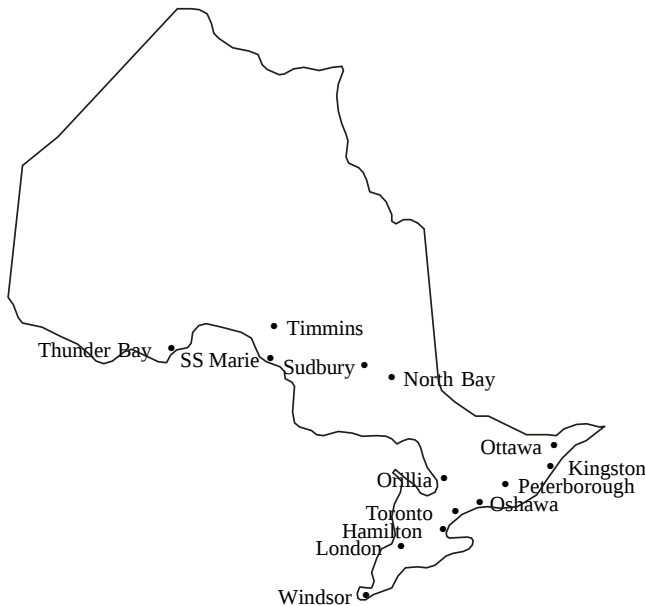


The Ontario Familial Breast Cancer Registry

Winter 2001 Newsletter



and more recently, from their family members. The first patients were approached to become a part of this Registry in 1996 and the first invitations to family members were sent in 1997.

Interesting facts about the Registry....

- 4904 women and men in Ontario have completed a Family History Questionnaire
- almost 2200 eligible* patients have agreed to be part of the Registry
- 7500 relatives have been invited to take part in this research
- more than 60% of relatives are interested in helping
- some families have been participating for 4 years

* Eligibility is based on having a first degree or several second degree relatives with breast or ovarian cancer or, a combination of first, second, and third degree relatives with these cancers. We also include patients who have no family history of breast cancer but are 35 years of age or less at the time of diagnosis or have 2 separate breast cancers occur, or are of Ashkenazi descent or are male. (1600 patients met one or more of these criteria). In addition, there is a randomly selected comparison group, that includes about 600 patients, who do not have any of the characteristics noted above.

News from the study office

We are delighted to report that our recent application to the US National Institutes of Health to further develop the Registry was successful. This means that we will have the necessary support to maintain the Registry and to learn more about the causes of breast cancer by continuing to study the families who are already participating in the Registry.

History of the Registry

In the fall of 1995, we began preparing to be a part of an international effort to determine the inherited and lifestyle factors that may lead to the development of breast cancer. At that time, a five-year plan was established. The first three years were devoted to inviting patients to become part of the Registry. Patients in Ontario (in certain age groups) were eligible if they had a diagnosis of breast cancer between January 1, 1996 and December 31, 1998.

During the past two years (since January 1999), we have been completing data collection (questionnaires and blood samples) from patients,

Are there any results to report?

With a study of this design and size, it will take several years before any results from analyses of genetic and/or lifestyle factors will be available. In the meantime, while we complete the data collection, we are beginning to examine such things as response rates to invitations to take part in this research and patterns of health/illness within families.

Our future plans

We will be contacting each patient currently participating in the OFBCR on a yearly basis to identify any changes in the family's medical history.

As well, in January 2001 we will begin again to invite women and men newly diagnosed with breast cancer to join this Registry. This will allow for a larger group to be studied which in turn will result in more precise knowledge about the familial, lifestyle and genetic factors that may be related to the development of breast cancer. We will keep you informed of our progress.

Recent support for genetic testing in Ontario

In April of 2000, the Ontario Ministry of Health announced funding for a Provincial Predictive Genetic Testing Service Program for families who have members who may be at a higher risk for developing breast cancer. This program will provide genetic counselling and testing for families with a history of breast, ovary or colon cancer. You may have been wondering how this might affect you or any of your relatives who are participating in the Registry.

The providing of funds by the provincial government for this service is not meant to replace ongoing research projects like this registry. It is widely acknowledged that there are still many questions about inherited cancer risk that can only be answered by continued participation in large studies. This new service will, however, allow some Ontario Familial Breast Cancer Registry (OFBCR) participants the opportunity to receive results from their genetic test more quickly than was previously possible.

If you are attending a high-risk clinic due to your participation in this registry, ask the clinic personnel if you also qualify for testing through the new service mechanism. You may be able to have service testing and contribute to research at the same time. If you have already contributed a sample to the OFBCR but would like to see if you are eligible for service testing, contact your local high-risk breast, ovary or colon cancer clinic. A doctor's referral will be necessary for you to utilize the new service program.

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

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

**Tel: (416) 946-4409
or
1 800 832-5949**

Ontario Cancer Genetics Network: Affiliated Clinics

Credit Valley Hospital: Familial Cancer Clinic
Hamilton Regional Cancer Centre
Kingston Regional Cancer Centre
London Regional Cancer Centre
Mount Sinai Hospital: Familial Breast Cancer Clinic
North Bay and District Health Unit: Genetic Services
Northeastern Ontario Regional Cancer Centre
Northwestern Ontario Regional Cancer Centre
North York General Hospital
Oshawa General Hospital
Ottawa Regional Cancer Centre
Peterborough Genetics Clinic
Princess Margaret Hospital Familial Ovarian Cancer Clinic
Timmins Porcupine Health Unit - Genetics Service
Toronto-Sunnybrook Regional Cancer Centre
Windsor Regional Cancer Centre
Women's College Hospital: High-Risk Clinic

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:

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