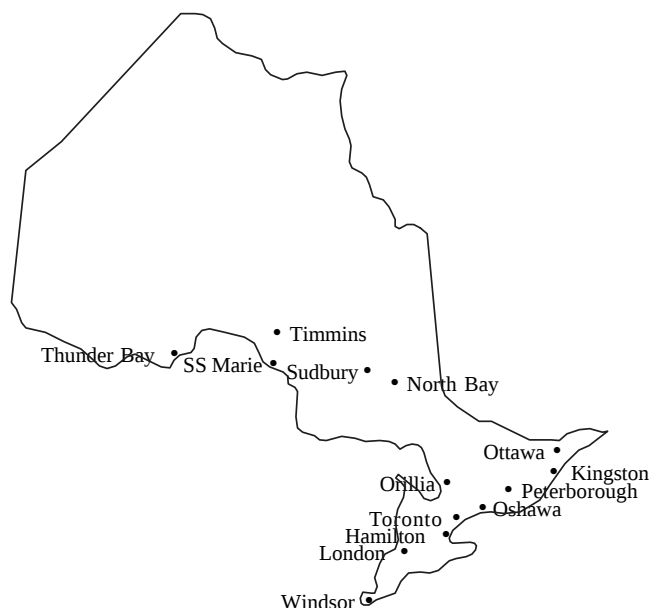


The Ontario Familial Colon Cancer Registry

Spring 2001 Newsletter



News from the study office

Year 2000 is over and we have now entered the new millennium. With your cooperation our data collection is progressing well. While we have crossed our deadline for inviting new cases into the Registry, many of you will continue to be approached for further participation, as we consolidate our efforts to complete data collection.

The Registry has been growing steadily. Over 3,000 participants have completed their family history questionnaire and more than 1,100 men and women are continuing on, completing additional questionnaires, giving blood and allowing access to their tumour tissue.

Also, approximately 1,600 relatives have agreed to participate in the study and over 1,000 relatives have already completed additional questionnaires. Many have given blood samples as well.

Who's Who: New voices

In the Fall of 2000, some of our staff members, with whom you may have closely interacted, have moved on for higher education in various fields such as genetic counselling, social service, etc. Teresa Bianco

and Sumayyah Mahmood are now calling patients to expand their family history and explain further steps for participating in the Registry.

Lisa Madlensky, our telephone genetic counsellor is now fully involved in her Ph. D with aims to study screening behaviour in the relatives of colon cancer cases. Christina Honeywell will now offer telephone genetic counseling.

How do we protect your confidentiality?

Many of you give us large amounts of information that we promise to keep confidential. You may wonder how we ensure this confidentiality. Here is a brief outline of various measures we take to guard the information you provide.

All the staff members of the Registry sign an oath of confidentiality. This oath forbids them from divulging any information about the participants except for performing Registry related duties.

All questionnaires, forms and specimens with names and/or addresses are stored in locked cabinets at the Registry and keys securely stored. Only the research staff who have signed the confidentiality oath have access to these files. All computer databases are password protected with restricted access. Rose Sarvaria is our on site data manager.

When you receive the first package from us, you may have noticed that there is a number at the back of the questionnaire as well as the consent form that you return to us. This is your unique identification number. A family also receives a number so that various members within a family can be identified. This enables the study to follow individuals as well as a family unit.

Researchers who analyze the data are provided only with these identification numbers and do not receive name or address information. The results of the study are published as a whole and never divulge the name of any individual or family.

These procedures protect your identity while allowing publication of study data.

“Release of Information” (ROI) form and Tissue sample

We need the release of information form and consent for blood and tissue to obtain important material from the pathology laboratories, to study the genetic profile of your tumour as well as carry out genetic studies on your blood sample.

Once we have identified all colon and/or rectal cancers that an individual may have, we request the pathology laboratory to send us tissues from these tumours. The laboratories require your signed ROI to release these tissues to the Registry.

The pathology laboratories preserve these tumours by embedding them in blocks of wax. Once these blocks arrive in our laboratory and are checked for identifiers, they are registered in a special database. This database is password protected and accessible only to the staff members directly responsible for the management of these blocks.

Special instruments are used to cut ribbons of varying thickness from these blocks, some as thin as 250th of a mm. Parts of this ribbon (sections) are subjected to various staining techniques whereas the remaining ribbon is permanently stored for future studies. All sections are identified by numbers and have no names on them.

Next issue

We will tell you about your blood sample in the next issue.

A special word of thanks

The Ontario Familial Colon Cancer Registry is truly grateful to all the individuals, and their relatives, who are working with us to develop one of the best resources in the world for studies of colorectal cancer. Your cooperation and participation are critical in developing new strategies to prevent this common and devastating disease.

Change in telephone numbers

Please note our new telephone numbers:
416-217-1310
Toll free: **1-866-225-2728**

If you have moved, or are planning to move, or would like to receive mail at an alternate address, please contact us by phone or email.

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

**610 University Avenue
Toronto, Ontario
M5G 2M9**

**Tel: 416-217-1310
or
1-866-225-2728**

**Email:
OFCCR@cancercare.on.ca**

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:

Dr. Darshana Daftary, the Project Coordinator, at **416-217-1310** or use our toll-free number **1-866-225-2728**.