



# CORE<sub>news</sub>

FRED HUTCHINSON  
CANCER  
RESEARCH  
CENTER

Colorectal Research In Epidemiology

Volume 1-3

## CORE Family Studies

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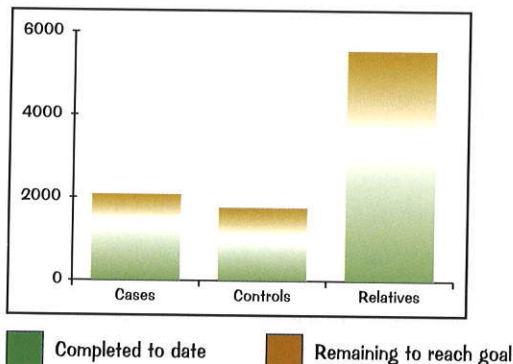
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number:

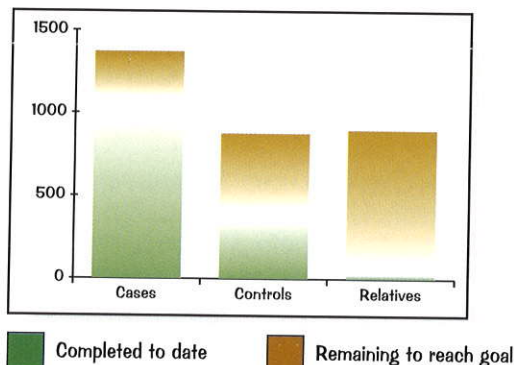
1-800-276-0127

## CORE Studies Enrollment and Data Collection Progress To Date

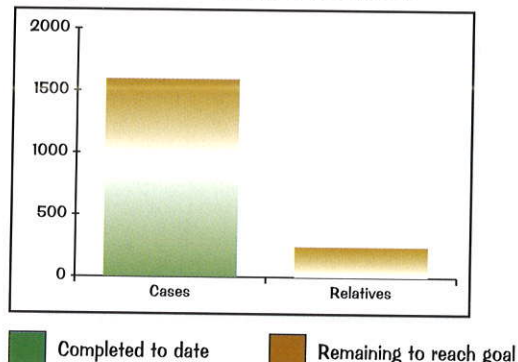
### Enrollment



### Blood Sample Collection



### Diagnostic Material Collection



**Cases:** Individuals with colorectal cancer  
**Controls:** Individuals without colorectal cancer  
**Relatives:** First-degree relatives (parents, siblings, children) of CORE Family Study Cases

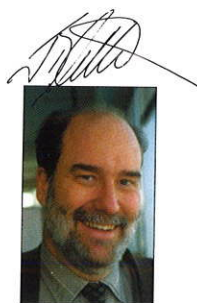
Greetings and welcome to the third issue of CORE News!

These newsletters are for participants and friends of the CORE (Colorectal Research in Epidemiology) Studies, to keep you informed of our study progress and provide you with news and information related to colorectal cancer. We hope you find them useful and we welcome any suggestions you have for future editions.

At the local level, this summer marked the beginning of the fifth year for our CORE Family Study and fourth year for our CORE Hormones and Health Study. As shown in the graphs to the left, study enrollment, blood sample collection, and diagnostic material collection are all progressing well. At this rate, we expect to complete enrollment for the Family Study by December 2001 and for the Hormones and Health Study by May 2003. We are **extremely grateful** to all of you study participants for your contributions to these research efforts.

At the national level, our funding agency, the National Cancer Institute, recently announced that it plans to extend our research on genes, lifestyle, and cancer risk for five more years! To begin planning this research agenda and grant application, CORE Family Study hosted a meeting of the Cooperative Family Registry for Colon Cancer Studies (CFRCCS). As you may recall, CORE is one of six colorectal cancer registries across the world that makes up the CFRCCS. More than 40 scientists from across the U.S., Canada, and Australia met in Seattle for this 2-day meeting to discuss our progress and develop our research plan. Even the weather cooperated!

