

# COREnews



Colorectal Research in Epidemiology

Volume 1-5

### CORE Family Studies

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Study telephone: 1-800-276-0127

### Figure 1: CORE Family Study Enrollment

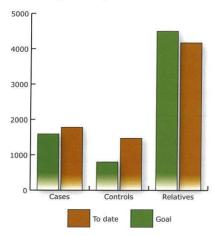


Figure 2: Family History of Colorectal Cancer Among Cases

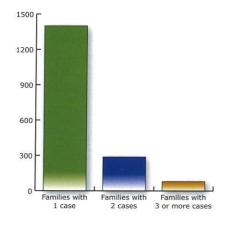
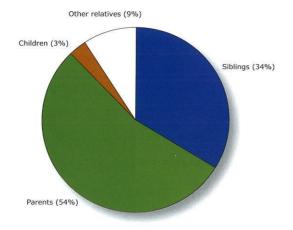


Figure 3: Family Members with Colorectal Cancer



#### Greetings!

We are pleased to bring you our fifth edition of **CORE News**. This is our way of staying in touch with you and informing you about the CORE Studies.

First, the grant we submitted to the National Cancer Institute last December to continue our colorectal research received an outstanding score, and we are funded for 5 more years! Together with our collaborators across the world, the Colorectal Cancer Family Registry consortium is the largest ever family-based study of colorectal cancer.

Since our last newsletter, we have surpassed our enrollment goals in the CORE Family Study for cases by 12% and for controls by 84%. We are close to meeting our enrollment goal for family members, and expect to meet our enrollment goals in our CORE Hormones and Health Study within the year. Thank you one and all!

Figure 2 shows that of the 1,800 families enrolled to date, 367, or 22%, have 2 or more cases of colorectal cancer within the immediate family. Of these multiplecase families, the majority (54%) report that the cases are a parent and son or daughter with the disease, and 34% report that siblings have the disease (see Figure 3). These families are key to helping us find genetic causes of this disease.

The cause of this family clustering remains one of the important research questions we hope to answer; to do so, we need to enroll all available family members. We greatly appreciate your help locating these relatives, including those living outside of the United States. While participation of family members is completely voluntary, nearly all of the relatives we have contacted have agreed to participate.

Thank you all again. We couldn't do this work without you.

Warmest Regards,



John D. Potter MD, PhD



Polly Newcomb PhD, MPH



Deborah Bowen PhD

### Hormone-Replacement Therapy Clinical Trial Ends Early

A friend swears by hormone-replacement therapy (HRT) to relieve hot flashes. Another worries about the risk of breast cancer. As we've seen in the media, many questions about the use of HRT remain unanswered or the answer ambiguous.



Thanks to the Women's Health Initiative (WHI), a large multi-site study coordinated at FHCRC, some answers to important women's health questions have emerged.

Between 1993 and 1998, WHI enrolled 161,809 postmenopausal women between the ages of 50 to 79 years into a set of clinical trials, including two trials of post-

menopausal hormone use. Women were randomly assigned to estrogen, estrogen plus progestin, or placebo. WHI researchers expected to show that estrogen plus progestin helped prevent coronary heart disease and improved bone mineral density in postmenopausal women. Contrary to their expectations, they found higher rates coronary heart



disease, stroke, blood clots, and invasive breast cancer in participants who took estrogen plus progestin compared to women who took the placebo. On the positive side, they found that women who took estrogen plus progestin had fewer cases of hip fractures and lower rates of colon cancer.

Overall, the potential harm was found to be greater than the benefits, leading the researchers to end the trial early. However, the researchers emphasized that trial participants and other women who have taken estrogen and progestin should not be unduly alarmed, and urge them to talk with their doctors about their use of this form of HRT.

For more information about study results, please visit the WHI website at: http://www.whi.org.

The results show that during one year, for every 10,000 women taking estrogen plus progestin, we would expect:

- 7 more women with heart attacks \*
- 8 more women with strokes
- 8 more women with breast cancer
- 18 more women with blood clots

\* In other words, for every 10,000 women taking estrogen plus progestin, 37 women would have a heart attack, compared to 30 out of every 10,000 not taking estrogen plus progestin.

The results also suggest that during one year, for every 10,000 women taking estrogen plus progestin, we would expect:

- 6 fewer colorectal cancers
- 5 fewer hip fractures
- Fewer fractures in other bones

### News Flash!



### Senate Committee Approves "Eliminate Colorectal Cancer Act" 07/15/2002

In an effort to boost colorectal cancer prevention in the United States, the U.S. Senate Health, Education. Labor and Pensions Com-



mittee voted to approve the Eliminate Colorectal Cancer Act.

