YOUR GUIDE IN THE FIGHT

Understanding Your Genetics

A **FIGHT COLORECTAL CANCER**™ *Resource*

for all stages of colorectal cancer

Understanding Your **Genetics and Cancer**

Genetics is the science of genes and how traits are passed on from one generation to the next.

Genetic testing can provide information about a person's risk for developing cancer in the future. This type of test can also identify certain mutations that may not respond to chemotherapy or that may respond to targeted therapies.

For a person with colorectal cancer, especially hereditary cancer, understanding the specific genetic changes that led to their cancer developing can help inform their treatment plan.

All cancers, including colorectal cancers, form because either the genes responsible for fixing genetic mutations didn't do their job or the genes responsible for containing unregulated growth of cells didn't do their job.

As your cells multiply, errors can occur due to various reasons, such as aging and exposure to carcinogens in the environment. Gene mutations are common, but normally healthy cells can detect and repair them to prevent cancer. However, if genes that are supposed to prevent cancer don't work, or too many mutations build up within a cell, cancer can develop.

More ***Information***

Scan here for more information on general cancer risk factors or visit ***FightCRC.org/Risks***

What if ***Cancer*** *Runs* ***in Your Family?***

Some gene mutations can be inherited from a parent. If a person has a first-degree relative (parent, sibling, or child) who has been diagnosed with colorectal cancer, their risk of developing the disease is two to three times higher than someone without a family history. The risk is even higher if multiple first-degree relatives have had colorectal cancer or if the relative was diagnosed at a young age.

Genetic testing can help identify specific gene mutations that increase the risk of colorectal cancer. Individuals with an increased risk may need to undergo more frequent screening or consider other preventive measures, such as surgery. It's important for people with a family history of colorectal cancer to talk to their doctor about their risk, ways to reduce it, and when to get screened.

Do I Have to Get Genetic Testing?

It is always your decision to undergo testing. However, it is recommended that all people with colorectal cancer undergo genetic testing to determine if they have a hereditary predisposition to the disease. This is especially important for individuals who were diagnosed at a young age, have multiple close family members with colorectal cancer, or have a personal or family history of other cancers associated with hereditary cancer syndromes.

Don't be nervous. Genetic testing can help guide you and your family. It can let you know if you and your family may need to be screened sooner than the recommended age. Understanding your genetics may save the life of a family member.

Questions to Ask *Your Doctor or Genetic Counselor*

- Should I get genetic testing based on my personal and family history of cancer or polyps? Why or why not?
- What are the benefits and risks of genetic testing? How will it affect my medical care?
- Will my insurance cover the cost of genetic testing? Will I be able to keep my health insurance if testing reveals a gene mutation?
- If I have a mutated gene, what actions can I take to lower my risk, and what medical care will I receive?
- How will knowing my genetic mutations affect the health of my children and other relatives? Do they need genetic counseling or testing?
- If I decide not to have genetic testing done, what other types of cancer screening tests and timing would you recommend?
- Do I need to do anything if I do not have a genetic mutation?

GENES PLAY A MAJOR ROLE IN COLORECTAL CANCER,

but not all cancers come from inherited genetic mutations.

Colorectal Cancer Can Be Sporadic, Familial, or Hereditary

What Is the ***Difference Between Hereditary*** *and* ***Familial Cancer?***

Hereditary cancer and familial cancer are types of colorectal cancers linked to family history, but differ in genetic causes and risk factors.

Hereditary colorectal cancer is caused by specific inherited gene mutations, such as Lynch syndrome or familial adenomatous polyposis (FAP), which can be passed down through generations and increase cancer risk. Those who have a specific inherited gene mutation may develop the disease at a younger age and have several family members with it.

- **Hereditary cancer tends to:**
  - Occur at a younger age (under age 50).
  - Affect many generations on one side of the family with the same (or related) cancers.
  - Lead to two primary cancers or two related cancers in the same person.

