



# CORE<sub>news</sub>

FRED  
HUTCHINSON  
CANCER  
RESEARCH  
CENTER

Colorectal Research In Epidemiology

Volume 1

## CORE Family Studies

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## Announcing the CORE Newsletter

CORE Studies is pleased to send you the first issue of our Newsletter. Our aim is to keep you updated on the CORE Studies and to provide you with an educational resource. In this issue, you will find articles on colorectal cancer genes, useful web sites, study goals, news on colorectal cancer, genes and cancer, healthy lifestyles, and frequently asked questions.

In each issue of CORE News, we will provide you with information about the progress of the study. We thank you again for your generous contribution as a study participant. We hope you benefit from the information in the newsletter and your participation in the study. We also hope you will let us know what you find useful in the newsletter and what other topics you would like to hear about.

## Study Staff

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### Genetic Counselor: Julie Culver MS

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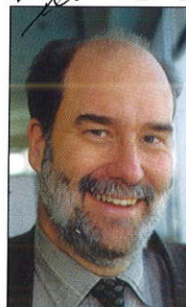
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Greetings!

*Thank you for your participation in our CORE Family Studies. These studies, which will continue through 2001, would not be possible without your involvement. We truly appreciate your participation and are pleased to report back to you on some of the progress we have made so far.*

The **CORE (Colorectal Research in Epidemiology) Family Studies** is part of an international effort aimed at investigating the many factors that may contribute to cancer risk. The Fred Hutchinson Cancer Research Center in Seattle, Washington is one of six research institutions around the world involved in this collaborative research on this serious disease. We hope the results of these studies—both from individual centers and from our collective efforts—may provide new information about how lifestyle, environment, dietary factors, ethnic background, and genetics contribute to cancer risk. Our goal is to find better ways to prevent, detect, and treat this disease.

We look forward to keeping you involved and informed.



*Polly A. Newcomb*



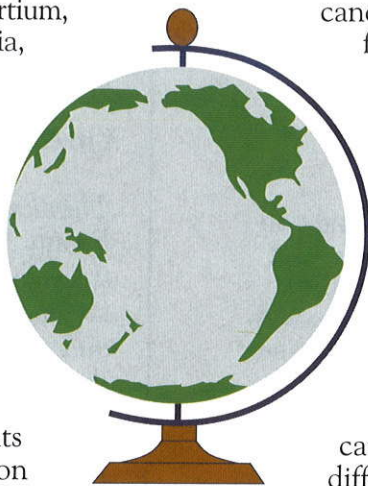


## The International Effort

CORE Studies at the Fred Hutchinson Cancer Research Center is one of six registries across the world that make up the international effort called the Cooperative Family Registry for Colorectal Cancer Studies (CFRCCS). The other registries include the Cancer Research Center of Hawaii; the Mayo Clinic in Rochester, Minnesota; Cancer Care Ontario in Canada; the University of Queensland in Australia; and the University of Southern California Consortium, including the Universities of Southern California, North Carolina, Colorado, Minnesota, Arizona, Dartmouth Medical College, and the Cleveland Clinic Foundation. Collectively, these registries plan to enroll more than 6,000 families. Families enrolled will be at low, intermediate, and high-risk for colorectal cancer and will come from geographically and ethnically diverse backgrounds. After enrolling families, the registries plan to:

1. Collect family history, medical history, and lifestyle information, along with blood or tumor samples, from participants with and without a family history of colon cancer. This will provide a resource for studies on the causes of colon cancer.
2. Identify a population at high risk for colon cancer that could benefit from new preventive and therapeutic strategies.

Without the collaborative effort of these registries and the help of the many individuals who participate, it would take years for any one researcher to be able to identify enough families and collect the key information needed to begin a study. This joint effort will quicken the pace of research on colorectal cancer.



## The Local Effort

Researchers at the Fred Hutchinson Cancer Research Center are studying the many factors that may contribute to risk of colon cancer, such as lifestyle, environment, dietary factors, ethnicity, and genetic background. The initial goal of the CORE Family Study is to establish a family registry, a collection of data from families both with and without colorectal cancer. This registry will provide a resource for further studies. Specific scientific questions we hope to answer are:

- What are the inherited genetic changes that increase risk of colorectal cancer?
- Why do some people with inherited changes develop cancer while others do not?
- Can lifestyle and dietary factors affect the risk of developing colorectal cancer?
- Are treatment courses for colorectal cancer with an inherited genetic basis different than colorectal cancer without an inherited genetic basis?
- How do families cope psychologically and emotionally with inherited cancer risk?

