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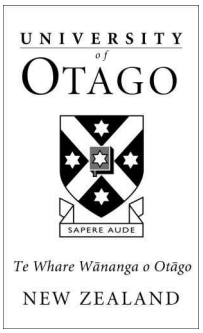

Genetic Predisposition to Gastric Cancer

INFORMATION SHEET

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

What is the Aim of the Project?

Gastric cancer (also known as stomach cancer) sometimes runs in families. This high cancer risk can be due to the inheritance of a faulty gene. We have previously shown that mutations in the *CDH1* gene predispose to stomach cancer, however, not all families with a high incidence of this disease have a mutation in that gene. In this project we are aiming to identify additional genes that explain the high incidence of stomach cancer in some families.

What Type of Participants are being sought?

Participants will be from stomach cancer families who have presented to genetics clinics in New Zealand and elsewhere for testing for the cancer syndrome Hereditary Diffuse Gastric Cancer (HDGC). All participants will have undergone *CDH1* testing and been found not to have a mutation in that gene. There will be no reimbursement or compensation for participating in this study.

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to provide a small (4ml) blood sample for DNA extraction. Alternatively, if your DNA sample is already in storage, we will simply ask your permission to access that sample for this study.

Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

We will collect information on your ethnicity, age, gender and the history of cancer in your family. You will have already provided this information to your genetic counsellor prior to *CDH1* testing. Your blood or DNA sample will be anonymised so that your identity is

protected at all times. The only person who will be able to link your personal information and the data generated in the study to you will be the study's Principal Investigator and another investigator in the Centre for Translational Cancer Research, Tanis Godwin. The results of the project may be published, but your anonymity will of course be maintained in the publication.

To find new stomach cancer genes, we will determine the DNA sequence of every gene in your genome, a process known as exome sequencing. Once we have obtained the DNA sequence, we will search for the presence of any mutations which could be causing your family's inherited cancer risk. If a mutation is found, we may need to confirm that it predisposes to cancer by determining its presence in other affected members of your family or even in other cancer families.

You will be informed if no cancer-causing mutations are found in your sample.

If a new cancer-causing mutation is found, genetic testing will be offered to you and your family as soon as the test is validated. It is anticipated that the testing procedure will be very similar to that which you have already experienced for the *CDH1* test.

Data obtained from the research will be retained for at least ten years in secure storage. This longterm storage will be particularly important for families in which no obvious mutation is initially found because new research may point to the significance of certain genetic changes that were originally overlooked. If you agree, we may also use the data in other cancer research projects.

It is possible that the study will identify genetic variations that are un-related to your cancer risk but may indicate other health risks. Although these other variations will not be specifically searched for, they may be noticed as part of the search for the cancer gene. If any genetic variations known to present a substantial risk to your health happen to be identified, your genetic counsellor will be informed and you will be contacted. However, researchers in this study are trained in cancer biology and have only a passing knowledge of other medical conditions; it is therefore possible that genetic variations associated with diseases other than cancer may not be noticed and therefore not brought to the attention of your genetic counsellor.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either of the investigators named below:

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This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.