Speaking With Your Family

Because *CDH1* gene variants are inherited, it is possible that other members of your immediate family carry the variant and are at risk, too. It can be tough to have conversations with family members about cancer and cancer risk but approaching the subject could save their life.

Below is a template for a letter to tell your family members about your genetic testing results. You can fill in and send the letter, changing anything you feel is appropriate, or use it as a guide for how to speak with them in person. In the letter, we name a few support organizations that you and your family may find helpful to check out; there may be others not listed here, and NCI cannot specifically endorse any particular organization.

We recommend that you provide your family with all the pages of your genetic test report. The information will be important for when any relatives speak with their health care provider or a genetic counselor.

Note that this information is only relevant to relatives related by blood, such as parents, children, grandparents, grandchildren, siblings, nieces, nephews, aunts, uncles and cousins.

Letter Template

Dear _____,

I recently had genetic testing to help me understand my risk of developing cancer. I was tested for inherited variants (aka mutations) in the *CDH1* gene. Variants in this gene cause most cases of hereditary gastric (stomach) cancer, and also increase the risk of breast cancer in women. My test identified a variant that runs in our family, relevant for anyone related by blood. As one of my relatives, you may have the same *CDH1* variant and could benefit from genetic counseling and genetic testing for this variant. If you find out that you have the variant, you can take steps to reduce your risk of cancer.

I am writing to you and all of our relatives who are at risk to recommend speaking to a genetic counselor. *CDH1* variants can be passed from parents to their children. Since I have the variant, my parents, children, sisters and brothers each have a 50%

chance of having it. My other blood relatives (aunts, uncles, nieces, nephews and cousins) also are at risk to have the variant.

Now that I know that I have a *CDH1* variant I can take steps to reduce my risk for developing gastric and breast cancer in the future. You could also benefit from knowing whether you have this variant. The first step is to discuss this with a genetic counselor who can provide you with more information about the implications of *CDH1* genetic testing. You can find a genetic counselor who provides telehealth or in-person services close to you at https://findageneticcounselor.nsgc.org/.

If you have genetic testing and find out that you have a *CDH1* variant, then you can consider joining a hereditary gastric cancer study being conducted at the National Cancer Institute. The study provides long term medical support for individuals with a *CDH1* variant by health care providers such as surgical oncologists, gastroenterologists, dietitians, nurses, social workers and genetic counselors. You can visit this website to learn more about this study: https://clinicaltrials.gov/ct2/show/NCT03030404 and to begin the enrollment process send an email to foregut@mail.nih.gov.

To read more about *CDH1* you can visit this patient resources page provided by the NCI Center for Cancer Research (https://ccr.cancer.gov/surgical-oncology-program/clinical-tea/patient-resources-for-hereditary-diffuse-gastric-cancer) or visit the websites of gastric cancer advocacy organizations such as the DeGregorio Family Foundation, Debbie's Dream Foundation, Hope for Stomach Cancer and No Stomach for Cancer.

While it can be concerning to learn that there is a risk for a genetic condition in our family, there are many resources available for families with *CDH1*, and I want to help make sure that our family knows about this important lifesaving information.

Sincerely,