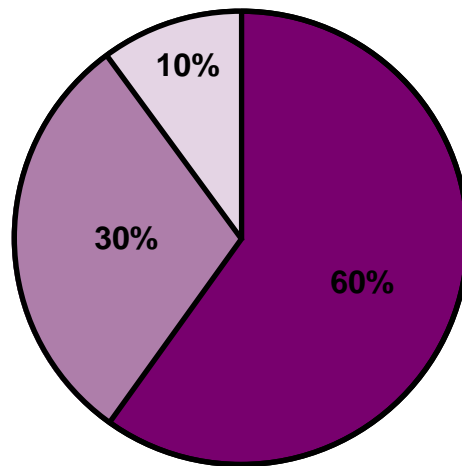


Familial Colon Cancer Registry

at Huntsman Cancer Institute



■ Chance
■ Family Risk
■ Known Inherited Syndromes

Figure 1: Causes of all colon cancer. Individuals in the family risk and known inherited syndrome categories are invited into the Registry.

Fact Sheets

- Understanding Genes
- Known Inherited Syndromes
- Family Risk
- Chance Colon Cancers
- How to Reach Us
- Colon Cancer on the Web

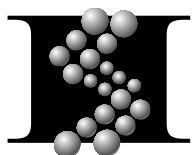
An Overview of the Familial Colon Cancer Registry: the Genetics of Colon Cancer

Cindy Solomon, M.S.

Everyone is touched by inheritance in some way; you may have been told that you have your father's smile, your mother's sense of humor, or your uncle's nose. It is easy to think of examples when it comes to physical or personality traits. At the Registry, we are in the business of thinking about the inherited nature not of personality or appearance, but of polyps, colon cancer and related cancers. We want to learn more about the causes, prevention, and treatment of cancer by studying syndromes or trends in families like yours. We have invited several groups into the Registry - each will help us focus on different aspects of cancer. The goal of this article is to help you understand the scope of the Registry and how you fit into our resource.

What are genes?

To understand the purpose of the Registry, it is helpful to have a basic understanding of the genetics of colon cancer. Genes are packets of genetic information (DNA) that are stored in every cell of the body. These genes provide specific information to the cells that make the body work. A human body has about 100 trillion cells and each cell has an estimated 35,000 genes that tell it what to do! Health problems may arise when certain genes have mutations or changes that prevent them from working correctly. Just as parents can pass on genes for physical traits like hair and eye color, they can also pass on mutations in genes that may prevent cells from working properly, thus leading to disease.



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What are “Known Inherited Syndromes”?

A mutated gene that is passed from parent to child can cause several conditions that increase the risk of developing polyps, colon cancer and related cancers. When genes that cause these conditions are identified, we call the conditions “known inherited syndromes.” Known inherited syndromes represent approximately 10 percent of all colon cancers (see chart). Some of the inherited syndromes include: familial adenomatous polyposis (FAP or Gardner syndrome), attenuated FAP (also known as attenuated APC or AAPC), hereditary non-polyposis colorectal cancer (HNPCC or Lynch syndrome), Peutz-Jeghers syndrome (PJS), and juvenile polyposis. Individuals who have one of these known syndromes, or who are at risk to inherit a known syndrome, are invited into the Registry. Participants in the Registry help us learn more about each of the specific conditions.

What if there is colon cancer in my family, but no known inherited syndrome?

If the known inherited syndromes cause 5-10 percent of all colon cancer, what causes the rest? We know that another 20-30

percent of all colon cancers occur in individuals who have a family history of colon cancer (see chart) but no known syndrome or genetic mutation. We refer to this group of people as having an increased “family risk.” These patients make us believe there are more colon cancer genes to be discovered! Therefore, the Registry invites individuals to join who have 1) a strong family history of colon cancer; 2) an early colon cancer diagnosis (before age 50); or 3) an unusual number of polyps but no known condition or genetic mutation. These individuals and their families may help us identify NEW genes that may lead to colon cancer. Of course, diet, environment, or a combination of these factors may also play a role.

The remaining colon cancer cases (approximately 60 percent) occur in individuals without a known syndrome or strong family history. We call this group the “chance” category, as shown on the chart. Genes, diet, environment, or a combination of these factors may play a role in this category of colon cancers. Although people in the “chance” category are not invited into the Registry, we hope that the more we learn from the “known syndrome” and “family risk” groups, the more knowledge we will be able to apply to the “chance” group.

In Summary:

The chart represents all cases of colon cancer. Sixty percent of colon cancers occur by chance. People who fall into this category are **not** enrolled in the Registry. The remaining 40 percent of cases represent the people who are invited to join the Registry. **You are invaluable to the future of colon cancer research. We could not do it without your help!**

How to Reach Us

Registry Coordinator:

Local: (801) 585-1936

Toll-Free: (877) 422-6860

Email: registry.coordinator@hci.utah.edu

Some Excellent Web Sites

Colon Cancer:

www.huntsmancancer.org

www.oncology.com

www.ccalliance.org/index.html

www.mayohealth.org

www.healthfinder.org

Diet:

www.aicr.org

www.eatright.org