The knowledge gained by answering these questions will allow for improved efforts in cancer prevention, early detection, counseling, and treatment.

## Local Participation

We are inviting three groups of individuals to participate in our studies: individuals from western Washington who have recently been diagnosed with colon and/or rectal cancer, their relatives, and individuals from the general population who have not had colorectal cancer. Depending on the group you are in, we got your name from one of the three sources below.

- 1) If you have recently been diagnosed with colorectal cancer, your name was provided to us by the Cancer Surveillance System (CSS), a registry that collects information on the incidence of cancer. Washington State law requires that all doctors report cases of cancer to the CSS. In fact, the law requires that many conditions of public health concern (such as measles and chicken pox) be reported to the state by hospitals, laboratories and physicians. CSS then releases limited information only to approved research projects, such as CORE Studies. Researchers who use this information are trying to identify potential causes of cancer, find possible treatments for cancer, and plan public health programs. Researchers follow strict ethical guidelines such as keeping all information completely confidential.
- 2) If a family member has been diagnosed with colorectal cancer, he or she may have provided your name to us and gave us permission to call you.
- 3) If you do not fit into the categories above, we obtained your name from the Washington Department of Licensing or the Health Care Finance Administration (which manages Social Security and Medicare). Fred Hutchinson has agreements with these organizations so that research studies can find individuals from the general population. These agreements provide us with limited information and have strict rules about confidentiality and security.

We hope you are comfortable with the way that we obtained your name. If you have any questions or concerns, please feel free to contact us at our toll-free study line 1-800-276-0127.



# Genetics 101—Genes and Cancer

by Julie Culver, MS

You may have heard that cancer is caused by genetic changes in cells. This article will explain how genetic changes are related to the development of cancer and why an individual who is born with an alteration in a gene may be more prone to developing cancer.

## What is cancer?

Cancer occurs when cells in the body become abnormal such that they divide and form more cells without control or order.

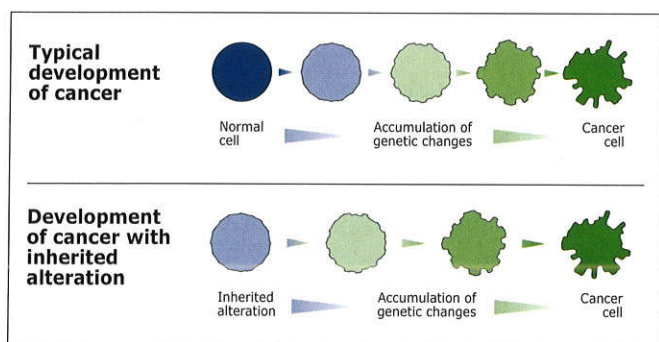
## What are genes?

Genes are the set of instructions inside our cells that tell the body how to grow and function.

## How are genes involved in cancer?

Certain genes are responsible for determining when cells divide. If such a gene has acquired an alteration causing it not to work properly, the cell may not be able to control when it divides. If the cell divides too quickly it may become cancerous. For a normal cell to become a cancer cell, several genes must acquire alterations. These changes accumulate slowly, which means that cancer is a process that develops over a period of time. Thus, cancer tends to occur more often in older individuals.

As an example, consider the development of colon cancer. Cells that have accumulated a few genetic alterations may grow into a benign growth called a polyp. If the polyp goes undetected, the polyp may acquire more genetic alterations and eventually develop into a cancer.



*This diagram shows how cancer can develop in fewer steps if someone has inherited a cancer susceptibility gene alteration.*

## What causes these genetic alterations that lead to cancer?

We know that some environmental factors, such as smoking or sunburns, can increase risk for genetic changes that can cause cancer.

However, most genetic alterations are thought to happen by chance. As we age, our cells undergo cell divisions, and with each cell division the genetic

material is copied. You can compare this process to retyping a letter. Just as there is an increased chance of making a typo when copying text, there is an increased chance for an error to occur when our cells are copying genetic material. Even though our cells have a "spell checker" that corrects errors, this mechanism can occasionally fail.

