

The NIH Hereditary Gastric Cancer study focuses mainly on patients with CDH1 mutations. However, we know that many patients that seem to fit criteria for HDGC syndrome do not have a detectable mutation in the CDH1 gene. We are very interested in knowing which other genes may be the cause of their cancer syndrome.

While there are other hereditary cancer registries, this is not a registry. It is a clinical study, probably best classified as a longitudinal cohort study. In addition, all of our laboratory research into HDGC syndrome is tied to this study.

Our goals are to provide expert clinical care, through cancer surveillance, genetic testing, and risk-reducing surgery, to patients and families that carry a CDH1 mutation. We are investigating what DNA changes in the stomach (or breast) in addition to the CDH1 gene mutation are required for cancer to develop. We also are investigating better ways to screen for stomach cancer.

Registries can be good as they voluntarily collect demographic and clinical data, but they are not as robust as the kind of study at NIH.

The study at NIH is likely the only of its kind in the U.S., as we are unaware of anyone combining clinical care, clinical research and basic science research in one study.

For patients that have a CDH1 gene mutation and have already had their stomach (and/or breasts) removed, they can still participate in the study. Some of the ways this is helpful for our research are:

- Access to you or your family's specific DNA mutation
- Access to tissue from your prior surgery

What are the potential ways that participation will benefit you?

- More in depth genetic analysis may provide information about other health risks to you
- Understanding the causes of gastric cancer in you or your family can help your children, grandchildren and other family members

We would love to have you participate. If you wish to participate we would ask you to contact the NIH Foregut Team at foregut@mail.nih.gov

Thank you.