

In Phase II of the Canadian Breast Cancer Initiative (1998 - 2003), project funding is available to support community capacity building among community groups with an interest in breast cancer issues. The need to support community capacity building was identified through consultation with partners and stakeholders in the Canadian Breast Cancer Initiative.

Eight projects were funded during 1998/1999. These included two national projects: National Networking Project, Part 1, and Towards ideal toll-free breast cancer information and support service(s). Provincial projects were wide-ranging in scope, including developing provincial networks in British Columbia and Ontario; addressing the needs of groups within communities: Aboriginal women in the NWT, Ethno-cultural women, women in rural communities and Francophone women; and developing skills for peer support volunteers. For further information on these projects, please contact the person named in the project summary.

During 1999/2000, fifteen projects are being funded across Canada. These include the continuation of the National Networking Project, Towards ideal toll-free service(s) and Responding to Diversity. In addition, projects to develop breast cancer networks focussing on the provision of both information and support are being funded in each province and territory.

## **COMPUTERIZED RESOURCE CENTRE ON BREAST CANCER**

**PROJECT # 6785-15.1998-0390214**

### **PROJECT DESCRIPTION**

The purpose of the Fondation québécoise du cancer project is to make available to all persons with cancer, and to health care workers, a wide selection (in French and English) of books, periodicals, articles, and audio and video cassettes that are currently available in its library through a computerized resource centre connected to the Fondation québécoise du cancer Web site.

Access to this information through an electronic library will enable health care institutions, agencies working with persons with breast cancer and anyone seeking additional information to consult the Resource Centre=s index without an intermediary and even make a loan request outside of regular office hours.

### **ADVANTAGES FOR PERSONS WITH CANCER**

For persons with cancer, having information gives them control over the situation by enabling them to anticipate the stages to come and be better prepared for the difficult situations they will have to go through.

Furthermore, information on prevention and early detection gives women, whether they are at risk or not, a better understanding of sound management and early detection.

### **THE CHALLENGES ENCOUNTERED**

For a number of reasons, project implementation has slowed down markedly in recent months.

All the computer equipment has been installed and the Académus software program has been selected. Data transfer is 80% complete. Unfortunately, the librarian in charge of setting up the project has been away since late August for health reasons. It is not known when she will be back.

As well, a problem of parameters between Académus and our Web site server has delayed the work of the computer technicians. The problem is now being resolved, and the transfer will be resuming during the week of November 1, 1999.

As soon as our librarian is back from sick leave, training will resume. At this stage, it is difficult for us to anticipate the completion date of this crucial phase.

### **FOR FURTHER INFORMATION**

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**Project Title:**

A Regional Strategic Planning Workshop for the Coordinated Development and Dissemination of Breast Cancer Information and Support

**Partners:**

British Columbia Cancer Agency  
British Columbia Women's Hospital & Health Centre  
British Columbia Oncology Nurses Association  
Bosom Buddies Support Group  
Breast Cancer Information Project, BC & Yukon  
Canadian Cancer Society BC & Yukon  
Canadian Breast Cancer Foundation, BC & Yukon  
Canadian Breast Cancer Network  
First Nations Breast Cancer Society  
Life Quilt for Breast Cancer Society  
Treasure Chests Support Group  
Vancouver Hospital & Health Sciences Centre  
Women=s Health Bureau, BC Ministry of Health

**Project Goal #1**

To create a collaborative coalition of individuals with breast cancer and the organizations and individuals with a provincial mandate in the area of breast cancer information, diagnosis, treatment and support.

**Objective 1** Seek input from consumers and health care providers, especially those outside the Lower mainland (Greater Vancouver), regarding the needs and preferences for Breast Cancer information and support.

**Objective 2** Establish a functional, collaborative coalition of individuals and organizations with an interest and/or a provincial mandate in the area for breast cancer information, diagnosis, treatment and support. It is anticipated that a rejuvenated and revitalized regional advisory panel on breast cancer information and support will grow out of the strategic planning workshop. The membership of such a panel will include breast cancer survivors, those at risk, health care provider organizations and regional representation.

