Creighton UNIVERSITY Medical Center

Early Detection Research Network

EDRN High Risk Registry

Spring/Summer 2005 Volume 4, Issue 2

Colon and Endometrial Cancer Screening Behaviors and Barriers

A group from the Hereditary Cancer Institute at Creighton University, along with consultants from the University of Nebraska Medical Center and the University of California at Irvine have studied colon and uterine (endometrial) cancer screening behaviors and the barriers to screening among individuals with a very high risk for those cancers. The men and women who took part in the study either have a genetic mutation, or they are at 50% risk of having a mutation for hereditary nonpolyposis colon cancer (HNPCC). Mutation carriers have an 85% risk for colon cancer. The risk for endometrial cancer for the female carriers is up to 56%. Those who took part in the study included 34 women and 29 males. Twenty were carriers and the other 43 were at 50% risk for being carriers. The participants completed a questionnaire about their screening behaviors in the last two years, their view of their cancer risk, stress related to cancer, specific barriers to screening and their cancer history. Their cancer screening during the last two years was compared to the recommended screening for those at very high risk. Only 17.4% had annual colonoscopies and only one woman had annual endometrial screening. In response to a question about when they intend to get the next colonoscopy, 55.7% indicated they would get a colonoscopy within the year, but 28.5% were unsure or did not plan to get one at all. Only 18% of the women intend to get endometrial screening within the year and 77% were unsure of whether they would get it done.

These results cause concern that many people in HNPCC families are not getting the cancer screening they should have. There seems to be a variety of reasons for people at high risk not to get their screening. One of the most common reasons seems to be that their personal physicians have not recommended the screening or at least not as often as it should be done It is very important that these physicians receive education about appropriate cancer screening for families with HNPCC. Cancer genetic service providers need to be sure that this education is made available to primary physicians. It is also important for family members to discuss their family history and the recommended screening with their physicians, and if necessary, to remind them every year when it is time for the screening to be done.

Registry Recruitment Update

The High Risk Registry began mailing Early Detection Research Network (EDRN) and Registry information to potential participants in March of 2001. Within the first 4 years, 1,556 information packets were sent and responses were received from 382 individuals interested in participating in the Registry. Follow-up is ongoing to determine the intent of many who have not responded. Short update questionnaires are forwarded to all Registry members at one year intervals from their Registry enrollment date.

Registry staff are making contacts with other hereditary cancer centers to extend member recruitment beyond the Hereditary Cancer Institute at Creighton University. During the upcoming year, the focus will be on forming collaborative arrangements with other centers to extend new member recruitment and increase Registry enrollment. Registry member participation in early detection studies is likely to increase as enrollment grows.

Several centers are making preparations to assist with the distribution of Registry recruitment materials. The following centers are currently distributing Registry recruitment materials:
Aegis Women's Healthcare (Bloomington, IN)
Alexian Brothers Hospital Network (Chicago, IL)
Capital Region Health Park (Latham, NY)
Children's Medical Center (Dayton, OH)
FAP Support Group (Atlantic City, NJ)
Geisinger Medical Center (Danville, PA)
GeneWISE (Slingerlands, NY)
Harvey Institute for Human Genetics (Greater Baltimore Medical Center)
Holy Cross Hospital (Fort Lauderdale, FL)
Inland Northwest Genetics Clinic (Spokane, WA)
Main Line Health System – Lankenau Hospital (Wynnewood, PA)
Markey Cancer Center (Lexington, KY)
Michigan State University (East Lansing, MI)
Minnesota Colorectal Cancer Initiative (St. Paul, MN)
Norton Healthcare Hereditary Cancer Institute (Louisville, KY)
Oakwood Hospital and Medical Center (Dearborn, MI)
Providence Health System (Portland, OR)
St. Vincent's Family Life Center (Indianapolis, IN)
St. Vincent's Hospital (Green Bay, WI)
Tulane Human Genetics Program (New Orleans, LA)
University of Arkansas for Medical Sciences (Little Rock, AR)
University of Florida Shands Cancer Center (Gainesville, FL)
University of Rochester Medical Center (Rochester, NY)
Vanderbilt University Medical Center (Nashville, TN)
Vermont Regional Genetics Center (Burlington, VT)
Waukesha Memorial Hospital (Waukesha, WI)
Wellmont Holston Valley Medical Center (Kingsport, TN)
Wright State University (Dayton, OH)

Your participation in the High Risk Registry is greatly appreciated. This unprecedented endeavor in cancer research provides a promising opportunity to improve medical practice in relation to cancer prevention. If you have any questions or concerns, please contact Mary Benedetto, High Risk Registry Coordinator at (402) 280-3189, 800-648-8133 extension 3189 or mbenedet@creighton.edu.

Myriad Genetic Laboratories Supports EDRN High Risk Registry Recruitment

Myriad Genetic Laboratories, Inc. has joined with the EDRN High Risk Registry to inform eligible individuals about Registry participation. In October of 2004, Myriad began inserting the EDRN High Risk Registry brochure in their packet of information to patients who test positive for deleterious mutations in genes associated with hereditary cancer. This process will continue for one year, with evaluation by Myriad and the Registry at the end of the one year term. Additional one year terms with evaluation at the end of each year are possible upon mutual agreement of Myriad and the Registry. The EDRN Registry is most pleased to have the support of Myriad and welcomes their enthusiasm to bring very high risk individuals the opportunity to participate in early cancer detection studies.

EDRN BEGINNING SECOND FIVE YEAR GRANT CYCLE

The Hereditary Cancer Institute at Creighton University has received another 5 year grant award to further the High Risk Registry. Several new projects are anticipated to include High Risk Registry participants during this 5 year cycle. Two new projects will be introduced to eligible Registry members in the coming months.

One project is called the Longitudinal Serum Biorepositry. All High Risk Registry members will be invited to participate in this biorepository. Participation will involve having a serum blood sample drawn each year and shipped to Creighton University for processing and storage. If pre-cancerous or cancerous lesions should develop in a participant, any previously drawn serum samples will be invaluable to researchers in their search for early cancer detection signals in the blood.

Another project will involve carriers of mutations on the MLH1 gene, at risk for Hereditary Nonpolyposis Colon Cancers (HNPCC). The purpose of this study is to determine if colon adenomas or cancers can be detected by tests of stool or serum. Blood and stool samples will be collected from consenting individuals who are scheduled for a colonoscopic exam. Eligible Registry members should receive information regarding this study by late summer or early fall of this year.

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Was this newsletter forwarded to you? Do you have a move coming up in the near future? Please keep the EDRN High Risk Registry informed of your current mailing address. You may call or e-mail us with your address update or complete and mail the address update form. Also if there have been recent changes in your medical history, please call the Registry at one of the numbers listed below.

(402) 280-3189 OR (800) 648-8133, extension 3189 mbenedet@creighton.edu

Name _____

Address _____

City, State, Zip _____

Telephone (Day) _____

Telephone (Evening) _____

Mail completed forms to: Creighton University Medical Center
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