

The Ontario Familial Breast Cancer Registry

Summer 1999 Newsletter



News from the study office

As you may recall, we have been inviting patients and their family members to become part of the Registry since early 1996. Our patients come from all regions of Ontario and their relatives live in all parts of the world. The research has involved a considerable amount of time and effort by each individual and we are most grateful for the tremendous support. This is an important study which will allow further investigation of the causes of breast cancer.

Many of you have asked for a report about our research findings. At this time we are still collecting information for analysis. However, we can tell you about the amount of data we have so far. From the statistics below, you will see that this is a very large research project.

Family History

As of July 1999, almost **4500** Family History Questionnaires inquiring about cancer within families have been completed and returned to us by patients. This represents about a 70% response rate, which is impressive for a project of this magnitude. From these responses, we have identified about **1600** families whose members are eligible to participate in additional parts of the research. These include answering two questionnaires about factors that may be associated with the development of breast cancer and providing a blood sample for genetic analysis.

Questionnaires: Diet and Personal History

The purpose of collecting information about risk factors for breast cancer (for example, diet, exercise patterns, alcohol use) is to try to understand the different roles of genetic and non-genetic factors in the development of breast cancer. About **1100** patients have completed these questionnaires so far.

Some of you may have received a telephone call from us to clarify answers. We do this in order to have complete and accurate information. Once we have all the information, the Diet Questionnaires are sent to Hawaii to be scanned and the analysis is returned to us. Information from the Personal History Questionnaire is entered into our database by our research team members.

Blood samples

We hope to collect a blood sample from each participant. These samples will be used to learn more about both rare and common genetic variations among families in which there are various patterns of cancer. Currently, we have **1000** samples of blood from patients.

Participation by family members

2500 relatives have replied to our invitation to participate in the Registry. We have received completed questionnaires from 1600 and blood samples from 750 to date.

Confirming cancer in family members

We will be asking participants to help us confirm the verbal reports of cancer within a family by signing a form to allow us to have information about their relatives' diagnoses. This is important to fully understand the patterns of cancer within families.

Completion of family information

If you look at the numbers above, you will know that we have some outstanding data to collect. At this time we are focusing our efforts on

completing our information about each family.

Additional research

We are comparing our findings with those from individuals in the general population. To do this, we are randomly choosing members of the general population and contacting them to ask if they will complete the same questionnaires as participants of the Registry.

We are also studying whether common genetic variations are related to the development of breast cancer. Again we will be studying blood samples from both Registry and the general population participants.

We are expecting to receive funding for a study comparing mammograms from women who have developed breast cancer and those who have not. We will be comparing the patterns that are seen on these x-rays.

Ontario Familial
Breast Cancer Registry
of the
Ontario Cancer
Genetics Network

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 Hospital/Princess Margaret Hospital:
Familial Breast Cancer Clinic
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:

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