To realize the full potential of collaborative research involving colorectal cancer families to reduce the global impact of the disease.

Colon CFR Update

Allyson Templeton
Colon CFR Consortium Coordinator; Fred Hutchinson Cancer Research Center

We are pleased to report on our collective effort to reduce the global impact of colorectal cancer. In 1997, the Colon Cancer Family Registry (CFR) set out to build a comprehensive, state-of-the-art resource to be used for collaborative research for years to come.

With your efforts, more than 39,000 participants have enrolled in the Colon CFR: 10,000 individuals affected by colorectal cancer, 25,000 of their family members and spouses, plus more than 4,000 individuals from the general population who do not have colorectal cancer. (See page 2.) Although most of the study participants live near Colon CFR recruitment centers in the United States, Canada, Australia, and New Zealand, they come from across the globe.

You have answered many questions, some of which required significant effort to answer. You have donated more than 30,000 blood samples, and nearly 10,000 of you who had cancer allowed us to collect tumor samples. These precious biospecimens have facilitated studies at the genetic and molecular levels.

Without your contributions, our collaborative mission to study and prevent colorectal cancer would not have succeeded. Instead, the information and samples you gave formed the basis of more than 184 research projects. These studies have ranged in scope from epidemiology, genetics, behavioral research, clinical and translational research, gene-environment interactions, and more. For all of your time and generosity, we thank you!
Colon CFR-Related Resources

Valeria Rodriguez
Colon CFR Management Associate; The Scientific Consulting Group, Inc.

The National Cancer Institute (NCI) has funded the Colon CFR infrastructure since 1997. The Colon CFR is one of the world’s largest resources for researchers who conduct population and clinic-based interdisciplinary studies on the causes, prevention, and clinical management of colorectal cancer. The Colon CFR has successfully enrolled families from across the spectrum of risk for colon cancers. For more information on family enrollment in the Colon CFR, visit [http://epi.grants.cancer.gov/CFRfamilies.html](http://epi.grants.cancer.gov/CFRfamilies.html).

NCI also provides information and resources to individuals diagnosed with or at risk for colon or rectal cancer. Specific information on topics such as prevention, treatment, complementary and alternative medicine, clinical trials, and support is available at [http://www.cancer.gov/cancertopics/types/colon-and-rectal](http://www.cancer.gov/cancertopics/types/colon-and-rectal).


Reducing the Risk of Colorectal Cancer

John Baron, M.D.
Professor of Medicine, Dartmouth Medical School; Co-Principal Investigator, Dartmouth Colorectal Cancer Family Registry Consortium

A variety of steps might prove helpful in preventing and detecting colorectal cancer. A few measures appear to be beneficial but cannot be recommended confidently because the evidence is not strong enough, they involve side effects, or their effects seem modest. Many of the dietary and lifestyle theories listed below are being studied further using information provided by Colon CFR participants and the scientific community.

- **Have a colonoscopy**
  Finding and treating colorectal cancer early may prevent death from colorectal cancer. Through colonoscopy, polyps that may result in cancer can be detected and removed. Colonoscopy should be repeated at intervals recommended by your health care provider.

- **Consider taking aspirin**
  Although it may take several years—probably 10 or more—before regular aspirin use reduces the risk of colorectal cancer, studies have shown its preventive benefits. Talk to your physician before taking aspirin for cancer prevention as it can have side effects such as bleeding.

- **Exercise more**
  A lifestyle that does not include regular exercise also may be linked to an increased risk of colorectal cancer.

- **Adjust dietary choices**
  Some experts believe that a low-fat diet high in fiber, fruits, and vegetables may reduce colorectal cancer incidence. Several clinical trials have been negative, however, and many studies have not found such an eating pattern to be beneficial.

- **Avoid red meat**
  Many studies show that red meat—especially processed, as in salami or hot dogs—is associated with an increased risk of colorectal cancer. It is not known, however, if dietary changes will reduce the chances of getting colorectal cancer.

- **Avoid overweight**
  This makes good sense in general, but also has not been tested specifically in trials for effects on colorectal cancer.

- **Increase intake of calcium and vitamin D**
  These have shown promise in reducing colorectal cancer risk but further research is needed.

