Colon Cancer Family Registry Update

The Colon Cancer Family Registry (C-CFR) has become the largest single resource for colorectal cancer (CRC) research in the world because of its size (over 35,000 participants) and the quality of data families such as yours have provided. Your participation has allowed and encouraged collaborative research with some of the best cancer research groups in the world.

Greetings!
We hope you’re warm and healthy this winter, and that this edition of CORE News helps you stay that way with health news you’ve made possible. There are several things we’d like to share with you in this newsletter:

► An article highlighting how certain medicines can cut the chance of dying from colon cancer. This research builds upon information from CORE Studies/Colon Cancer Family Registry (CCFR) participants like you.
► Two potential sources to help cover the cost of colon screenings.
► New ways of working together. Now you can email us! Also, some of you will be asked to do a paper version of our interviews. Many of you have asked about these methods of communication, and now they’re available.
► A personal story from David Little, who shares how his lifestyle influenced his decision to join and continue participating in the Registry.
► Finally, we formally invite you to provide feedback about your experience being a part of CORE Studies.

Every time you take time out of your day to complete a questionnaire or respond to other questions, you help advance the world’s knowledge of the causes and treatments of colorectal cancer. As always, thank you so much for everything you do for the registry, as well as for those who benefit from this work.

Sincerely,

Polly A. Newcomb
Principal Investigator

Bill Grady
Co-Principal Investigator

Help Us Help Everyone
From time to time, we get asked, “Can’t I just fill out a questionnaire and mail it back to you?” Phone interviews, which usually take about fifteen minutes or less to conduct, aren’t for everyone. For some, the demands of daily life make them wish there were other options.

Now paper versions of the interviews are here! You’re likely to receive one of the paper follow-up interviews if you meet one of these criteria:

► You asked us for a paper version the last time we talked on the phone;
► You tell us about circumstances that make it difficult to stay on the phone (for example, certain physical conditions, or unpredictable phone connections);
► We have a valid mailing address for you, but we haven’t been able to reach you by phone.

Look for a tan envelope in your mailbox. Inside, you’ll find 1) a multiple-choice questionnaire with the same questions we’d ask you by phone, 2) a contact update form, 3) an inquiry about your interest in being contacted by email in the future, and 4) a request for feedback about your experience being a part of this study.

Pop those into the pre-paid return envelope, and your interview is complete! (It’s possible we might call once or twice to clarify an answer.) We’re developing an online follow-up interview that we hope to debut sometime in 2012.
David Little: A Body in Motion

The idea of eating his main meal in the evening doesn’t sit that well with David Little. “You don’t want to sit there with a full stomach in the evening,” he says. Eating in the mid-afternoon allows for additional work before calling it a day.

In fact, sitting around in general doesn’t agree with him. So although David is retired and living outside a small Swedish village, he keeps busy year-round. On a day in late October, his schedule included: helping a neighbor move furniture; removing rocks to plant berries bushes; a midday (main meal) of homegrown kale, bread and cheese; and then more small tasks around the house.

David’s interests influenced his decision to participate in the Colon Cancer Family Registry. “I thought it’d be interesting to compare my diet,” and its effect on his health to that of his ten siblings. Mostly vegetarian for the past 40 years, all the vegetables he and his partner Elizabeth will eat for the year are home grown.

During the summer, he works in the garden about six hours a day, six days per week. Beans, potatoes, leeks and other plants populate the large garden. Neighbors also share their apples and mushrooms, which he preserves for winter meals.

You’re probably thinking it’s easy for a retired 67-year-old guy to say everyone should raise their own veggies and be more active. And even David admits he’s not exactly part of the mainstream. But research supports some of David’s ideas. A study led by Dr. Anne McTiernan found that regular, moderate-to-vigorous exercise reduces a risk factor tied to development of colon polyps and cancer in men.

And if David Little has given you some food for thought, he’d probably count that as a job well done.