Senate bill 710 seeks to improve screening practices by reducing financial barriers to vital screening. This Act, which was introduced by Senators Edward Kennedy (D-Mass) and Jesse Helms (R-N.C.), would require private insurance companies to pay for colorectal cancer screening for individuals 50 years of age and over, as well as persons under the age of 50 who are at higher risk for the disease. Currently available screening methods make colorectal cancer highly preventable, according to the American Cancer Society (ACS), but only a small proportion of adults in the U.S. are screened.

For more information on S.710 visit the United States Senate web page at www.senate.gov.

First of all I want to thank you for the opportunity to share my story, and secondly to let everyone know how much we appreciate all the hard work the CORE Family Studies is doing on behalf of, not only all the yet undiagnosed colorectal cancer victims, but the uninformed public who are unaware of this deadly killer of mankind.

My story begins during the late eighties with a phone call to Western Clinic. I was a young man in his mid forties in seemingly good health, asking for an appointment to determine the cause of trace amounts of blood in my stool. During a sigmoidoscopy the doctor found my colon to be

free of polyps and the cause of my bleeding was the result of a hemorrhoid. After that I experienced only an occasional spotting of blood, but knowing it was because of hemorrhoids I came to ignore the signs all together.

Life continued with very little change until late 1990, when I had my cholesterol levels checked, due to a family history of coronary heart disease. My cholesterol level was 251, especially high for one with a family history of heart disease. I was

immediately instructed to change my dietary habits and begin a low fat diet, which I did, and continue to follow to this very day, eventually bringing my numbers down to an average of 165.

In September of 1992 I underwent coronary bypass surgery, after which daily exercise has become a part of my life. I believe that the change in my eating habits, coupled with incorporating daily exercise, including running and bicycling, into my sedentary life style, may have cured the occasional spotting of blood in my feces.

During 2000 the bleeding symptoms began to occasionally reappear, and by the middle of 2001 was becoming a daily ritual. By now I knew something serious was occurring, and I was coming to believe it might be some sort of cancer. An appointment was made with my gastroenterologist, who scheduled a colonoscopy. The procedure discovered a 2.5 cm tumor growing on the wall of my sigmoid colon, which my doctor believed to be cancer. The pathologist's report confirmed his diagnosis.

#### I HAD COLORECTAL CANCER!!!

My doctor recommended seeing a surgeon as soon as possible. Within a matter of hours I was in the surgeon's office, and after a brief discussion of what lay ahead of me, he performed a sigmoidoscopy to determine the

exact location and size of the tumor. He determined the position of the tumor would not require a colostomy. Armed with the cold facts, the doctor explained all aspects of the surgical procedure I was to undergo.

The wheels of motion began to turn rapidly and by the following Friday, I was admitted into the hospital for surgery. All aspects of the surgery went as planned, successfully removing the 2.5 cm cancerous growth and 10 inches of my colon. Five days later, my doctor brought additional good news: the pathology report revealed the cancer had not spread! Lymph node status: 12 lymph

nodes identified; all negative for metastatic carcinoma. My level of colorectal cancer was Stage 1, T2. The doctor gave me a survival rate of 85%, which would later be confirmed by an excellent oncologist. This summer, my gastroenterologist will perform another colonoscopy, and if my luck holds true, I will be one year closer to confirming my doctor's long-term prognosis.

Life's journey carries with it many hopes and dreams, its varied trails

are full of happiness and, at times, disappointment, but there can be no turning back as we make our way to the golden years of life. Although we can seek to have the deck reshuffled, we must play the hand we are dealt. When I was a young boy, one of my favorite actors was Roy Rodgers. His theme song, *Happy Trails*, is a fitting ending for my story.

It's the way you ride the trail that counts, Here's a happy one for you.

Happy trails to you until we meet again Happy trails to you, keep smilin' until then. Who cares about the clouds when we're together? Just sing a song and bring on the sunny weather. Happy trails to you 'til we meet again.

— Joseph L. Gavett



Are you interested in telling your story? If so, it would be great to feature you in an upcoming newsletter. Please contact Laurie Lucero (206) 667-5393 to discuss this opportunity to help others.

