Greetings!

Hello again from the CORE Family Studies—the Seattle Colon Cancer Family Registry! All of us here hope 2013 brings you happiness and good health. You’ve shared so much with us over the years, and we’d like to share some of what we’ve learned from you. A few items you’ll find:

- Illuminating survey responses from you about being in the Registry, organized by theme
- Selected examples of what happens to all the information you provide
- The launch of our new website!

And like us, the National Cancer Institute believes the longer we stay in touch with our participants, the more we learn about cancer’s impact on multiple generations of a family. So as we’ve been doing since 1999, we will contact you for another brief follow-up interview (about ten minutes long). Choose to do the interview over the phone or on paper—either way works for us!

Everything we know about colorectal cancer begins with people like you: individuals affected by colorectal cancer who are willing to share what they know with researchers. Thanks to all of you for your participation, and for the time and effort you’ve committed to this important work.

Sincerely,

Polly A. Newcomb, PhD, MPH
Principal Investigator

You collect a lot of information. What do you do with it?

As a registry, we collect colorectal cancer-related information via questionnaires, medical records, and biospecimens like tumor samples. We do this so carefully screened researchers can use the data to study specific aspects of this disease. Here are two examples of how the information is used:

1. Researchers at the Hutchinson Center, the University of Melbourne (Australia), and the Mayo Clinic are developing a model for predicting colorectal cancer risk. The ultimate goal is to develop a method by which a person could answer a series of questions, then get feedback from a database on their risk of developing colorectal cancer.

2. Scientists are looking at the various characteristics of colorectal cancer tumors to understand which types of radiation and chemotherapy are most effective in treating different types of cancers.
We’re Nothing Without You: Scientific Articles Based on CORE Studies

In our participant surveys last year, some of you urged us to share scientific conclusions that arise from the information we collect – even if they were “preliminary results,” as one person put it. We hear you! Below are short summaries of a few studies.

- Colorectal and other cancer risks for carriers and noncarriers from families with a DNA mismatch repair gene mutation: a prospective cohort study. 
  Journal of Clinical Oncology. March 20, 2012; Volume 30(9); pages 958-64.
  A study concluding Lynch Syndrome (a pattern of symptoms resulting in a higher incidence of colorectal and certain other cancers) increases the risk of developing colorectal and six other types of cancer.

- Prediagnostic smoking history, alcohol consumption, and colorectal cancer survival: the Seattle Colon Cancer Family Registry. 
  Cancer. November 1, 2011; Volume 117(21); pages 4948-57.
  A study showing people who smoked at the time of colorectal cancer diagnosis were more likely to die of the cancer, especially if their tumors showed a common feature seen in tumors of people with Lynch syndrome.

- Prediagnostic non-steroidal anti-inflammatory drug use and survival after a diagnosis of colorectal cancer. 
  A study concluding people taking non-steroidal anti-inflammatory drugs (NSAIDs) at the time of their colorectal cancer diagnosis had a better disease outlook than people who were not regular NSAID users.

Just a Click Away from CORE Studies

Up until recently, our online home on the Fred Hutchinson Cancer Research Center’s website has been a bit of a well-kept secret. But we’d like to change that with our new website: www.fhcrc.org/corestudies. Here’s what you’ll find:

- A summary of what the Registry does to advance scientific knowledge about colorectal cancer
- Links to published studies using CORE Studies data
- Frequently asked questions
- Links to further resources about colorectal cancer
- Newsletter back issues

And when the online version of our follow-up questionnaire is ready for use, this site will be where you’ll complete it. Visit the site and let us know what you think! Again, the website is www.fhcrc.org/corestudies.

Your Thoughts

Here are just a few of the comments you provided about your experience with the Registry and about having or knowing someone who had colorectal cancer.

Your survey comments:

AN ATTITUDE OF GRATITUDE

“Even though the participation you have asked of me has been small things, I am proud to be a part of your studies.”

“With this type of cancer so prevalent in my family history, it is comforting to know I’m ‘being watched over’ and will be made aware of all that is being done to eradicate this disease.”

“The research that comes out of this study is the best means we have to find new, better & more effective means of detecting this disease and then treating it. If you have the opportunity to participate, please do; the life you save may just be your own!”

You can look these articles up on our new website! Or we can send you a paper copy if you specify which one(s) on the enclosed form. Then please return it to us in the postage-paid envelope we’ve provided. Make sure to put your name on the form!
Thinking About Genetic Counseling?

