

What is involved?

This project is focused on collection of detailed information on study participants and their relatives to help create a resource that will be helpful to colon cancer researchers. To enroll in the Colon CFR a person must sign a written informed consent and provide a detailed family history. Specific other family members would also be invited to enroll, if the participant is agreeable to their being invited into the study. The enrollee will also be asked to complete a detailed questionnaire about medical history, diet, exercise, medication use and many other lifestyle issues. A blood specimen will be collected. In addition, the investigators will ask for release of medical records and samples of tumor tissue if there is a history of cancer and if that tissue is stored somewhere. No other procedures are required.

This study will not make your health better, nor is there any assurance that you will get any sort of test results from this study. If you would like to consider doing something to help make progress in understanding colorectal cancer, you may be interested in enrolling in this study.

How can I learn more or become involved?

Your Mayo Health Care provider has shared this brief introduction with you because they thought you might be interested in the Colon CFR. Please understand that your current and future care at the Mayo Clinic will not be affected by whether or not you participate. If you would like to learn more about this study, you can call us or write to us at:

Mayo Clinic
Attn: Sherry Gustafson
Charlton 6-124
200 1st St SW
Rochester, MN 55902
866-514-8452 (toll free)

Colon Cancer Family Registry:

**A Multinational National
Institute of Health-Sponsored
Consortium**

Introduction:

It is known that colorectal cancer (CRC) can cluster in families. That is why families have served as the cornerstone for studies of the causes of this common disease. While a few specific hereditary disorders have been discovered, the cause of colorectal cancer in most individuals and families remains unexplained. Recognizing the importance of identifying causes for susceptibility to colorectal cancers, both environmental and genetic, the National Cancer Institute (NCI) in 1997 funded the Cooperative Family Registry for Colorectal Cancer Studies, renamed the Colorectal Cancer Family Registry (Colon CFR) in 2001.

What is the Colon CFR?

The Colon CFR is an international consortium of six Registry centers and an Informatics Center. The participating centers are:

- University of Hawaii - Honolulu, Hawaii;
- Fred Hutchinson Cancer Research Center - Seattle, Washington;
- Mayo Clinic - Rochester, Minnesota;
- University of Southern California - Los Angeles; California
- University of Queensland - Brisbane, Australia
- Cancer Care Ontario - Ontario, Canada.
- Research Triangle Institute – Research Triangle Park, North Carolina

This consortium is dedicated to establishing a registry that will assist in discoveries about the causes of colorectal cancers. Currently about 12,000 families from around the world are enrolled. Researchers can apply to the Colon CFR for use of this resource as an efficient way to conduct their research. That is, many different researchers can study the same families instead of each researcher having to recruit their own study population.

How is my privacy and confidentiality protected?

No person's identity is ever shared with any researcher outside the Mayo Colon CFR and information learned about you through this study does not become part of your medical record. All identities are protected by use of a unique identifier number and only the Mayo CFR study personnel know your identity.

Who could enroll?

If you had colorectal cancer and have two first degree relatives (parents, brother, sister, children) with colorectal cancer, one of which was diagnosed under 50 years of age, you could enroll.

or

If you had colorectal cancer and your family has a known genetic condition that can cause colorectal cancer, you could enroll.