Familial colorectal cancer is when the disease happens more frequently in a family, but there is no known inherited gene mutation. People with a family history have a higher risk than the general population, but not as high as people with hereditary colorectal cancer. Screening, lifestyle changes, and prevention efforts can help those with familial cancer or hereditary syndromes to potentially prevent cancer.

- **Familial cancer tends to occur later in life (over age 50).**
- **Familial cancer is a result of:**
  - Multiple minor gene variants that increase cancer risk slightly.
  - Shared environment *(similar diets and environmental exposures)*.
  - A combination of both.
- **Appear in multiple family members.**

It's important for individuals with a family history of colorectal cancer to speak with their doctor to determine if they have hereditary cancer syndrome and to discuss when to be screened and ways to prevent it.

If you have close family members diagnosed with colorectal cancer, your risk is also likely increased. Talk to your doctor about when to start screening and about genetic testing.

Continued ➞

Current guidelines recommend that all individuals with a first-degree relative (a parent, sibling, or child) with colorectal cancer begin screening at age 40, or 10 years prior to the youngest diagnosis of colorectal cancer in the family. If you notice symptoms, you should get screened regardless of family history. Not all doctors are aware of the recommendations about early screening for families with cancer predispositions, so speaking with a specialist may be helpful.

Learning if you have an inherited gene mutation that puts you at higher risk of getting cancer is essential. People with hereditary cancer risks will be encouraged to consider:

1. Increased, earlier, and more frequent screening for colorectal cancer and other types of cancers (if appropriate).
2. Taking certain medications to lower cancer risks (such as aspirin with Lynch syndrome).
3. Having preventive surgery to remove an organ before cancer develops. For example, women with Lynch syndrome who are past child-bearing age or not planning on having biological children may be encouraged to have a total hysterectomy.

What's ***Sporadic Cancer?***

Most cases of colon and rectal cancer are considered sporadic, meaning you did not inherit a mutated gene from a biological family member. Sporadic cancer appears as individual cases, is unpredictable and, even when it affects more than one person in a family, is not hereditary.

- **On average, a person's lifetime risk of developing sporadic colorectal cancer is 5% (1 in 20).**
- **Sporadic cancers typically:**
  - Form later in life.
  - Don't have a clear familial pattern.
  - Are not due to an inherited gene mutation.

5%-10% OF COLORECTAL CANCER CASES ARE HEREDITARY.

20%-30% OF COLORECTAL CANCER CASES ARE FAMILIAL.

60%-70% OF COLORECTAL CANCER CASES ARE SPORADIC.

Why You Should **Get Genetic Testing**

Genetic testing may be recommended for people with colorectal cancer if there is suspicion of a hereditary cancer syndrome based on your personal or family history. The National Comprehensive Cancer Network recommends genetic testing for all people with colorectal cancer who meet certain criteria, such as:

* A personal or family history of colorectal cancer or other cancers associated with hereditary cancer syndromes, such as ovarian or endometrial cancer.
* A diagnosis of colorectal cancer at a young age (before age 50).
* Multiple relatives on the same side of the family with colorectal cancer or other related cancers.
* A family history of known hereditary cancer syndromes, such as Lynch syndrome or Familial Adenomatous Polyposis (FAP).

IT'S IMPORTANT TO REMEMBER THAT GENETIC TESTING CAN HELP:

Identify inherited gene mutations that increase the risk of developing colorectal cancer (or other related cancers) for you and your family members.

Inform you of ways to reduce your risk of cancer and when to be screened.

Determine who else may benefit from earlier or more frequent screening.

Empower you and your family to be proactive about your health instead of reactive.

4 Steps *for Learning Your* ***Test Results***

Step 1: Talk to Your Family About Cancer. Is there cancer in your family tree? Ask family members about your family history of cancer. See if they remember at what age family members were diagnosed. Discussing health history with your family is crucial.

Step 2: Find a Genetic Counselor. Your doctor or health care team can refer you to a genetic counselor. If they don't suggest it, advocate for yourself and ask for one. You can also ask your insurance provider. They may have a list of in-network genetic counselors in your area. Don't underestimate the power of a personal recommendation. Ask for recommendations from friends, family members, or other health care professionals who have had experience with genetic counseling. Often, genetic counseling can be done remotely by telemedicine without the need to visit a clinic.