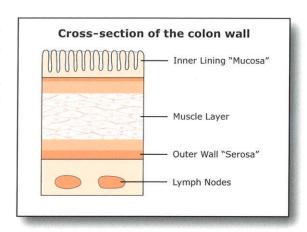
### **Frequently Asked Questions**

### What does the lining of the colon look like?

The colon is a long, tube-like structure. A cross-section of the colon wall shows that it has several distinct layers, similar to the growth rings on a tree trunk. These layers include the inner lining, or mucosa, where many colon cancers begin. There is a muscle layer in the center of the colon wall that expands and contracts to help stool move through the colon. Finally, the outer layer of the colon is called the serosa.

### How is colorectal cancer staged?

Staging is a careful attempt to learn the extent of a cancer within the body. A doctor determines whether an individual's cancer has spread from the original site and, if so, to what parts of the body. Knowing the stage of the disease helps the doctor plan treatment. Below are illustrations of some of the stages of colorectal cancer, along with a description of each.



### **Stages of Colon Cancer**

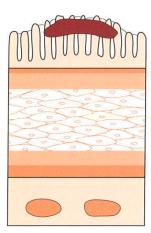
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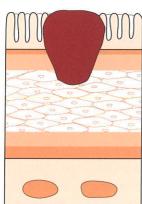
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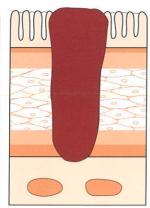
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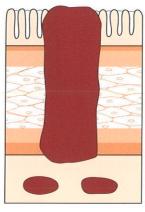
Carcinoma *in situ*; the cancer is in its earliest stages and is found only in the innermost lining of the colon.



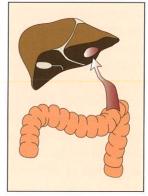
The cancer involves more of the inner layers of the colon or rectum, but has not spread outside the colon.



The cancer has grown through the wall of the colon. It may have spread outside the colon to nearby tissue, but not to the lymph nodes.



The cancer has spread to nearby lymph nodes, but not to other parts of the body.



The cancer has spread to other organs in the body, such as the liver or lungs.

### **Colorectal Cancer Glossary of Terms**

**Benign:** Not cancerous; does not invade nearby tissue or spread to other parts of the body.

**Lymph Node:** One of many small, bean-shaped organs of the immune system that serve as filters to remove waste products. Lymph nodes trap cancer cells or bacteria that are traveling through the body.

Malignant: Cancerous; a growth with a tendency to invade nearby tissue and spread to other parts of the body.

**Metastatic Cancer:** Cancer that has spread from the place in which it started to other parts of the body.

Mucosa: The moist tissue that lines the colon and makes mucus (a thick, slippery fluid).

**Polyp:** An abnormal growth that develops on the inside wall of a hollow organ such as the colon.

**Serosa:** The outermost layer of the colon.

### The Northwest Cancer Genetics Network

The Northwest Cancer Genetics Network (NWCGN) is one of eight sites across our nation that make up the Cancer Genetics Network. This registry provides a broad foundation for supporting



scientific research on the genetic causes of cancer. Participants are asked questions during a telephone interview that include information about family history, medical history, and demographics. Saliva samples are collected from all participants (through a simple at home procedure) and blood samples are collected from some participants.

The long-term goal of the NWCGN is to help scientists explore genetics by creating a registry of individuals at varying risks for cancer. What they learn now will help generations to come. For more information, contact the NWCGN study line at **1-800-616-8347** or visit their website at http://www.fhcrc.org/phs/cgn/.

### Colorectal Cancer and Health On the Web



National Cancer Institute www.cancer.gov

An excellent site for information on cancer treatment and support resources, as well as research studies related to colorectal cancer

### Better Health Foundation www.betterhealthfoundation.org

Provides information on colorectal cancer awareness in the workplace, support services for patients, and health tips

### American College of Gastroenterology www.acg.gi.org

A resource for individuals seeking information on digestive health, including facts on common GI problems and how to locate a specialist

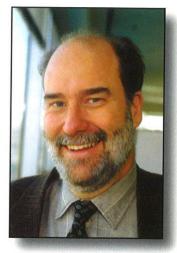
### National Colorectal Cancer Research Alliance www.nccra.com

Presents a variety of information on colorectal cancer and ways to promote awareness, including a health checklist and information on clinical trials

### **Dr. John Potter to Become PHS Director**

by Barbara Berg

On November 1, 2002, Dr. John Potter, Head of the Cancer Prevention Research Program and the Principal Investigator for CORE Family Studies, will become the new Director of the Public Health Sciences Division of the Fred Hutchinson Cancer Research Center. He will replace Dr. Ross Prentice, whose leadership since 1983 helped to establish



the division as a premier center for research in biostatistics, cancer prevention and epidemiology.