Your Views And Your Contact Information

What’s it like on your end of the phone line? Please tell us: what you like—or don’t like—about being part of the Registry, things you’d like us to do differently, why you stay involved.

Now we can use email to communicate about upcoming interviews and other aspects of participation in the Registry.

You can share your experiences being in the Registry, update your contact information, and tell us your preferences regarding email contact by:

1. Calling and talking with Lisa, Kassidy, or Lederle;
2. Emailing us at corestudies@fhcrc.org; or
3. Filling out the enclosed form and returning it in the postage paid envelope.

When you tell us what you think, we can improve two things: your experience with the registry, and the quality of our research into the causes and prevention of colorectal cancer.

Free Cancer Screenings in Washington State

If you live in Washington state, there’s another potential resource for a free colonoscopy: the Breast, Cervical and Colon Health Program. Don’t be thrown by the name—the early detection program provides free access to services to both men and women who are considered low-income. This refers to people who fall below 250% of the federal poverty level, a measurement that changes every year.

You’re eligible for the program if you are:

- A woman between 40 and 64 years old
- A man between 50 and 64 years old
- Uninsured or underinsured
- Low-income
- A person of color or a member of a sexual minority

Usually the patient receives a fecal occult blood test (FOBT) or fecal immunochemical test (FIT) first. Then, if the person is at high risk for developing colorectal cancer, a colonoscopy will follow.

Despite statewide funding cuts, the program is still available in all 39 counties. As of November 2011, providers in the most heavily populated counties (King, Pierce, Snohomish and Spokane) confirmed they were screening patients.

To find a provider near you, call the Breast, Cervical and Colon Health Program at 888-438-2247. Or go online at http://www.doh.wa.gov/cfh/bcchp/default.htm.
Seeds of Hope: The Figg Tree Foundation

People at risk for certain cancers seem to find offers of help everywhere. A quick Google search for “breast cancer screening programs” and “colon cancer screening programs” reveals more than 14 million results for the first…but about four million for the second. Sometimes it seems people who need low-cost or free colonoscopies get left behind, so to speak.

Tammy Figg was 27 years old—and six weeks away from her wedding day—when she got sick. She was lucky, though: a foundation was set up to help pay bills related to her colon cancer treatment. Now she’s turned the Figg Tree Foundation into a financial resource for others challenged by colorectal cancer. “We’re not a Susan G. Komen kind of organization, with lots of public funding,” Tammy says. “It’s just my husband and me, doing fundraising events seven times a year.”

Still, the Figg Tree Foundation fulfilled 31 grants in 2011, mostly for colonoscopies. The Missouri-based non-profit organization prioritizes prevention. It also provides financial assistance to cover:

- Other diagnostic testing including fecal occult blood tests and MRIs
- Medical bills for cancer treatments
- Laboratory expenses
- Infertility due to cancer treatments

Once approved, the foundation can offer up to $10,000 in financial aid per individual, per calendar year. Unfortunately, there is a grant wait list. But Tammy notes her organization is one of the only non-profits to offer financial aid with few restrictions. “I don’t care how many kids you have,” Tammy explains, “I don’t care if you have kids. No one’s prepared to get sick.”

Now that her treatment is complete, she runs the foundation, raises a family with her husband, and holds a full-time job.

Over time, she hopes her foundation will share something in common with the big-name foundations: sponsors who could help fund more grants.

For more information, go to http://www.figgtree.com/.

Protection in an Over-the-Counter Pill?
NSAIDs and Colorectal Cancer (CRC)

“I don’t take any pills. Can we skip these questions?”

We ask you those questions about medications at each interview because two recent studies—one of which uses information contributed by readers of this article—show long-term use of certain over-the-counter pills can reduce the risk of dying from CRC.

Previous studies have shown using NSAIDs (non-steroidal anti-inflammatory drugs) can help protect people from developing new and recurring tumors. That use may also “…translate into slower growth of tumors,” says Anna Coghill, a researcher at the Fred Hutchinson Research Center. And the longer one used the pills, the more effective the protection.