Much of the research regarding colorectal cancer prevention has focused on “sporadic” (nongenetic) cancers. It is likely that these factors apply to high-risk groups as well, but that is not known for sure. Because of its large numbers of participants, the Colon CFR is well poised to study these measures in both sporadic and high-risk groups.
Genetic Studies in Colorectal Cancer

Noralene Lindor, M.D.
Professor and Clinician, Mayo Clinic; Principal Investigator, Mayo Colorectal Cancer Family Registry

Tumor Genetics
It is widely appreciated that cancer of all types, at its root, is a genetic disorder. This does not mean that all cancer is inherited. In fact, most colorectal cancers develop related to mostly nonhereditary reasons, such as the simple act of aging. As we age, our cells have undergone more cell divisions than younger people’s cells, thus creating more chances for genetic errors to be introduced as the DNA is copied. Aging sometimes may result in enough “wear and tear” on the genes within the cells to produce an “out-of-control” cell that we call cancer. The Colon CFR is involved with exploring the genetic alterations found in nonhereditary colorectal cancers to try to better understand what makes a cell grow like a cancer and how cancers can differ from one tumor to another. This ultimately may help explain differences in tumor response to chemotherapy or radiation treatment. Studies on mutations in the BRAF gene in tumors and levels of methylation (which shuts off or turns on some genes) are being conducted in the Colon CFR with an eye toward identifying differences across ethnic groups. This study may help pinpoint why people with different ancestry have different risks for colorectal cancer despite having similar lifestyles.

Personalized Medicine
Genome-wide association studies (GWAS) are a recent development in genetic research. Using powerful new technologies, more subtle genetic differences can be sought more rapidly and cost-effectively than before. This has allowed comparisons of the genetics of people with colorectal cancer with those who do not have colorectal cancer. The Colon CFR is participating in several GWAS that have identified specific places where minor differences in the spelling of part of the human genome seem to result in small increases in colorectal cancer risks. These findings are quite different from discoveries of hereditary colorectal cancer syndromes (see below). Although not yet ready for clinical use, the long-term vision is that one day we will be able to test people for a panel of a dozen or more spelling variations that combine to determine risk for colorectal cancers. These types of variants may explain families who do not have typical hereditary colorectal cancer but still seem to have more colorectal cancer than is expected for an average family.

Hereditary Cancers
Fewer than 5 percent of colorectal cancer likely is due to a true hereditary condition, but these conditions tend to affect younger people and therefore affect lives greatly. The large number of families enrolled in the Colon CFR has allowed improved analyses on some of these hereditary conditions that are too rare to be studied adequately by any one medical center. The largest study ever done on families with Lynch Syndrome due to the MSH6 gene mutation is soon to be published in the Journal of the National Cancer Institute. The Colon CFR collaborated with centers in Europe to generate results that suggest that the cancer risks are similar to those seen in the more common Lynch Syndrome genes and that the cancers may develop on average in slightly older individuals. The largest study to date on families with Lynch Syndrome due to mutation in the PMS2 gene was published in a collaboration between the Colon CFR and researchers at The Ohio State University. This study showed some evidence for cancer risks that were somewhat lower than for the more common Lynch Syndrome genes. Families with MYH mutations now have more information based on a large study led by Colon CFR investigators in Toronto; even more detailed information is expected in the coming year. The Colon CFR also is helping to advance research on the pesky DNA misspellings known as “variants of unknown significance” that are discovered with some regularity when families have DNA testing for suspected hereditary syndromes. Only large-scale collaborations present much hope of unraveling the meaning of these variants. This information will be used to provide more selective cancer screening recommendations to families. If you or your family have a hereditary colorectal cancer disorder, be assured that your participation is making a difference in what is known about these disorders.

Family Health Promotion Project

Dennis Ahnen, M.D.
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Al Marcus, Ph.D.
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Jan Lowery, Ph.D.
Co-Investigator, FHPP, Assistant Professor, Department of Epidemiology, Colorado School of Public Health, University of Colorado Denver

The Family Health Promotion Project (FHPP) is a prospective randomized trial to evaluate a telephone-based intervention to promote colonoscopy in members of high-risk colorectal cancer families enrolled in the Colon CFR. A total of 632 participants were enrolled and completed a baseline questionnaire and followup surveys at 6, 12, and 24 months. More than 90 percent of the participants completed the 2-year study. Analyses of the baseline survey data show that these high-risk participants believe that colonoscopy screening is very effective and generally recognize and are concerned about their increased colorectal cancer risk. Baseline colonoscopy screening rates increased with age, income, and risk level. Having colorectal cancer in the family is particularly stressful for women. Most participants are aware of the role of genetics in determining colorectal cancer risk and know that genetic testing is available, but the rates of genetic advice and testing remain low in this group and among participants at risk for having an inherited predisposition for colon cancer. Preliminary analysis of outcomes data suggest that the intervention was effective in increasing colonoscopy rates by as much as 26 percent as compared to only 8 percent in the control arm. Analyses are under way to explore potential mediating variables to explain this positive effect.
Testimonials by Study Participants

We invited a few study participants to share what participation in the Colon CFR has meant to them. Reasons for joining the study vary, but one characteristic is constant for all participants—the contribution that each and every participant makes helps us further our knowledge of the causes and prevention of colorectal cancer.