## What about individuals who have inherited genetic alterations that increase the risk of cancer?

You may have heard of individuals with a strong family history of cancer who are born with an inherited "susceptibility" to developing cancer. This means that a person may carry an inherited alteration in a certain type of gene that controls the growth of cells. Although the development of cancer requires alterations in several genes, a person who is born with such an alteration is one step closer to developing cancer than the average person.

In upcoming issues of the newsletter, this column will highlight new genetic discoveries to help keep you updated on this rapidly growing field.



## Julie Culver, MS — Genetic Counselor

Genetic counselors are health professionals with experience in the areas of medical genetics and counseling. With their unique blend of knowledge and psychosocial skills, they help to bridge the gap between the genetic information explosion in science and medicine by translating these genetic advances in a meaningful way to those who are affected by genetic conditions.



We at CORE Family Studies are fortunate to have our own genetic counselor on staff. Julie Culver, MS, is an invaluable resource for our research study. She is instrumental in the development of our newsletter and in keeping us updated about the latest in genetic developments. She also provides the study staff with ongoing consultation about genetic issues which directly impact decisions about this study.

If you are interested in finding a genetic counselor in your area, you can visit the Pacific Northwest Regional Genetics Group (PacNoRGG) website at <http://mchneighborhood.ichp.edu/pacnorgg/>.



## Specialist's Corner: Colorectal Cancer & Genetics

by John Potter, MD, PhD

Cancer of the colon and rectum, also called colorectal cancer, is the third most common cancer and is the second leading cause of cancer death in the United States. In year 2000 alone, an estimated 130,200 new cases of colorectal cancer will be diagnosed and 56,300 men and women will die from the disease. The average American has a 1-in-25 (4%) chance of developing this disease in his or her lifetime. These figures highlight the importance of colorectal cancer and the need for this disease to be better understood. Our research study, the CORE Family Study, is actively studying the genetic factors that are involved in causing this disease.

Most cases of colorectal cancer are not caused by inherited genetic factors. An individual who develops colorectal cancer is usually the only person in the family to get the disease. However, in some cases, colorectal cancer can occur in several family members. Such families may have a gene that increases the risk of colorectal cancer. The colorectal cancer genes that are already understood are explained here:

**HNPCC** (hereditary non-polyposis colorectal cancer)—sometimes also known as Lynch Syndrome—causes no more than 5% of all cases of colorectal cancer. Individuals who inherit an HNPCC gene are more likely to have colorectal cancer before age 50, and have an 80% likelihood of developing colorectal cancer during their lifetime. Typically, the individual's family members may also be affected with colorectal cancer or uterine cancer.

**FAP** (familial adenomatous polyposis)—FAP is responsible for less than 1% of all cases of colorectal cancer. FAP is an inherited condition in which hundreds of polyps<sup>†</sup> develop in the colon of affected young adults. Virtually all individuals with FAP are likely to develop colon cancer if the colon is not removed. FAP is also called adenomatous polyposis coli (APC) which is the name of the gene that, when inherited in an altered form, causes FAP.

**APC (I1307K)**—is a specific alteration in the APC gene that causes an increased risk of colorectal cancer. This alteration may be found in individuals with Eastern European Jewish (Ashkenazi Jewish)

descent and may lead to a somewhat elevated lifetime risk of colorectal cancer.

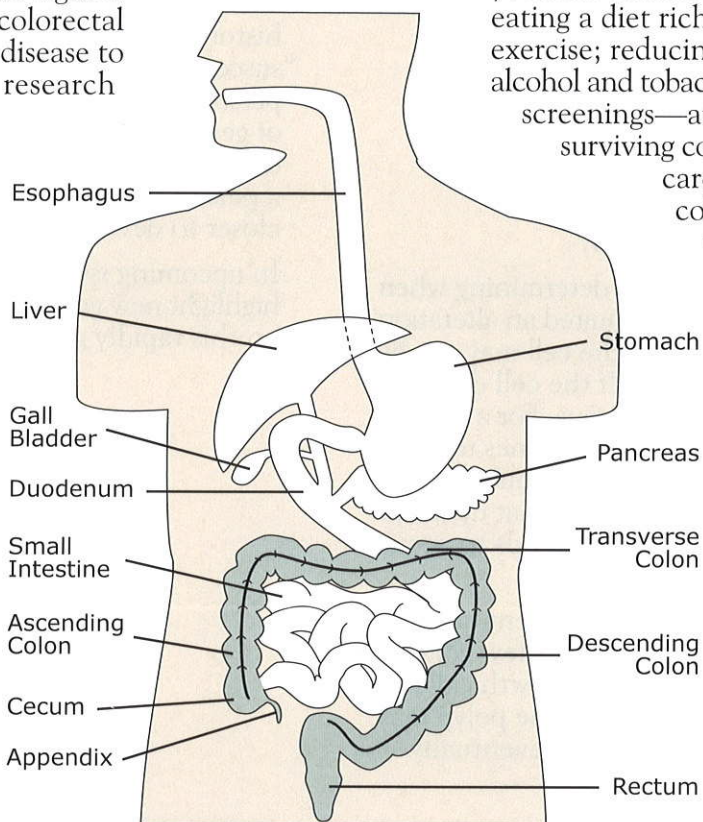
If you are interested in finding out whether you or your family members carry these genes, you should talk to your health care provider or a genetic counselor.<sup>††</sup>