Warm Regards,



John Potter,  
MD, PhD



Polly Newcomb,  
PhD



Deb Bowen,  
PhD





**"Get tested. This is one cancer that can be cured."**

The National Colorectal Cancer Research Alliance (NCCRA) was co-founded by Katie Couric, Lily Tartikoff, and the Entertainment Industry Foundation in March 2000 with two immediate goals:

1. Raise awareness of the seriousness of colorectal cancer and increase the number of people receiving preventive testing for this disease;
2. Use celebrity endorsement to promote education, fundraising, research, and early medical screening for colorectal cancer.

All of the money raised by the NCCRA goes into public awareness and education programs. NCCRA also funds cutting-edge research designed to develop better tests, treatments, and cures for colorectal cancer. The NCCRA advisory board is made up of 8 renowned scientists from across the U.S. who specialize in biological, clinical, and epidemiological research. Each of these scientists is considered to be at the top of his or her field of research and is committed to finding better methods for screening, prevention, treatment, and ultimately a cure for colorectal cancer.

## **NCCRA Prevention and Early Detection**

### **Choices You Make**

- Exercise daily—even a small amount—if possible.
- Don't smoke.
- Keep your weight in check.
- Limit your alcohol intake.

### **Actions You Take**

- Regular preventive testing, such as a Fecal Occult Blood Test, Sigmoidoscopy, Double Contrast Barium Enema, or Colonoscopy.
- Talk to your doctor about your risk factors.
- Talk to your family to see if anyone has had polyps or cancer in the colon, rectum, breast, or any gland.
- Check with your physician about taking a multivitamin containing folic acid, an aspirin a day, aspirin-like drugs, and Fecal Occult Blood testing.

© 2001 Entertainment Industry Foundation

## **NCCRA Founders**

Katie Couric, co-anchor of NBC's *Today* show, lost her husband, Jay Monahan, to colon cancer in 1998. Monahan, a TV legal analyst, was only 42 at the time of his death. Since then, Couric has worked to raise awareness about colorectal cancer, in part, by co-founding the NCCRA. Her first priority is removing the stigma of this disease. She urges people to get over any embarrassment they have and get screened. "Get your butt to the doctor! It could save your life," urges Couric. While she admits that that expression may be a bit coarse, she is determined to do whatever it takes to break down the taboos. "I want to get people talking.... While it may not be the stuff of cocktail party conversation, talking to your doctor can save your life when it comes to this disease. No one should have to die of embarrassment."

Lily Tartikoff, a former member of the New York City Ballet, lost her husband, Brandon Tartikoff, also to cancer. Brandon, the youngest-ever president of NBC, was first diagnosed with Hodgkin's disease at the age of 23; he died of the disease 25 years later, at the age of 48. Lily credits the scientific advances from cancer research to extending the life she shared with him. Today, Lily is one of our country's principal cancer prevention fundraisers, having raised tens of millions of dollars for breast and ovarian cancers, and now for the NCCRA. "We are going to spread the word far and wide about colorectal cancer and how an easy, routine test can stop the disease early, when it is over 90% curable."

The Entertainment Industry Foundation (EIF), a California-based non-profit organization, evolved from The Motion Picture Charities Committee established in 1942 by Samuel Goldwyn. Goldwyn's vision was to create an organization that would conduct a single unified campaign for charitable giving within the entertainment industry. Fifty-five (55) years later it has maintained its commitment to promote and coordinate philanthropy, and has raised and donated more than \$140 million to charitable organizations, including the NCCRA.

To learn more about the NCCRA, please call 1-800-872-3000 or visit their website at <http://www.nccra.org>.



**News from  
The National  
Cancer Institute:**

## **Katie Couric Honored with Second Annual Eleanor Nealon Extraordinary Communicators Award**

In recognition of her personal and professional efforts to raise awareness of colorectal cancer and to teach Americans about the disease, Katie Couric has been named the 2001 recipient of the National Cancer Institute's (NCI) Eleanor Nealon Extraordinary



Communicators Award. The award, a tribute to outstanding communicators, is given in conjunction with the Eleanor Nealon Extraordinary Communicators Lecture Series. The Nealon Award was presented to Couric by NCI Director Richard Klausner, M.D. on May 18, 2001.



