed after giving it, this will not affect my present or future treatment.
- **I consent to my spare tissue(s) being stored in the Tissue Bank, for later use in research which must be approved by an accredited Ethics Committee.**
YES / NO
- I consent to gifting a blood sample of up to 10mls to be collected with other routine bloods
YES / NO
- I consent to researchers accessing my medical records
YES / NO
- I consent to my tissue(s) being sent overseas for use in collaborations with New Zealand researchers
YES / NO
- I consent to my tissue(s) being used by commercial research organizations in collaboration with New Zealand researchers
YES / NO
- I consent to any remaining tissue(s) being disposed of using standard disposal methods at the end of the research
YES / NO
- In addition I also choose to have my samples disposed of with an appropriate karakia
YES / NO

ETHNICITY: (as asked in the 2006 census)

Which ethnic group do you belong to?

Mark the space or spaces which apply to you

- NZ European
- Maori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- Other (such as Dutch, Japanese, Tokelauan), please state

Patient name

Patient signature Date

Information before consent given by:
(printed name)

Role: Signature Date