

# **Canadian Breast Cancer Initiative**

## **Breast Cancer Information Exchange Pilot Projects**

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**Summer 1995**

On December 15, 1992, the federal government announced a contribution of \$2.7M over 5 years to five existing cancer centres or other health care institutions across Canada for the development of Breast Cancer Information Exchange Pilot Projects. The Disease Prevention Division, Systems for Health Directorate at Health Canada is coordinating these projects to facilitate networking across the country and prevent duplication of efforts. The initiative also has an important evaluation component. The following is a brief overview of the activities of the five sites selected.

### **Objectives**

The prime objective of the Breast Cancer Information Exchange Pilot Projects is to assist persons living with breast cancer and their families, care givers, and those at risk of contracting breast cancer in making informed decisions about a variety of concerns related to breast cancer.

These five year Pilot Projects will further our understanding of the feasibility and effectiveness of various information strategies.

A secondary objective of the Pilot Projects is the encouragement of partnerships among all those involved in the collection and dissemination of breast cancer information.

## Atlantic Region

### **Project carried out by the four Atlantic Divisions of the Canadian Cancer Society (CCS)**

(Newfoundland, Nova Scotia, New Brunswick, Prince Edward Island)

(project located at the Prince Edward Island (PEI) Division of the CCS in Charlottetown)

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The objectives of the Atlantic Breast Cancer Information Project (ABCIP) are the provision of specific information to women who are “hard-to-reach”; the development and enhancement of partnerships among existing agencies in Atlantic Canada which collect and disseminate breast cancer information; the provision of general information on breast cancer, accessible through a 1-800 telephone line; and the provision of specific information for health professionals.

The project is led by a Steering Committee made up of the presidents of the four Atlantic Divisions of the CCS, chaired by the president of the PEI Division. Key priorities for the pilot project have been identified by the 20-member Advisory Panel and sub-committees established to respond to them. An Evaluation Team ensures that the project is carrying out its objectives. With the announcement in March, 1995, by the national office of the CCS, of the development of a National Cancer Information Service (1-800 line), the Steering Committee reassessed the development of a separate toll-free information line for breast cancer in the Atlantic. The project will refocus on linking the regional resources developed by the project to the national line.

Activities include the development of a resource manual for regional information; input and update of database information; development of regional information on unconventional therapies; focus group discussions in each province, with emphasis on cultural, language, geographic and age barriers; development of information menu cards and information packages for card requests; development, in collaboration with the other 4 pilot projects, of a booklet entitled “Breast Cancer: Questions you Might Want to Ask”. ABCIP has linked with the Internet through Advisory Panel member, Dr. Jon Church, who developed an Internet based cancer discussion and support group following the first ABCIP Advisory Panel meeting last year. Recently, he has created the Atlantic Breast Cancer Archive, based at Memorial University in Newfoundland, which will include connections to major Internet based cancer information sites, such as CancerNet, Breast Cancer Information Clearinghouse, and Oncolink. Other components will include ABCIP Regional Resources and an electronic version of the “Guide to Unconventional Cancer Therapies”, developed by the Ontario Project.

## Quebec Region

### Project located at Hôpital Hôtel-Dieu de Montréal

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The objectives of the Quebec Breast Cancer Information Exchange Network are: to facilitate information exchanges at all levels within a region, between regions and between individuals involved in the campaign against breast cancer; to facilitate optimum penetration of interventions by setting up new communications channels; and to assess all interventions in order to ensure maximum effectiveness.

The project is led by an Executive Committee composed of the director of the project, the Director of Finances at Hôpital Hôtel-Dieu, the project coordinator and a representative from the Quebec Ministry of Health. The project has invited major women organizations and professional associations with multiplier effect to become members of their Advisory Committee. These groups are: Breast Cancer Action Montreal, Association féminine d'éducation et d'action sociale, Association québécoise des infirmières en oncologie, Collège des médecins du Québec, Direction de la Santé publique (Régie régionale de la Santé et des Services sociaux), région 03 (Québec City) et 06 (Montréal-centre), Ordre des infirmières et infirmiers du Québec, Ordre des technologues en radiologie du Québec, Canadian Breast Cancer Network -Quebec section, Canadian Cancer Society, spécialité professionnelle ou clinique en oncologie de l'Association des Pharmaciens des établissements de santé du Québec.

As a first step, a survey was carried out to validate the concepts contained in the project and verify the needs and expectations of potential partners in the network. This was followed by a general survey to determine how much Quebecers know about cancer in general, prevention and early diagnosis. The project toured the province between April and June, 1995, to set up network's substations. Activities planned or underway include, developing a human resources directory (October, 1995) and a materials resources directory (February, 1996); publishing a Journal on Breast Cancer (3/year, first issue "Special Screening" to be published in October 1995); organizing a symposium in Montreal on October 13-14, 1995; and working on self-financing. It must be noted that the underlying philosophy to all of the Network's projects and activities is to work with the partners in the various regions of the province and to avoid duplication of any kind.