## Genetics 101 — The A, C, G, and T's of Genetic Testing

by Ksenia P. Koon, MS

In the past decade, we have witnessed tremendous growth in our knowledge of human genes. The discovery of disease-causing genes has led to hundreds of new genetic tests. As we learn even more, we can only expect the number of genetic tests to increase. Yet we are still learning how useful genetic tests will become in our society. This will depend on the accuracy and the interpretation of the tests, as well as many ethical issues that accompany genetic testing. Here are some basics about genetic testing:



- A genetic test is usually done by a simple blood test, or is occasionally done by testing other body fluids or tissues.
- Genes are made up of DNA, the information in our cells that instructs the body how to grow and function.
- DNA is coded by 4 chemicals, which are symbolized by the letters A, C, G, and T (Adenine, Cytosine, Guanine, & Thymine).
- A genetic test looks for changes, or mutations, in the DNA which could lead to a disease. Such changes can be as small as a single altered chemical (such as "A" changed to a "C"). Other changes could be much larger, such as a loss of several hundred or thousand chemicals.

A genetic test can be used to confirm a disease diagnosis or to look for a future predisposition to disease. There are several types of genetic tests that are currently available. Carrier testing can help couples learn if they carry, and are at risk of passing to their future children, a trait for certain disorders. Prenatal testing is available for pregnant women if an unborn child may have a genetic condition. A third type of genetic testing attempts to identify changes in genes that can explain an existing disease in a child or adult. Finally, predictive gene testing identifies people who are at future risk of getting a disease, before symptoms appear. Predictive gene tests are available for many different diseases, including several types of cancers that run in families. It is important to understand that inherited forms of cancer represent only about 5 to 10 percent of all cancer. The great majority of people who get cancer such as breast, colon, or prostate cancer have not inherited an altered gene as the underlying cause of their disease.

Genetic testing can have many risks and benefits. It is important to discuss these risks and benefits with a professional (such as a medical geneticist or genetic counselor) before undergoing genetic testing. Both positive and negative results can provide relief and reduce uncertainty about genetic status when a genetic test is used appropriately. A negative test may reduce the need for frequent checkups or surgeries and create a sense of well-being that one is not at increased risk for a disease compared to the general population. A positive test can increase knowledge and encourage an individual to use appropriate preventive measures to reduce risk.

Yet, most predictive tests only estimate lifetime probability, but not certainty, of developing disease. Sometimes genetic testing can lead to results that are not personally useful and emotions that are not expected. For example, the uncertainty of a predictive test may lead to heightened anxiety and emotional distress for some individuals. Furthermore, genetic testing may not only reveal

information about the person undergoing testing, but about the genetic status of a relative who might not want to know this information. Finally, if a test reveals an increased risk of disease, some individuals are concerned about possible discrimination by insurance companies or by employers.

Cancer prevention and early detection are important for everyone. An individual may not necessarily need a genetic test in order to practice good cancer screening measures. Regular checkups by a doctor and a healthy lifestyle are beneficial for everyone.

## Eating for Good Health



Here is a simple and healthy variation on an old favorite.

### Caesar Salad

- 2 cloves garlic
- 2 anchovy fillets
- 1/4 tsp. ground black pepper
- 2 Tbs. fresh lemon juice
- 2 Tbs. dijon mustard
- 2 Tbs. honey
- 1 1/2 oz. parmesan cheese (grated)
- 1/2 cup non-fat plain yogurt
- 2 heads romaine lettuce
- 1 cup low fat croutons

Place the garlic, anchovies, pepper, lemon juice, mustard, honey, parmesan cheese and yogurt in blender and process until smooth. Chill.

Rinse the lettuce and drain. Cut crosswise and place in refrigerator until needed.

Toss dressing together with the romaine lettuce and croutons.

Serves 8. Calories: 98 • Fat: 3g  
(Traditional Caesar has 280 calories and 18 g fat)

### To make your own croutons, use this recipe.

- 2 cups bread (1/2 inch cubes)
- 1 tsp. unsalted butter
- 1 clove garlic (minced)
- 1 Tbs. fresh parsley (minced)

Place the cubes of bread on a cookie sheet. The sides of the cubes should barely be touching. Divide the teaspoon of butter into 4 pieces and place randomly over the cubed bread. Sprinkle the garlic and parsley over the top and bake at 300°F, stirring frequently until barely toasted.