Dr. Potter, also Professor of Epidemiology at the University of Washington, has been involved in the study of colorectal cancer for more than 20 years. With his colleagues, he has made major contributions to the understanding of the dietary factors that are associated with colorectal cancer risk.

Dr. Potter was named the top candidate for the directorship, said Dr. Lee Hartwell, Center president and director. "During the course of this recruitment effort, we had some of the top people in the field visit the Center," he said. "Their input made it clear that John was the obvious choice for the position. We agreed."

Congratulations, Dr. Potter!

### **CORE Staff Update**

CORE is pleased to announce four new staff members. Amy Cory joined our staff in July as our Data Coordinator Lead (see the Staff Spotlight in this issue). Joyce Dahners, our new Data Coordinator for Recruitment, replaced Abby Majercik, who moved down the hall to a position with the Wilms Tumor Study Group. Beth Nolan re-joined CORE in September as our Data Coordinator for Blood Collection. Beth replaced Stephanie Whitten who moved to North Carolina to be closer to her family. Finally, Amber Wilson joined as a summer assistant. We are pleased that she will continue on with us part-time while she attends her freshman year at the UW.

While we were very sad to say goodbye to Abby and Stephanie, we wish them the best, and feel fortunate to have such a fantastic group of new staff members.

### Spotlight: CORE Studies' **Data Coordinator Lead: Amy Cory**

Hi! My name is Amy Cory and I joined the CORE studies in July as the Data Coordinator Lead. Nicknamed the study "Ambassador" I'll be working closely with study participants to complete family enrollment and data collection. In addition, I'll be



helping to write our biannual newsletter as well as fielding your questions on our toll-free phone line.

I received my BA in Human Biology from Stanford University and am close to finishing my Master of Science degree in Public Health from the University of Colorado. My thesis project, which examines factors such as age, gender, and family history in relation to the location of cancer within the colon, is near completion and I hope to officially graduate in November. I hope that my thesis research ultimately will help physicians and their patients make individualized decisions about screening options for colorectal cancer.

While living in Denver, I worked as a research assistant for the Rocky Mountain Cancer Genetics Network (CGN), where I worked closely with study participants to collect family history information and answer questions about the research process. I now work down the hall from my former colleagues at the NWCGN, which is located here at Fred Hutchinson Cancer Research Center (see the NWCGN feature on the following page).

Now that I've joined the CORE team here in Seattle, I look forward to working with all of our participating families to make sure that their experience with CORE is positive, rewarding, and lasting. I am committed to helping sustain and develop this research, so vital to our understanding of colorectal cancer and its prevention.



### Contact us!



- Have you moved? Are you planning to move?
- Do you have comments or suggestions for a future newsletter?

Please call the study line at 1-800-276-0127 to keep us updated or to request information at any time.

### **Eating for Good Health**

Start your morning with this tasty treat packed with fiber, vitamins, and protein. Fiber from wheat bran, carrots, flaxseed and apples aids in healthy digestion. Carrots are a great source of vitamin A, thought to be a cancer-fighting antioxidant. Flaxseed is a good source of alpha-linolenic acid, an omega-3 fatty acid that has been associated with reduced risk for heart disease.

### **Healthy Morning Muffins**

½ c. wheat germ 11/3 c. unbleached white flour

1 c. flaxseed meal

1 c. wheat bran

2 tsp. baking soda

1 tsp. baking powder

½ tsp. salt

2 tsp. cinnamon

½ c. maple syrup

1/3 c. honey

1/4 c. molasses

1 tsp. vanilla

2 eggs, beaten

2 carrots, peeled and shredded

2 apples, peeled and shredded



#### Directions:

- 1. Mix dry ingredients (wheat germ through cinnamon) in a large bowl.
- 2. Add shredded carrots and apples to dry ingredients, mix well.
- 3. In another bowl, mix together wet ingredients (maple syrup through eggs).
- 4. Add wet ingredients to flour mixture and mix until moist.
- 5. Pour batter into paper-lined or greased muffin tins and bake at 350° for 15-20 minutes. Cool completely on a wire rack.

It is important to remember that different individuals may have different nutritional needs. For instance, a high-fiber diet may not be recommended for people with certain types of cancer. It's always a good idea to check with your doctor before starting a new dietary regimen.