## Ontario Region

**Project located at Toronto-Sunnybrook Regional Cancer Centre, Toronto, Ontario.**

Contact: **Ms. Natalie Parry**, Tel. (416) 480-5899, Fax (416) 480-6002

The purposes of the Ontario Breast Cancer Information Exchange Project are to facilitate easy access to state-of-the-art, user-friendly information regarding breast cancer and other related concerns; to serve as a catalyst for co-operative activity regarding the exchange of information about breast cancer and other related concerns; and to fill identified gaps, when appropriate, in collaboration with partners.

An Advisory Panel provides the strategic direction for the project. A six-member Project Team is responsible for the day-to-day operations and an Executive Committee, composed of 5 survivors from the Advisory Panel and the Project Team, provides a mechanism to link the Panel and the Team. The project has three directions: coordinating breast cancer information; access to information by women and their families; access to information by health professionals.

Activities to date include the development of a newsletter highlighting breast cancer activities across the province; development of a database of provincial services and resources; analysis of breast cancer informational gaps; setting up of a Multicultural Communities Initiatives Work Group; development of a process by which hard-to-reach populations can be understood and targeted; development, release, promotion and evaluation of "A Guide to Unconventional Cancer Therapies"; funding of two consortium of northern Ontario organizations (in two different regions) to undertake projects to address their specific informational needs; revision of the Burlington Breast Cancer Support Services' pamphlet "What you Need to Know About Breast Cancer"; telephone surveys of family physicians, breast cancer surgeons and nurses to determine their informational needs as well as their perceptions of their patients needs.

## **Prairies Provinces and the Northwest Territories (NWT) Region**

### **Project under the direction of the Alberta Cancer Board, the CCS, Alberta/NWT Division and the University of Calgary (Community Health Sciences)**

(located at the Tom Baker Cancer Centre in Calgary, Alberta)

Contact: **Ms. Joanne Pawelek**, Tel. (403) 670-2113 Fax (403) 283-1651

Breast Cancer Info Link, Prairies/NWT is a framework to disseminate information and to respond to women's questions with answers that they themselves find helpful. The overall objectives are: to establish an Advisory Panel and exchange network process model that facilitates collaboration between women and relevant multi-disciplinary groups; to facilitate the articulation of questions by women and primary health care providers outside of major urban areas; in so doing, to generate an informal needs assessment in these areas; to devise dissemination strategies that meet the breast cancer information needs of people in rural and remote areas throughout the region; to develop a framework for information exchange that can be used as a model in other areas within the region; and to diffuse the information generated from this project throughout the region.

The project is directed by a consortium composed of representatives from Screen Test, the Alberta Program for the Early Detection of Breast Cancer; the Alberta Cancer Board; the Tom Baker Cancer Centre; the CCS - Alberta/NWT Division; and the University of Calgary. The activities are carried out under the leadership of an Advisory Panel composed of breast cancer survivors, users and providers of breast cancer information coming from Alberta, Saskatchewan, Manitoba and the Northwest Territories and the consortium members.

Activities to date include consultations with a number of survivors, organizations and community groups from various locations across Alberta; setting up a pilot project in a rural area to test the establishment of a volunteer community contact person; development of a Reference Manual for women newly diagnosed; development and pilot testing of a breast health/cancer education program for aboriginal women as well as for nurses and community health representatives working in urban and rural clinics frequented by aboriginal women; and a video entitled "I Will Walk This Road With You: Supporting Breast Cancer Patients", portraying a range of support possible for breast cancer patients and offering practical advice on how to get that support. An Assessment Sub-committee has developed a protocol for a needs assessment and process evaluation.

## **British Columbia and Yukon Region**

### **Project under the direction of the British Columbia Cancer Agency (BCCA) and the Canadian Cancer Society (CCS), B.C./Yukon Division**

(project located at the CCS in Vancouver, British Columbia)

Contact: **Ms. Jennifer Bradbury**, Tel. (604) 872-4400, Fax (604) 879-9267

The objectives of the B.C. & Yukon Breast Cancer Information Project are to disseminate accurate information on early detection, treatment and follow-up care of breast cancer in a credible, timely and understandable fashion, to persons living with breast cancer, their families, care givers and all those at risk; and to encourage partnership among those involved in the collection and dissemination of breast cancer information to help ensure that consistency and currency of information is received by those in need.

The pilot project is guided by an Advisory Panel consisting of 15 members, 8 of these being breast cancer survivors, and a Joint Operations Committee consisting of 2 representatives from the CCS, 2 from the BCCA, 2 survivors from the Advisory Panel and the pilot project coordinator.

Activities to date include the expansion of the CCS cancer information line (CIL), with regard to breast cancer; development and distribution of new pamphlets, business cards and note pads advertising the CIL; publishing a quarterly newsletter "Abreast in the Nineties", for women, health care professionals and others concerned about breast cancer; development and implementation of an information and support needs assessment survey of 1,020 women living with breast cancer; and promotion, distribution and sale of the book "Breast Cancer: All You Need to Know to Take an Active Part in Your Treatment". Planned activities include the translation of that book from English to Chinese; revising the BCCA/CCS booklet "Food Choices and Breast Disease: Information for Patients and Health Care Professionals"; and setting up a "World Wide Web Page" to hold the B.C. and Yukon breast cancer information on the Internet.

#### **For further information, contact:**

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