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Annual report

Give to MSK

The purpose of this study is to examine how people with a family history of colon cancer and other related cancers respond to recommendations for cancer screening after genetic counseling. Investigators hope to learn more about whether people with a personal and/or family history of colorectal cancer and other cancers follow cancer screening recommendations, and to determine the effect of these screening recommendations on their quality of life.

Some families have a pattern of cancers called hereditary non-polyposis colon cancer, or HNPCC. The HNPCC pattern means that several people on the same side of the family have had colon, endometrial, ovarian, or certain other cancers, most often occurring in the abdomen. People with an HNPCC pattern of cancer in their family receive recommendations to have screening tests for several kinds of cancer in addition to colon cancer. People without the HNPCC pattern usually receive fewer screening recommendations. Genetic counseling (and testing, if a person chooses to be tested) helps determine whether an individual has an HNPCC pattern in his or her family. As part of the study, investigators will compare the experiences of people with and without HNPCC.

The study consists of a written questionnaire at the time of genetic counseling, a telephone interview six months later, and then yearly questionnaires. Questions will cover thoughts and feelings about being at risk for colon cancer, cancer screening practices, and general quality of life. The questionnaires and interview will be confidential. The study is a survey only, and does not include any kind of counseling or medical treatment.

Who Can Join

To be eligible for this study, patients must meet several criteria, including but not limited to the following:

Eligible participants include those who come to Memorial Sloan-Kettering for genetic counseling due to a concern about an increased risk for colon cancer; individuals who come for genetic counseling after learning they have a mutation in

any gene associated with HNPCC; and individuals who, in the context of genetic counseling, received stricter colorectal and/or gynecologic screening recommendations than that of the general population, regardless of genetic test results.

Patients with a diagnosis of familial adenomatous polyposis may not participate.

Participants must be able to read, write, and communicate in English

Participants must be age 18 or older.

For more information and to see if you are eligible for this study, please contact <u>Dr. Zsofia Stadler</u> at <u>646-888-4050</u>. In addition, individuals interested in scheduling a genetic counseling appointment can call Clinical Genetics at <u>646-888-4050</u>.

Protocol

04-144

Investigator

Zsofia K. Stadler

Co-Investigators

Kenneth Offit

Diseases

Colorectal Cancer

Colorectal Cancer > Colon Cancer

Hereditary Cancer & Genetics

Psychiatry & Behavioral Sciences

Locations

Memorial Sloan Kettering Cancer Center

Memorial Sloan Kettering Commack Nonna's Garden Foundation Center

Memorial Sloan Kettering Basking Ridge

Memorial Sloan Kettering Skin Cancer Center Hauppauge

Memorial Sloan Kettering Westchester

Memorial Sloan Kettering Monmouth

ClinicalTrials.gov ID

NCT00582296

ClinicalTrials.gov

Visit ClinicalTrials.gov for full clinical trial description

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