

### Length of study and ability to withdraw

You will be enrolled into the Gastrointestinal Cancer and Polyposis Registry indefinitely, or until you request removal from the registry. If you decide to participate, you may leave the study at any time. Withdrawal from the registry will not interfere with your future care. You may withdraw by sending written notice to the Principal Investigator for the Gastrointestinal Cancer and Polyposis Registry. This study may also be stopped at any time by the Principal Investigator.

### Voluntary Participation

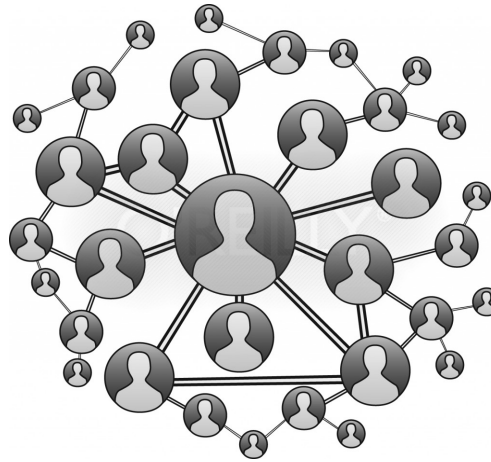
Your participation in the registry is not mandatory and will not affect your access to medical treatment now or in the future. If you decline, you can still pursue clinical genetic testing. If you agree to participate in the registry, there will be no additional cost to you. You will not be paid for participating in this registry.

### Questions or concerns

If you have any questions or concerns regarding your participation or your rights as a research subject, you should speak with the Principal Investigator. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs at the University of Pennsylvania by calling: 215-898-2614.

### More information

You may ask more questions about the registry at any time. A member of the Gastrointestinal Cancer Genetics Program will be available to answer questions as they arise, and our clinic office can be reached at 215-349-8222.



Penn Medicine

### Division of Gastroenterology Gastrointestinal Cancer Genetics Program

IRB Approved Protocol:  
Identification and Analysis of Hereditary  
Gastrointestinal Cancer and Polyposis  
Syndromes  
ID #: 826004

Principal Investigator:  
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Location:  
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## Division of Gastroenterology

### Gastrointestinal Cancer and Polyposis Registry



*A voluntary research registry  
offered to patients of the  
University of Pennsylvania's  
Gastrointestinal Cancer  
Genetics Program*

**ID #: 826004**

## Goal

The Gastrointestinal Cancer and Polyposis Registry is a patient registry for those who either have or are at risk of having a hereditary gastrointestinal cancer or polyposis syndrome.

The purpose of this registry is to store medical and family history information, including genetic testing information (if applicable), to facilitate research on gastrointestinal cancer and polyposis syndromes. Additionally, being part of the registry will give our program the option to contact you in the future, if and when the following opportunities arise:

1. We have updated information on any of your genetic testing results.
2. New testing options become available that may benefit you or your relatives.
3. There are new research opportunities available that may benefit you or your relatives.
4. There are clinical trials or new therapies for which you may be eligible.
5. There are other new opportunities or advances related to your condition, genetic testing results, or your familial risk, which may benefit you or your family.

The timeline for this study is open-ended. Participation does not guarantee a re-contact will occur.

## Possible benefits of the study

Enrollment in the registry may enable you to take advantage of new testing and treatment options. Registry enrollment may facilitate future research to better understand, diagnose and treat hereditary conditions related to gastrointestinal cancer and/or polyposis.



## Possible risks of the study

There are no additional health risks that result from enrollment in the registry. Although extreme care is taken to maintain the confidentiality of this registry, there is always a small risk of a breach of this confidentiality with regards to your genetic testing results and other personal and family history information. Additionally, in terms of general risks associated with genetic testing, learning about genetic risk for cancer could cause worry, anxiety, depression or fear for the future. This information could be upsetting to family members and could possibly strain personal relationships. Finally, learning about the presence of genetic risk for cancer could lead to concerns about insurance or employment discrimination. Fortunately, the Genetic Information Nondiscrimination Act of 2008 (GINA) provides significant protection against genetic discrimination in health insurance and employment. However, the protection of GINA does not cover life, disability, or long-term care insurance.

## Security of your information

Information that will be collected as part of your participation in the registry includes:

1. Name, address, phone number, date of birth, email and certain other demographic information.
2. Medical record number.
3. Personal and family medical history, including results from tests and procedures.
4. Genetic test results. (if applicable)
5. Tumor test results. (if applicable)

The registry is secure and password protected, and is only accessible to members of the Gastrointestinal Cancer Genetics Program. The registry is not accessible to hospital employees, or insurance companies. If information from the registry is ever used for research purposes, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier.

## ***Please keep in touch...***

*It is important to note that enrollment in this registry does not assure that all updates to your genetic testing results will be communicated to you, nor does it assure that you will automatically be updated on new clinical recommendations or opportunities that may affect your care. Therefore, you may need to continue to contact the Gastrointestinal Cancer Genetics Program on at least an annual basis for updated information and recommendations about your health.*