Regardless of whether you carry a gene that increases your risk of colorectal cancer, the key is to protect yourself. Studies show that healthy behaviors—eating a diet rich in vegetables; getting regular exercise; reducing meat consumption; avoiding alcohol and tobacco; and getting regular colorectal screenings—are helpful in preventing and surviving colorectal cancer. Ask your health care provider more about what colon screening is appropriate for your age group and family history.

Regardless of your genetic makeup, living a healthy lifestyle and participating in colon screening are the most effective defenses against this disease.

<sup>†</sup> Polyps are abnormal, mushroom-like growths. They are found in the colon and rectum and are the earliest detectable and not yet cancerous stage of colorectal cancer.

<sup>††</sup> A listing of local genetic counselors is available from the Pacific Northwest Regional Genetics Group. See "Genetics Counseling and Testing Centers" box.



### On the Web

Want to know more?  
Here are some informative links:

[http://cancernet.nci.nih.gov/wyntk\\_pubs/colon.htm](http://cancernet.nci.nih.gov/wyntk_pubs/colon.htm)

What You Need To Know About™ Cancer of the Colon and Rectum—a brochure with information about risk factors, early detection, symptoms, and treatment of colorectal cancer.

[http://cancernet.nci.nih.gov/Cancer\\_Types/Colon\\_And\\_Rectal\\_Cancer.shtml](http://cancernet.nci.nih.gov/Cancer_Types/Colon_And_Rectal_Cancer.shtml)

Links from the National Cancer Institute on treatment, clinical trials, genetics, screening, and support for patients and families with colorectal cancer.

<http://www-dccps.ims.nci.nih.gov/CFRCCS/index.html>

Cooperative Family Registry for Colorectal Cancer Studies, which is the international research effort on colorectal cancer that includes the CORE Family Study.



## Frequently Asked Questions

### What is colorectal cancer?

"Colorectal" refers to the large intestines, which are made up of the colon and rectum (*see diagram on insert page*). Colorectal cancer is cancer that originates anywhere in either of these two organs. It is the third most common cancer in the US after breast and lung cancer in women and prostate and lung cancer in men. There are about 130,200 new cases of colorectal cancer each year in the US.

### Who is at risk for colorectal cancer?

Here are some facts about colorectal cancer risk:

- Both men and women are at risk for colorectal cancer.
- Colorectal cancer is more common in people aged 50 years and older.
- A family history of colorectal cancer increases the risk of developing colorectal cancer.
- Colorectal polyps are early non-malignant manifestations of colorectal cancer. They can be detected and removed during a colonoscopy.
- Certain diseases of the bowel—such as ulcerative colitis—can increase the risk for colorectal cancer.

### What are the screening tests for colorectal cancer?

The tests that are currently available include:

- **Fecal Occult Blood Test (FOBT)**—a test that checks for blood in the stool.
- **Sigmoidoscopy**—an examination during which a trained doctor looks at the inside of the rectum and lower portion of the colon through a lighted tube. The doctor may collect samples of tissue or cells for closer examination.
- **Colonoscopy**—an examination during which a trained doctor looks at the inside of the entire colon and rectum through a flexible, lighted instrument called a colonoscope. This examination requires some dietary preparations. The doctor may collect samples of tissue or cells for closer examination.
- **Double Contrast Barium Enema**—a procedure that involves X-rays of the lower intestine taken after a patient is given an enema containing a white dye, or barium, followed by an injection of air. The barium outlines the intestine on the x-ray film.