Step 3: Get Genetic Testing. Your genetic counselor will advise you if and how to undergo genetic testing. The specific genetic test recommended to you depends on your personal and family medical history. Your provider or your genetic counselor can help determine which test are appropriate for you. You will typically only need to provide a blood or saliva sample for testing.

NOTE: You can learn more about genetic testing, types of tests, and other things to consider at FORCE (Facing Our Risk of Cancer Empowered, *facingourrisk.org*).

Important: The genetic testing we are referring to is not an over-the-counter test. These are specific tests that are ordered by your doctor.

Step 4: Understanding Your Test Results. When you get your genetic test results, try not to be anxious. It's best to wait until your appointment with your doctor to go over them together. The results will help determine what tests and treatments you or your family members may need to make sure your care is well-managed.

THERE ARE THREE TYPES OF GENETIC TESTING RESULTS:

Positive means a harmful genetic mutation was found, indicating a hereditary cancer syndrome and increased risks for certain types of cancer for the individual and their family members.

Negative means no harmful genetic mutation was found, reducing the risk of a hereditary cancer syndrome, but not ruling it out entirely.

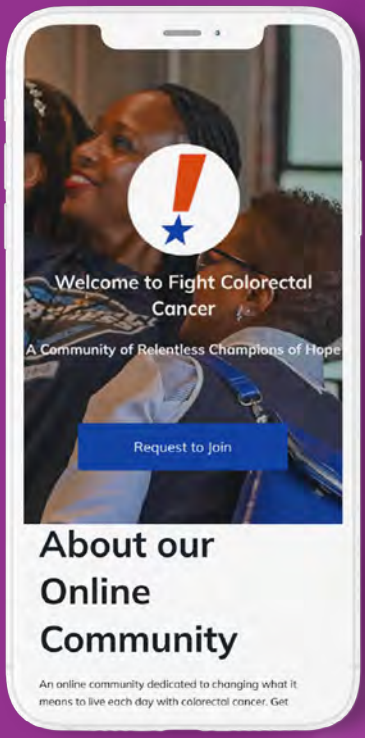
Variant of uncertain significance (VUS) means a genetic variant was found, but it's unclear if it's harmful, and requires further evaluation. A VUS result may not provide clear information on cancer risk.

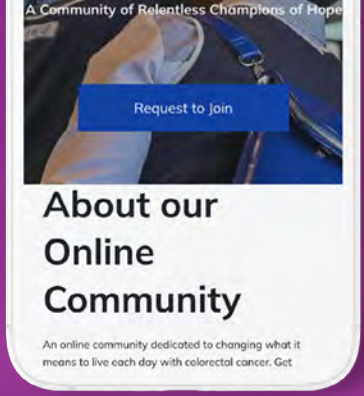
Genetic testing is not perfect, and we have not yet discovered all of the genes linked to hereditary colorectal cancer. But, genetic testing is an important first step.

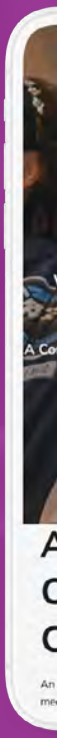
SCAN HERE *to learn more* >>>

KNOW YOUR RIGHTS

The Genetic Information Nondiscrimination Act (GINA) was signed into law on May 21, 2008. GINA protects individuals from health insurance and employment discrimination based on their genetic information.







COMMUNITY *of* ***Champions***

If you have questions or you're feeling uncertain about genetic testing, hearing from others who have been through the process can be helpful.

In our Community of Champions, you'll find a supportive group of people who have undergone genetic testing and can share their experiences with you.

SCAN HERE
to join the community

Search at
community.FightCRC.org

SCAN HERE
to find a Hereditary GI Cancer Center near you

Search at
cgaigc.com/find-a-clinic

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