Some of you have already spoken with our genetic counselor Mercy Laurino, and we hope your conversations were valuable to you and your family. Mercy joined us after we realized some outcomes of CORE Studies research generated the need for a genetic counselor on staff.

You might already know genetic, environmental, and lifestyle factors can combine to cause cancer. That being said, if you know you carry one of these gene mutations, clinical cancer experts strongly recommend you be screened for cancer earlier, and more frequently, to decrease your risk of developing the disease. (This may also be true for colorectal cancer survivors.)

Keep in mind genetic counseling (discussing how inherited genes may contribute to your risk of cancer) is separate from genetic testing (examining blood or tissue samples for genes known to cause cancer). Also, counseling does not always lead to testing; the counselor or geneticist may advise differently based on your personal and family history.

Perhaps you’ve already met with a clinical genetic counselor or geneticist. But if not, and you want to know more about genetic counseling, here’s what you can do:

- Discuss your questions with your health care provider FIRST.
- Find a genetic counselor in your area by visiting the National Society of Genetic Counselors’ website, www.nsgc.org.

Our staff genetic counselor Mercy can answer questions about your registry participation and provide general information about genetic testing and resources. She is available at 206-667-6071 or mylaurino@fhcr.org until May 31st, 2013. After that date, we can refer you to a genetic counselor in your area.

Your Thoughts

Here are a few more comments you provided about your experience with the Registry, and about having or knowing someone who had colorectal cancer.

Your survey comments: SURVIVING AND THRIVING

“At 81 years old, my health is remaining stable despite having coronary heart disease. Since being included in the CORE Studies, I have paid close attention to my diet in respect to adequate fiber and to annual fecal occult blood screening.”

“It has been 7½ years since my last chemo treatment, and I am doing very well.”

“I’m nearly ten years out from my colon surgery and enjoy good health.”

Your survey comments: YOU VALUE OUR NEWSLETTER

“I do enjoy your recipes that are included in the ‘CORE News’! Thank you!”

“I continue to enjoy reading the CORE News. And I am glad to know that the Colon Cancer Family Registry is the largest single resource for colorectal cancer in the world.”

Your survey comments: PREVENTION & SCREENING ARE CRUCIAL

“If my brother had not enrolled me in CORE Family Studies I probably would never had a colonoscopy. Now I’ve had 2—both with healthy results.”

“I call my sister my “lifesaver”. Her doctor strongly suggested that all her siblings have a colonoscopy as soon as possible... I sure am glad I followed her doctor’s advice: I had 9 polyps removed... My GI doc called me a veritable polyp factory.”

Your survey comments: YOU’RE CONCERNED ABOUT DIET AND EXERCISE

“No one should have to watch a parent have her life stripped away by organ. If there are actions in my life, like changing my diet and exercise routines, that I can take to help make certain others are not subjected to that fate, then rest assured I will take them.”

“Some may say a vegan diet is too difficult to follow, but surgery and chemotherapy are even more difficult. I am participating in CORE in the hope that diet will become a more important and publicized factor than just screenings in the future for prevention promotions.”
Comfort Food

This pot pie recipe takes about 20 minutes to make and 45 minutes to cook—just over an hour to good and healthy food! You can also add one pound of sautéed, chopped, skinless chicken breast or 1 pound beef stew meat if you like.

Ingredients

- ¾ cup each of 3 to 4 different fresh or frozen vegetables
- 2 small red potatoes, chopped into one-inch pieces
- 1 can of cream of celery or mushroom soup
- 1 cup vegetable stock or water
- 1 tsp finely chopped rosemary
- 1 tsp finely chopped thyme
- 1 pie crust (store-bought or homemade)
- 1 egg white
- Salt and pepper to taste

Mix vegetables, cream soup, stock (or water) and herbs in a large bowl. Salt and pepper to taste. Roll out enough pie crust dough for four top crusts. Place serving bowls upside down on the dough, and cut in a circle about ½ inch from the casserole. Then place vegetable mix in the casserole and place the pie dough on top, rolling the extra dough just inside the top of the dish so the outer rim of the crust is thick.

[If using a pie pan, line the bottom with a crust. Use a fork to poke several holes before adding the mixture. Place the second crust on top.]

Brush egg white on the top crust. Poke several holes in the top with a knife. Cook for 45 minutes at 350 degrees until the crust is light brown and the insides are bubbling. Let sit 10 minutes before serving. Makes four servings.