

## The New Zealand Familial Breast Cancer Study (NZFBCS)

### Principal Investigators:

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|---|---------------------------------|
| • Dr Logan Walker (Scientist)                     | logan.walker@otago.ac.nz        |
| • Professor Bridget Robinson (Medical Oncologist) | bridget.robinson@cdhb.health.nz |
| • Dr Caroline Lintott (Genetic Associate)         | caroline.lintott@cdhb.health.nz |
| • Jan Sullivan (Genetic Associate)                | jan.sullivan@cdhb.health.nz     |

# Study Information

### WHAT IS THE AIM OF THE STUDY?

We now know that cancers have abnormal genes in them. In about 5-10% of breast cancers the woman has inherited (carries) genetic changes that increase her risk of cancer. Several genes are already known to be involved, so that women who carry a genetic change (or "mutation") in one of these known genes are at high risk of developing breast or ovarian cancer. Men carrying these mutations are at increased risk of developing prostate cancer and breast cancer. Both men and women may carry a mutation and pass it to their children. However, not all mutation carriers develop cancer, and the reasons for this are unknown. For most people with breast cancer, the genetic changes underlying their disease remain undetermined.

This is a national research study which aims to identify the genetic changes that prevent genes from working properly, and that are associated with an increased chance of cancer occurring in some individuals and their close relatives.

The people who can best help us in this study are men and women, both with and without cancer, who have

- at least 3 close relatives on the same side of the family with breast and/or ovarian cancer, or
- at least 2 close relatives on the same side of the family with breast or ovarian cancer, one with breast cancer in both breasts, ovary cancer as well as breast cancer, coming on at age 40 or younger, or a male with breast cancer, or
- already had genetic testing and carry a mutation in a gene involved in breast cancer.

### WHAT WILL BEING IN THE STUDY MEAN FOR ME?

- (1) We would interview you about your general health, lifestyle, and the history of cancer in your close relatives. This would take about 15 minutes and could be by phone or at a convenient place for you. The information will be stored on a secure confidential database.
- (2) We would seek your consent to access your relevant medical and pathology records (including tumour material) and any cancer genetic test results.
- (3) We would like to collect a 30 ml (6 teaspoons) blood sample.
- (4) We would also ask you whether your close relatives or whanau would like to be involved in the same study. This is optional, and is **not** required for your own involvement in the study.

Feel free to discuss the study with the investigators or your whanau and friends. There will be no cost to you, and if you do not want to take part, this will not affect your future medical care. You will also be free to withdraw from the study at any stage if you no longer wish to continue.

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 New Zealand Familial Breast Cancer Study.

### WHAT WILL THE BLOOD AND TUMOUR TISSUE SAMPLE BE USED FOR?

The blood and tissue will be stored in the Cancer Society Tissue Bank. DNA, RNA and protein will be extracted and analysed to find changes that have caused the genes to be faulty, causing cancer. Your blood may also be stored as long-lived cell lines (samples that are treated to make the cells stay alive) to be used for further biochemical and genetic tests. Some of your sample will be kept indefinitely for future research studies. We cannot know now exactly what uses there will be for the stored samples in the future. For some research it may be necessary to insert small fragments of the DNA taken from your blood into bacteria or yeast cells in order to analyse it. We can assure you, however, that any research that is carried out on your blood sample will be approved by an accredited Ethics Committee, a registered Biological Safety Committee and the Canterbury Tissue Bank Board.

After study, any remaining samples will be disposed of by standard disposal methods (incineration) under the Healthcare Waste Management Standard NZS 4304:2002. You may choose on the consent form to have your sample(s) disposed of with an appropriate karakia (blessing).

### **HOW IS MY PRIVACY PROTECTED?**

Your blood and any information relating to it will remain confidential and be identified by a code that only The New Zealand Familial Breast Cancer Study will be able to decode. Since the results of any research on your tissue may be of benefit to you or your family or whanau in the future we will keep a confidential file of your name and contact address. It is possible that information about the study might be published in scientific journals. However, no information that might identify you will appear in these publications.

Some results may not be just about you but could be about your blood relatives as well (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 blood, 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.

### **CAN I WITHDRAW FROM THE STUDY?**

You may withdraw from the study at any time, and all your information will be removed from the database. Any remaining blood samples or cell lines that have been stored will be destroyed.

### **WILL I FIND OUT THE RESULTS OF THE RESEARCH USING MY BLOOD?**

This type of research can take a long time and uses samples from many people before the results are known. However, you will receive a newsletter that will contain information about The New Zealand Familial Breast Cancer Study. You can contact the Principal Investigators at any time if you have any questions about the study. If we find some information which could be very important for the health of yourself or your close relatives, we will contact you to advise about seeking help from appropriate health professionals.

### **FURTHER RESEARCH USING YOUR INFORMATION AND SAMPLES**

We often work with overseas researchers, and this could involve sending your sample overseas. The research project would be ethically reviewed in New Zealand to ensure there is equivalent ethical, cultural and biological guardianship in place. We separately seek your consent to send your sample overseas, if necessary.

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

### **ARE THERE ANY RISKS IF I PARTICIPATE?**

Taking a blood sample may cause slight bleeding, minor bruising or pain.

The genetic research will be targeted to just the genes under study, and we will not release any other information about your genes to anyone. The research data is not definitive for making health decisions.

### **WHAT IF I HAVE MORE QUESTIONS OR A COMPLAINT ABOUT THE STUDY?**

If you have any questions about the study, please contact:

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| • Dr Logan Walker (Scientist)                     | logan.walker@otago.ac.nz<br>Phone: 03 364 0544 |
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#### **Dr Logan Walker, MSc(Hons), PhD**

Principal Investigator, New Zealand Familial Breast Cancer Study  
Sir Charles Hercus Health Research Fellow  
Mackenzie Cancer Research Group  
Department of Pathology, University of Otago Christchurch