### Is the information I provide confidential?

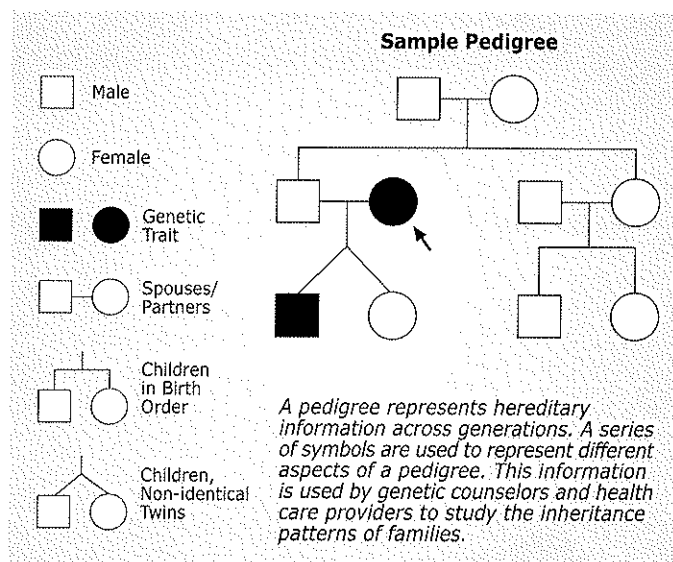
Yes! Confidentiality is an integral part of the CORE Family Studies. All information you provide will be kept confidential and is protected by a federal Certificate of Confidentiality. This certificate protects against the release of information about you collected during the course of this research to anyone, including a court of law.

In addition, all information you give us is stored using only an identification number. All computer data files are password secured and can only be accessed by designated study staff. Study results will only be reported for the study as a whole and never in ways that allow the individuals involved to be identified.

### What is a pedigree?

A pedigree, commonly referred to as a family tree, is a simplified diagram of family ancestry. It includes information about how families are related and how a particular biological trait or condition has been inherited.

See our next issue for "Discovering Your Family Tree."



## Genetics Counseling and Testing Centers



With the increasing availability of genetic testing for cancer susceptibility, many consumer and professional groups have recommended genetic counseling for those who are interested in genetic testing. Genetic counseling can provide information about genetic risk factors, screening recommendations, and risk-reduction techniques, while attending to psychosocial needs.

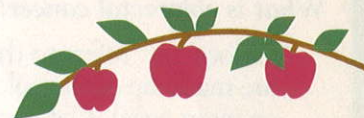
The Pacific Northwest Regional Genetics Group (PacNoRGG) is a federally-funded group of genetic services providers, consumers, public health professionals, and educators working together to improve genetic services for families in our region.

The PacNoRGG web site, <http://mchneighborhood.ichp.edu/pacnorgg/index.html>, includes a complete listing of genetics services providers in AK, ID, OR and WA. PacNoRGG can also be contacted by phone, 541-346-2610 or e-mail, [pacnorgg@oregon.uoregon.edu](mailto:pacnorgg@oregon.uoregon.edu).



## Eating For Good Health

Hundreds of research studies have found that eating fruits and vegetables can help fight cancer, heart disease, and stroke. By eating a minimum of 5 fruits and vegetables per day, you will improve your diet for a longer, healthier life!



- Make fruits and vegetables part of every meal.
- Drink 100% fruit or vegetable juice.
- Pile vegetables on sandwiches, such as cucumber, sprouts, tomatoes, peppers, and carrots.
- Include more vegetables and less meat in stir-fry, casseroles, and other dishes.
- Choose dark green salad greens—they are more nutritious.
- Mix vegetable colors, such as green (such as broccoli or spinach), orange (carrots or squash), and red (tomatoes or bell peppers).
- Add fruit to cereal, ice cream, or pancakes.
- Snack on fruit and veggies at work.
- Make eating veggies and salads easier by buying pre-cut vegetables and salad mixes.

### How can we improve this newsletter?

Comments or suggestions for articles and features to improve our newsletter can be emailed to Allyson Templeton: [atemplet@fhcrc.org](mailto:atemplet@fhcrc.org). We would love to hear from you!

### How should I give you my new address & phone number if I move?

If you move, please call the project line at 1-800-276-0127.



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