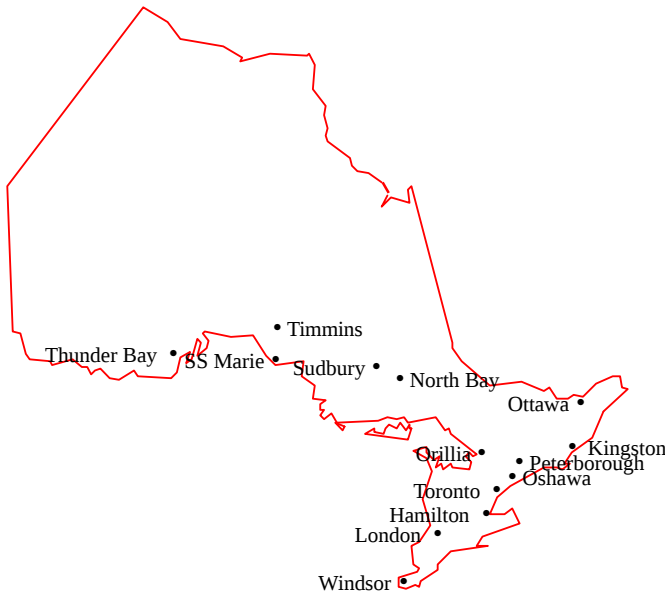


The Ontario Familial Colon Cancer Registry

Winter 1999 Newsletter



News from the study office

This is our first newsletter! We plan to write to you, the participants in the Ontario Familial Colon Cancer Registry, on a regular basis to keep you posted on the progress of the research.

It seems that every week the newspapers carry articles about cancer. Currently, there is much interest in the role of heredity in the development of colon and other cancers. To that end, researchers are studying the role our genes have, as well as other factors in our lives, on our risk of getting various diseases.

The development of the Ontario Familial Colon Cancer Registry is part of an international effort to study families to learn more about the causes of colon cancer. The Ontario Cancer Genetics Network has a major role in facilitating this project.

The Ontario Cancer Genetics Network

On the front of this newsletter is a map of Ontario showing the locations of the cancer

genetics clinics in the province. The Network was established in 1994 to counsel people at high risk for developing certain cancers and to provide a foundation for carrying out research concerned with the hereditary aspects of cancer. Researchers across the province work on projects related to the hereditary components of such diseases as colon, breast and ovarian cancer.

The Ontario Familial Colon Cancer Registry is one of the larger studies that has been undertaken in the province. Information about family patterns of colon cancer, diet and other risk factors, and genes associated with the possible development of colon cancer will be gathered. The Ontario Cancer Genetics Network is an essential part of this effort. It funds cancer genetics clinics that provide genetic counselling for families undergoing genetic testing. For a listing of the clinics, see the back page of this newsletter.

Who's Who in the Registry

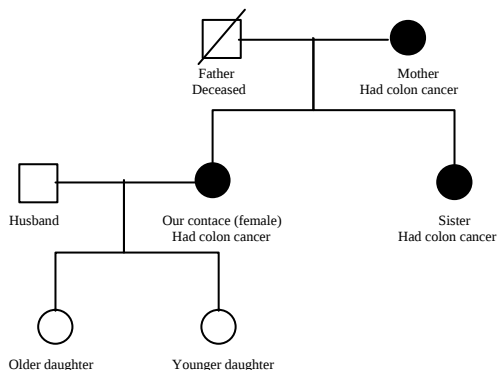
Dr. Steven Gallinger and Dr. Eric Holloway head the study. Dr. Gallinger is a surgeon at Mount Sinai Hospital and a consultant at the Princess Margaret Hospital. His laboratory studies the genetic changes in different types of cancer. Dr. Holloway is a medical doctor and Director of the Ontario Cancer Registry. Both researchers are located in Toronto.

There is a staff of 10 in the study office. In future newsletters we will introduce some of the people you have talked to on the telephone.

What Happens To Your Family History Questionnaire When It Arrives At The Study Office?

From the Family History Questionnaire, a "pedigree" or family tree is drawn. (An example of a pedigree that we have made up can be seen

on the next page.) The arrow points to a woman with colon cancer who gave the family history. She has a mother and father, a sister, a husband and two daughters. Both her mother and sister have also had colon cancer.



Our Genetic Counsellors, Lisa Madlensky, Melyssa Aronson and Pardeep Kaurah, review the family's medical history and, according to guidelines set out in the research design, select the families who will be

invited to participate in further stages of the study.

Families with various patterns of cancer are studied. Some families will have only one affected person while other families will have several members affected by colon cancer. Many different types of families are contacted. It is important to remember that if you are called it does not mean your family has a hereditary cause of cancer or that your family members are at an increased risk for cancer.

Enthusiastic Participation

Patients and their relatives have been very interested in this research. Since the fall of 1997, almost 1100 men and women with colon cancer have completed a Family History Questionnaire. Approximately 200 meet the criteria and will continue on to complete questionnaires and provide blood samples. We have just begun to invite interested relatives to become part of the Registry.

**Ontario Familial
Colon Cancer Registry
of the
Ontario Cancer
Genetics Network**

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or
1 800 832-5949**

Ontario Cancer Genetics Network: Affiliated Clinics

Algoma District Health Unit: Genetic Counselling Clinic (Sault Ste. Marie)
Credit Valley Hospital: Genetics Department
Hamilton Regional Cancer Centre
Kingston Regional Cancer Centre
London Regional Cancer Centre
Mount Sinai Hospital: Familial Gastrointestinal Cancer Clinic
North Bay & District Health Unit: Genetic Counselling Group
Northeastern Ontario Regional Cancer Centre (Sudbury)
Northwestern Ontario Regional Cancer Centre (Thunder Bay)
Oshawa General Hospital: Genetics Service
Ottawa Regional Cancer Centre
Peterborough County City Health Unit: Genetics Department
Porcupine Health Unit: Genetics Service (Timmins)
Simcoe County District Health Unit: Genetic Services (Orillia)
Toronto-Sunnybrook Regional Cancer Centre
Windsor Regional Cancer Centre

Future Newsletters.....

We would like to tell you how the study progresses in our upcoming newsletters. If you have suggestions for the newsletter or other comments, please contact:

Heather Sutherland, the Project Coordinator, at **(416) 946-4409** or use our toll-free number **1 800 832-5949**.