For more tasty and healthy recipes, visit Dr. Gourmet online at <http://www.drsgourmet.com>



## Frequently Asked Questions

### *How is colonoscopy different from a sigmoidoscopy?*

Both a colonoscopy and a sigmoidoscopy are outpatient procedures to examine the colon using a slender, lighted tube. The main difference is that a colonoscopy examines the entire colon (large intestine) whereas a sigmoidoscopy examines only the rectum and sigmoid region of the colon (lower 1/3rd). Furthermore, during a colonoscopy, if a small polyp is found, it can be removed during the procedure, or if a large polyp, tumor, or other abnormality is found, a biopsy can be done at that time.

Both procedures are well tolerated but require some preparation to cleanse the bowel for visibility. Bowel preparation for a colonoscopy usually involves liquid foods starting 1-2 days before the procedure and a special beverage to clean the colon. For a sigmoidoscopy, only an enema immediately before the procedure is required. During a colonoscopy, patients are sedated during the procedure, while this is not necessary during a sigmoidoscopy.

### *What is the virtual colonoscopy I keep hearing about?*

While promising, this new procedure is not yet generally available. The virtual colonoscopy uses a computed tomography (CAT) scan to create an image of the colon. As with a colonoscopy, pre-procedure bowel cleansing is required and the colon must be inflated with air to make it easier to examine. A full CAT scan of the abdomen region is then taken. A computer then reconstructs the images into a 3-D model that is studied and interpreted by a specialist.

### *What are the recommended screening guidelines?*

Although specific guidelines may vary slightly, the American Cancer Society (ACS) guidelines are commonly accepted. For those persons aged 50 and older and with no other risk factors for colorectal cancer, the ACS recommends screening by one of the following methods:

- Yearly fecal occult blood test (FOBC)—a test that checks for blood in the stool—along with a flexible sigmoidoscopy every 5 years; or
- A colonoscopy every 10 years or a double contrast barium enema—a test that uses barium sulfate, air and x-ray technology to examine the interior colon wall—every 5–10 years.

The ACS also provides separate guidelines for screening those at increased risk.

## News Flash! ⚡

July 6, 2001 (ACS NewsToday)

This week marked Medicare's expanded coverage of colonoscopy for colorectal cancer screening to include the test once every 10 years for beneficiaries age 50 and over with an average risk.



## On the Web

Want to know more?

### Links for Colorectal Cancer Screening Guidelines

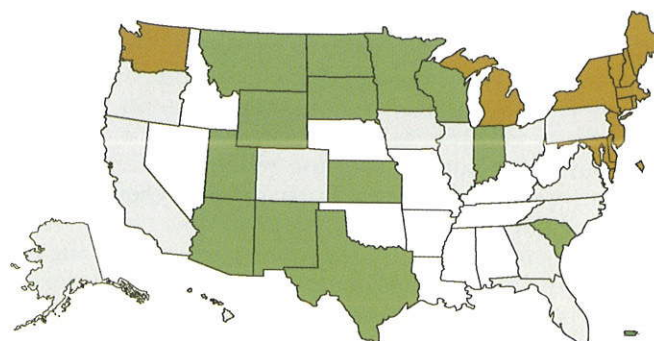
- For the Center for Disease Control's Report: Trends in Screening for Colorectal Cancer—United States, 1997 and 1999: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5009a2.htm>
- For information on "Screen for Life," the national colorectal cancer action campaign developed by CDC and the Health Care Financing Administration (HCFA) to promote colorectal cancer screening: <http://www.cdc.gov/cancer/screenforlife/>
- American Cancer Society: <http://www.cancer.org/>
- Interdisciplinary Task Force: <http://www.gastro.org/colcancer>

### Other Informative Links

- Links from the National Cancer Institute on treatment, clinical trials, genetics, screening, and support for patients and families with colorectal cancer: [http://cancernet.nci.nih.gov/genetics\\_prevention.html](http://cancernet.nci.nih.gov/genetics_prevention.html)
- This complete site covers all aspects of the Human Genome Project: <http://www.nhgri.nih.gov/HGP/>
- Visit this site for more information about the National Colorectal Cancer Research Alliance: <http://nccra.org>