Coghill and Dr. Polly Newcomb, one of the lead scientist of CORE Family Studies/ Colon Cancer Family Registry, examined the information provided by people like you. They learned patients who used NSAIDs regularly before their diagnosis were about 20% less likely to die of colorectal cancer, compared to those who never used them. People with proximal disease (colorectal cancers found on the right side of the colon or in the part that crosses the abdomen) were most likely to survive.

This bit is important: cancer screening is less effective in finding proximal disease, and these patients usually have a lower chance of surviving their cancer diagnosis.

Coghill also analyzed data from the Women’s Health Initiative (WHI), the long-term study of women and colorectal cancer, cardiovascular disease, and breast cancer. The results strengthened the conclusions of her previous research. Women who’d taken NSAIDs before enrolling, and continued use for at least three years, were 30% less likely to die of colon or rectal cancer.

But before you stockpile ibuprofen, Coghill recommends consulting with your doctor first. While useful, NSAIDs can also affect your risk of heart disease, especially if you’re taking a COX-2 inhibitor like Celebrex.

If you would like to read a summary of Coghill’s latest study, contact us at: corestudies@fhcrc.org.
Here's a recipe for roasted vegetables that can help you eat healthier year-round. Use a dash of fresh or dried herbs, and consider including a veggie you haven't tried before. Kassidy, one of our interviewers and chef in this photo, tested this dish's appeal on hungry teenagers—and they actually came back for seconds!

Kassidy's Simply-Roasted Vegetables

| 2 carrots | 1 large sweet potato or yam | Olive oil |
| ½ Danish squash | 2 cups green beans | Salt |
| 1 red onion | 1 yellow bell pepper | Pepper |
| 1 bunch asparagus | 1 red bell pepper | Dried rosemary |

1. Preheat oven to 425 degrees.
2. Wash and cut up vegetables. The smaller you slice them, the quicker they cook. Peel and seed squash. Slice squash, onion, carrots, and red and yellow peppers into 1 ½” pieces. Peel sweet potato or yam and slice into ½” thick rounds. Cut the bottoms off of the asparagus. Snap off ends of beans.
3. Put all vegetables in a large bowl and drizzle lightly with about 2-3 tablespoons of olive oil. Mix to coat. Season with salt, pepper and rosemary.
4. Spread the mixture in a single layer on a baking sheet and put it in the oven on the middle rack. Check the vegetables for doneness every 10 minutes, moving them gently with a spoon.
5. Vegetables should be done in about 30 minutes, when they are cooked through, but still firm. Serve with rice as a main dish, or by itself as a side dish.

If you have a favorite healthy and tasty recipe you’d like to share, please email us at corestudies@fhcrc.org.

Study Staff

Investigators:
Polly A. Newcomb, PhD, MPH
Bill Grady, PhD, MD

Project Manager:
Doug Fisher, MA

Newsletter Editor:
Lisa Myers Bulmash

Genetic Counselor:
Mercy Laurino, MS, CGC

Correspondence Coordinator:
Renae Lydum

Biospecimens Team:
Cara Ganders, Jessica Falksen,
Terry Huang, Hannah Purkey,
Candace Hamilton, Carie Deems

Study Phlebotomist:
Kassidy Benoscek

Research Interviewers:
Lederie, Lisa, and Kassidy

Database Team:
Douglas Snazel and Hiliya Negede

Contact us:
Fred Hutchinson Cancer Research Center
P.O. Box 19024, M4-B402
Seattle, WA 98109-1024
1-800-276-0127 corestudies@fhcrc.org

Address Service Requested

1100 FARRVIEW AVE N, M4-B402
Fred Hutchinson Cancer Research Center
Seattle, WA 98109-1024
P.O. Box 19024

PERMIT NO. 147
SEATTLE, WA
PAID
U.S. POSTAGE
PAID
STANDARD
PRODUCT