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The Jefferson Familial Colorectal Cancer Registry

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The Jefferson Familial Colorectal Cancer Registry

Colorectal cancer is the second most common form of cancer in industrialized nations, accounting for approximately 11% of new cancer cases and 10% of cancer deaths. In 1998 there will be an estimated 131,600 new cases of colorectal cancer and 56,500 deaths from the disease in the United States. Studies indicate that early detection and intervention significantly decreases the morbidity and mortality of colorectal cancer [1].

Recognizing that family history inheritance plays an important role in colorectal cancer,[2] the Jefferson Familial Polyposis Registry was formed in the mid-1980s. In 1996, as part of the multidisciplinary approach to the prevention, diagnosis and treatment of colorectal cancer, the former Jefferson Familial Polyposis Registry expanded its the scope to include individuals diagnosed with cancer at a young age as well as those with a significant family history. The Jefferson Familial Colorectal Cancer Registry (the Registry) provides the critical link between the physicians who diagnose and treat colorectal cancer, and the physicians and scientists who study the molecular basis of the disease.

Participation in the Registry enables a patient to know his/her genetic profile and colon cancer risk, and confers the benefit of physicians recommending appropriate screenings for the individual as well as at-risk family members. The identification and increased screening of high-risk individuals enhances the diagnosis and prevention of colon cancer thereby reducing mortality due to the disease.

The objectives of the Familial Colorectal Cancer Registry are to: 1) establish a family registry for colorectal cancer studies, 2) collect biological specimens from affected individuals and their close relatives, 3) determine the impact of genetic counseling and molecular diagnostics on colorectal cancer detection and prevention, and 4) evaluate risk factors and develop strategies for clinical intervention for individuals at high risk of developing colorectal cancer.

Since 1996 the Registry has expanded to include individuals with familial and inherited patterns of colorectal cancer as well as those diagnosed with colorectal cancer before the age of 55. As of October 1998, approximately 100 individuals have agreed to participate in the Registry. For more information about the Registry, please call Deborah Rose at 215-955-0026.

References

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About the Authors

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