## National Colorectal Testing

*Proportion of respondents using fecal occult blood test and/or sigmoidoscopy within recommended period, by state — Behavioral Risk Factor Surveillance System, United States, 1999*



47.0% - 56.1%

38.7% - 43.5%

43.6% - 46.9%

25.6% - 38.6%



## Specialist's Corner: CORE=Colorectal Research in Epidemiology

by Laurie Lucero

We have frequently mentioned that **CORE** stands for **Colorectal Research in Epidemiology**, but what is epidemiology? Literally, from its Greek origin, **EPI** means upon, **DEM** means people, and **OLOGY** means study. To put it simply, epidemiology is the study of groups of people.



Epidemiologic methods are the cornerstone of CORE Studies. Our CORE Family Study is part of one of the largest studies to combine careful personal and family medical histories with biological analysis in the study of colorectal cancer. This will enable us to evaluate many environmental exposures and behavior patterns that may be relevant to disease prevention.

Generally, epidemiology is an observational science that looks at exposures and disease patterns in their natural state. This is distinguished from experimental science that assigns individuals to specific treatments or interventions. While both designs help answer important questions relating to the cause and prevention of disease, many potential causes of disease could not be studied experimentally. Imagine randomly assigning individuals to *start smoking, gain weight, or stop exercising!*

Epidemiological studies have three major functions:

- To **DESCRIBE** the health status of a population in a particular location at a particular time.
- To **EXPLAIN** the occurrence of diseases by identifying factors which cause diseases or trends.
- To **CONTROL** diseases in a population by preventing new occurrences, treating existing cases and otherwise improving the health status of the population.

You may have wondered why we ask so many questions during our telephone interview. In order to conduct a genetic epidemiological study, like CORE, we need a full family history. Additionally, we need information on known or suspected environmental factors, such as things one might be exposed to at work and lifestyle factors, like diet and exercise habits. These factors appear to play an even more important role in determining cancer risks than genetics alone. You are the best source for this important information. Further, because some of these factors are relatively uncommon, for example the long-term use of certain medications, large numbers of individuals and families are needed.

We hope these data will ultimately be used to better understand the causes of colorectal cancer and how individual genetic differences may change cancer risk. This understanding will help individuals and their physicians to encourage lifestyle choices that can help reduce cancer risks.

## Spotlight: Deborah J. Bowen, PhD



Dr. Deb Bowen (right) with student Kyli Atrial

Dr. Deborah Bowen is a collaborator for the CORE Family Study. A behavioral scientist by training, she has a special interest in how and why people make lifestyle choices that may affect their risk for cancer. Her studies often focus on cancer prevention screening, smoking cessation, and dietary change.

For example:

- In her research study entitled "Population-based genetics risk information via the Web," Dr. Bowen is using the Internet to offer personalized, accurate, and up-to-date risk information to the general public.
- "Eating for a Healthy Life" seeks to improve the eating habits of members of religious organizations. She is collaborating with many religious organizations of various sects and denominations throughout the Puget Sound to see whether a program, designed by scientists and faith community members together, can help people improve their dietary habits.
- "Breast Cancer Risk Information Study" invites women from the general population to use a website to learn more about breast cancer, prevention methods, and genetic testing available for cancer susceptibility.

Last fall, Dr. Bowen invited some randomly-selected CORE participants to assist her with a small study. Participants were asked to complete a questionnaire focusing on perceived risk, screening behaviors and intentions, family communication, and satisfaction with health care providers. In this small study, she tested the practicality of collecting data using a mailed survey method. Of the 137 CORE participants contacted, only one chose not to participate! She sincerely thanks all of you who were contacted.

Dr. Bowen received her A.B. degrees in Psychology and Biochemistry from Mount Holyoke College in Massachusetts and her Ph.D. in Health Psychology from the Uniformed Services University of the Health Sciences in Bethesda, Maryland. She is a faculty member at the University of Washington Department of Psychology and Health Sciences. In addition to teaching courses in psychology, she mentors numerous students and postdoctoral fellows. She has been on staff in the Cancer Prevention Research Program at Fred Hutchinson since 1986. We are fortunate that she chose to share her many talents with our study network on both a local and international level.



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