### **Colon Cancer Alliance (CCA)**

The Colon Cancer Alliance is an organization dedicated to the elimination of suffering caused by colorectal cancer. Members include survivors of colorectal cancer and their families,



people with a genetic risk for the disease, and health professionals. The CCA helps maintain support networks for individuals affected by colorectal cancer, and provides educational resources related to cancer. The CCA spearheads Voices, a campaign designed to encourage public awareness and support for colorectal cancer interventions. Goals of the CCA include:

- Providing patient support.
- Educating the public about colorectal cancer.
- Encouraging early detection through screening.
- Supporting research on effective prevention and treatment.
- Advocating legislation to support public funding for colorectal cancer.

To learn more about the Colon Cancer Alliance, visit the organization's website at www.ccalliance.org.

### Colon Cancer Alliance's 3<sup>rd</sup> Annual Colorectal Cancer Conference

The CCA will hold its 3<sup>rd</sup> Annual Colorectal Cancer Conference during the spectacular cherry blossom season, April 4-6, 2003, in Washington, D.C. This conference will bring together survivors of colorectal cancer, their friends and family members, as well as health professionals dedicated to the fight against colorectal cancer. The three-day event will provide participants a forum in which to share current colorectal cancer knowledge and ideas, and focus on colorectal cancer advocacy issues. Visit the Colon Cancer Alliance website at www.ccalliance.org for more information.

### **Study Update**

Thanks to the help of 30 CORE Study participants, Dr. Scott Ramsey successfully completed the first phase of his study *Preferences for Genetic Testing for Hereditary Nonpolyposis Colorectal Cancer.* 



For this study, 3 groups of

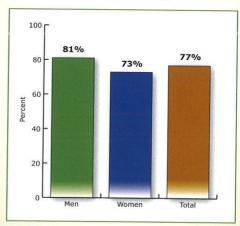
CORE participants—individuals with colorectal cancer, family members, and population controls—met with study staff to discuss their perceptions about genetic testing and the issues that might determine whether they would choose to have genetic testing or not. Dr. Ramsey and his study team are currently reviewing the data looking for ways to improve the survey, which he hopes to test with additional willing study participants in the near future.

Dr. Ramsey credits this opportunity to interact with CORE participants with his better understanding of how individuals feel about genetic testing for the type of colon cancer that is hereditary. Thanks to all who participated!

### For Your Health

The National Cancer Institute recommends eating at least 5 servings of fruit and vegetables each day for good health. Eating fruits and vegetables has been found to reduce the risk of cancer and other diseases. However, less than 25% of adults in the United States eat the recommended 5 servings a day.

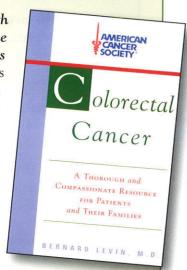
### Percentage of Adults Who Reported Eating Less than Five Servings of Vegetables per Day, 2000



Source: Behavioral Risk Factor Surveillance System, Centers for Disease Control and Prevention, 2000.

### **Book Spotlight**

Colorectal Cancer: A Thorough and Compassionate Resource for Patients and their Families tackles a wide spectrum of issues related to colorectal cancer. Dr. Bernard Levin addresses topics ranging from how to deal with a cancer diagnosis, to specific information on cancer prevention tools and treatment options. Complex issues such as cancer biology, chemotherapy, and screening techniques are covered in an understandable and



engaging way. Importantly, Dr. Levin's

book takes into account the perspective of the cancer patient, with thoughtful narratives and case histories. This easy-to-read guide is a valuable resource for anyone seeking a healthier lifestyle, and includes colon-healthy recipes and a quick reference of additional reading materials. For more information, visit the American Cancer Society website at <a href="https://www.cancer.org">www.cancer.org</a> or check with your local bookstore or library.



**Address Service Requested** 

## Where can I get more information about cancer?



The Cancer Information Service at **1-800-4-CANCER** (1-800-422-6237) will answer your questions about cancer prevention, diagnosis, and treatment, and send you information at your request.



### **Study Staff**

Investigators: John D. Potter, MD, PhD

Polly A. Newcomb, PhD, MPH

Deborah J. Bowen, PhD

Project Manager: Allyson S. Templeton, MS

Project Lead: Amy Center Cory

Genetic Counselor: Ksenia P. Koon, MS Newsletter Coordinator: Laurie Lucero, MEd

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