Megan, Australasian Colorectal Cancer Family Study

“I was very happy to be of help. Anything that could save lives in the future is worthwhile. My immediate family (mother and sister) also agreed to be involved. I recommended that the research team contact my auntie, as I knew she also would take part. Apparently, it grew and grew, with more and more family members participating. The study has been a painless experience. My mother, husband, sister, brother-in-law, niece, and I went to our local regional hospital to give the blood sample. The staff members were wonderful, happy to take our blood and help with the research project.”

In 2002, Carolyn joined the Colon CFR on behalf of her late beloved brother, David. “I felt that anything that might help in research of this disease would be worthwhile,” she said. The experience also led her to urge friends to have regular colonoscopies. “I tell them that if my brother had been told to have one a year earlier, he might still be here.”

Ontario Familial Colorectal Cancer Registry

In Memoriam

Professor Jeremy Jass, founding Principal Investigator of the Australasian Center of the Colon CFR, passed away at the age of 57 of brain cancer. Dr. Jass was a brilliant world-class colorectal pathologist who produced original work in the form of papers, books, and lectures. He made major contributions to the understanding of colorectal cancer, particularly the pathology of different forms of colorectal cancer and cancers that occur in Lynch Syndrome. To honor his memory and his many contributions, the Colon CFR has named its vast repository of pathology data and tumor material the Jeremy Jass Memorial Pathology Bank. We request that all scientists who make use of this resource acknowledge this bank in Dr. Jass’s name. We will miss Dr. Jass’s wit, gentle soul, warmth, and passion for science and for helping patients, but we are comforted by knowing that his work, which meant so much to him, will live on through the Colon CFR and the careers of the many scientists that he influenced.

Pamela McAllister
Community Representative, Colon CFR Steering Committee, Colorectal Cancer Coalition

“My journey into patient advocacy and interest in gastrointestinal cancers began with the loss of my 46-year-old brother and 48-year-old uncle to colon cancer and followed with my own diagnosis of mucinous cystadenocarcinoma of the appendix at 47 years old in 1993. After survival, I retired from medical research and devoted myself to patient advocacy. I hope to assist patients, their loved ones, and the general population through my efforts to represent the needs and wishes of the patient community to nonprofit and government groups that provide services to reduce the burden caused by colon cancer.”

John Stubbs
Community Representative, Colon CFR Steering Committee, Cancer Voices Australia

“I have been a bone marrow transplant survivor of chronic myeloid leukemia for more than 8 years. Currently, I am Executive Officer of Cancer Voices Australia; hold government positions at both the board and committee levels; and have contributed to government policy on cancer, cancer services, and the value of consumer involvement. In my advocacy role, I have contributed to and edited a number of booklets, including “Cancer—how are you travelling?” I also am a regular speaker at medical conferences and seminars on cancer advocacy, clinical trials, and health-related issues.”

Carolyn with her brother, David

Megan (top row, left) and her family

Carolyn (top row, middle) and her family

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Bob’s Quick One-Pan Posole Recipe

This is an easy to make, low fat, low calorie recipe with lots of flavor. A perennial favorite at our house!
Preparation time: 40-45 minutes from chopping to serving
Serves 4-6

Note: This can be made as a vegetarian recipe. Just ditch the chicken or pork and use vegetable stock. It’s still delicious.

Ingredients

- 1 lb boneless pork loin or chicken breast (chopped ¼ to ½ inch pieces)
- 1 29-ounce can hominy (drained)
- 1 cup chopped sweet onion
- 1 chopped green pepper
- 1 chopped sweet red pepper
- 4 cloves chopped garlic
- 2-3 teaspoons oil
- 5 cups low sodium chicken or vegetable stock
- About half a jar of green salsa
- Some chopped cilantro
- Taste first, then season with salt and pepper to your liking
- Several 6 inch corn tortillas

Directions

In a large pot heat oil and lightly brown pork, about 5 min. Add onion, garlic and peppers, allow them to sweat, about 2 min. Add chicken stock and hominy and bring to a boil. Lower heat and add the salsa, simmer for about 20 min. About 5 minutes before you are ready to serve up, place several corn tortillas (we do 2 each) in your oven or a toaster oven. Cook until they start to ‘bubble’ up. You can break them up and dunk them in the soup like corn chips or break them into smaller pieces and put them in the soup. Sprinkle the cilantro atop the soup when serving.

Where can I get more information about cancer?

You can call the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) and they will answer your questions and send you information at your request.
Greetings

We hope you enjoy this special consortium-wide edition of our newsletter. After more than 13-years in existence we thought you may be interested in taking a peek at the magnitude of our combined accomplishments, site by site, person by person. The efforts of researchers and participants alike have made this Colon Cancer Family Registry the richest and most comprehensive resource of its kind. Inside you'll find, among other things, information on recruitment numbers, a sample of some studies utilizing the information participants have provided over the years, and also statements from other folks like you who have contributed to this resource. Plus, we included another yummy recipe since it's our staff's favorite newsletter feature.

Happy reading!

Polly a Newcomb

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