

Genomic Analysis of Hereditary Diffuse Gastric Cancer Arising in Individuals with Germline CDH1 Mutation

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?

Individuals who inherit a mutation in the CDH1 gene have about an 80% lifetime risk of developing stomach cancer. Stomach cancer develops because additional genetic changes beyond CDH1 mutation occur that cause stomach cells to form tumors. In this project, we aim to identify what additional genetic changes occur in stomach cancers arising in individuals with inherited CDH1 gene mutation in the hopes of developing new diagnostic tests and treatments.

What types of participants are being sought?

Participants will be either individuals with inherited CDH1 mutation who have developed stomach cancer or a family member of such an individual. In order to have enough material to perform extensive genetic testing, a visible stomach tumor and adjacent normal tissue from a stomach resection is required. Surgical resection specimens are generally kept for several years in the pathology department of the hospital in which the procedure was performed. If you are an individual or a relative of an individual who had such a procedure, we would like your permission to obtain the surgical specimen. 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 sign a consent form approving of the use of your surgical specimen or your relative's surgical specimen for research. We will then work with you to obtain the surgical specimen.

What data or information will be collected and what use will be made of it?

We will collect information on you or your relative's age, gender, and history of cancer in your family. You or your relative's surgical specimen will be anonymised so that the 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. The results of the project may be published, but your anonymity will of course be maintained in the publication.

To find new genetic changes, we will determine the DNA sequence of the tumor's entire genome, a process known as whole genome sequencing. Once we have obtained the DNA sequence, we will search for the presence of any mutations, duplications, and deletions which lead to the development of stomach cancer. If common genetic changes are found in different tumors, we will attempt to confirm these genetic changes in additional tumor specimens.

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 the Principal Investigator:

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