

Gastrointestinal Cancer Risk Evaluation Program (GI-CREP): Frequently Asked Questions

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1) Is genetic counseling and/or testing considered research?

- Your visit to the Gastrointestinal Cancer Risk Evaluation Program (GI-CREP) is a clinical service, not research (although we have separate research studies that might be discussed if applicable and of interest to you). Therefore, your visit is billed to your insurance company in a similar manner to other specialist visits.
- Cancer genetics is a medical specialty focused on assessing your risk for cancer (e.g. colon, pancreas, other gastrointestinal cancers) and/or developing colon polyps. We can discuss genetic testing options, a diagnosis of a hereditary cancer condition and/or medical management recommendations for you and your relatives.
- Some individuals may be eligible for research participation, which is always optional.

2) Insurance coverage for appointment

- Penn Medicine accepts most insurance plans. If there are issues, we help you to guide this process.
- In general, if you have coverage to see a specialist at Penn Medicine, you will have similar coverage for your appointment.
- The cost of genetic testing is separate from the fees related to your clinic appointment.
- CIGNA and United Healthcare require a patient to be evaluated by a qualified genetics provider (ex: genetic counselor, advanced practice nurse, experienced physician in cancer genetics) prior to genetic testing.

3) Insurance coverage for genetic testing

- Most insurance companies include coverage for genetic testing, if medically indicated.
- Your eligibility, any potential out-of-pocket costs and pre-authorization for genetic testing will be discussed in detail at the time of your first visit.
- The majority of commercial genetic testing labs have a "patient protection" mechanism in place. This means that when a sample is sent to a lab, the lab will contact a patient if there is an expected cost to the patient above a certain threshold (usually \$100). If there is an out-of-pocket expense exceeding the threshold, the patient has the option to select a payment plan or cancel the test.
- Our office does not determine eligibility or insurance coverage of genetic testing prior to your appointment. Your appointment will include a thorough evaluation of your personal and family history, at which point our recommendations regarding genetic testing will be discussed.

4) Why do you need my family member's genetic testing result?

- If there is a known gene mutation in the family, the laboratory performing your testing will require a copy of your relative's result.
- There are many different genes that lead to hereditary cancer risk. Also, mutations can occur in many different ways and are typically specific to each family.
- Providing a copy of your relative's test result ensures that we are ordering appropriate testing for you at a lab that can accurately perform your test.
- If your relative's genetic testing was "negative" (no mutations found), we may want to review which genes were tested and the methods used to test those genes (how thorough your relative's test was).

5) Discrimination concerns (Will a positive genetic test result cause me to lose my health insurance?)

- A federal law, the Genetic Information and Nondiscrimination Act (GINA), was passed by Congress in 2008 and works with other laws to prevent health insurers from using your genetic information for decisions regarding coverage, rates or preexisting conditions.
- GINA also protects you from being hired, fired or not promoted due to your genetic information.
- GINA does not address concerns about disability, life, or long-term care insurance, and some people choose to purchase these types of insurance prior to undergoing genetic testing. More information may be found at www.GINAhelp.org

6) Who will I meet with during my appointment?

- You will meet with a gastroenterologist (Dr. Bryson Katona, Dr. Anil Rustgi or Dr. Kirk Wangenstein), whose expertise relates to hereditary cancer risk and related medical management, including various endoscopic procedures.
- A genetic counselor may meet with you to discuss your family history, cancer risk assessment and genetic testing options.
- As a teaching hospital, your visit may also include trainees or observers, such as physicians pursuing advanced training in gastroenterology or genetic counseling students.

7) What will happen during the appointment?

- Your personal and/or family history of cancer and/or colon polyps will be discussed.
- Your other medical history will be reviewed.
- A brief physical exam will be performed.
- Based on our assessment, genetic testing may or may not be recommended. This will be discussed in detail with you during your appointment.

8) What do I need to do to prepare for genetic testing?

- Genetic testing may require a saliva sample or a blood sample.
- You do not need to fast in preparation, but we recommend that you do not eat/drink/chew gum during the appointment in case you need to provide a saliva sample for testing.
- Medications that you take will not affect your genetic testing result.

9) What if I do not know my family history information in detail?

- Please do the best that you can in terms of filling out the New Patient Form.
- If you do not know some information, you can estimate or leave blank.
- Any information that you can provide in advance of your appointment will help make your visit more informative and efficient.

10) Where can I get more information regarding the Gastrointestinal Cancer Risk Evaluation Program and/or the research being done at Penn?

- Please visit our website: <https://www.pennmedicine.org/cancer/navigating-cancer-care/programs-and-centers/gastrointestinal-cancer-genetics-and-risk-evaluation-program>