**Project Goal #2**

To create and build consensus around a plan for sustained access to effective breast cancer information and support in BC and the Yukon that will reduce redundancy and enhance inclusion and accessibility to information.

**Objective 1** Build on the experience of the Breast Cancer Information Exchange Pilot Project. BC & Yukon region since 1994.

**Objective 2** Set strategic goals and objectives for the region around the provision of Breast Cancer Information and Support for the next 3 B 5 years.

**Accomplishments**

During the first day of the Workshop for Breast Cancer Information & Support, the invited participants collectively worked to build a past together (where have we been?), discussed current trends (where are we now?) and looked forward to the future (where do we want to go?).

By the end of the day, a clear picture was created through the various techniques defining global, regional and personal aspects of breast cancer information and support in BC and the Yukon. Gaps and links, commonalities and differences were all on the table making it obvious in which direction breast cancer information & support needed to go in the next 3 B 5 years. By the end of Saturday March 27, the large group gained consensus on 5 main goals for strategic planning for the next day. Those goals were:

- Collaborative, Cooperative Network / Umbrella Group
- Regional Linkages
- Sustainability
- Comprehensive Information and Support
- Equal Access to Information and Support

As was evident from the evaluations of the two-day strategic planning workshop on breast cancer information and support, success was achieved on many levels. Consensus was achieved in that the value-added resources and the networking initiated by the Breast Cancer Information should be maintained and future needs and goals were articulated. The needs established were to be inclusive at the community/regional levels and to provide an alliance of individuals committed to furthering and enhancing breast cancer support over the next 3 B 5 years. A collaborative coalition of individuals and organizations with a mandate for breast cancer, many of whom had not been meeting together prior to this project, are continuing to collaborate to build and sustain the Alliance for Breast Cancer Information & Support.

### **Challenges**

Designing the workshop process

Inviting 75 participants to a two day workshop on a weekend.

Identifying a diverse and representative makeup of participants to get the broadest views at the workshop.

Bringing a group together unknown to one another and moving them from separate agendas to a common ground.

Maintaining the energy created at the workshop as the process continues after the workshop.

### **Contact name:**

Deborah Rusch, Coordinator, Alliance for Breast Cancer Information & Support

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**PROJECT TITLE:****Community Contact Program - A Personal Guide to Breast Health / Cancer Information and Support.****PARTNERS:**

- The Community Cancer Program Network (CCPN) of Manitoba Cancer Treatment and Research Foundation (MCTRF) - provided Acontacts@ in 11 Manitoba communities who partner with MCTRF.
- Hope Breast Cancer Information and Resource Centre (HBCIRC) B program sponsor contacted and recruited community citizens for participation in program, coordinated and hosted the training workshop, provided on-going support of the community contacts, and evaluated community contacts= needs related to project sustainability.
- Breast Cancer Infolink B facilitated / conducted training workshop, provided training materials, and acted as a resource for HBCIRC in the implementation of the program.

**GOAL:**

To improve the availability of, and access to, current information on breast health / cancer and support services for rural women of Manitoba by linking women looking for information with local resources, experts, and support services.

**OBJECTIVES:**

- To provide reliable breast cancer information using existing and new dissemination strategies.
- To enable compassionate, trained peer support, and promote communication between caregivers.
- To establish and promote two-way referrals between and among already existing resources, physicians, and health care professionals.
- To support, understand, and communicate ongoing breast cancer research.
- To reach and support women throughout the province of Manitoba
- To observe for gaps in breast care programming.

**ACTIVITIES:**

- Identification and recruitment of a total of 17 Acommunity contacts@ targeted from: each Regional Health Authority; Aboriginal communities; and communities with a CCPN program.
- Training of Acontacts@ during a two-day (weekend) conference.
- Promotion of program in designated communities through fostering proactive relationships among persons/agencies concerned re breast health, development of referral mechanisms, and assessing and supporting Acommunity contact@.
- Conduct an evaluation of the process of implementation of the steps of the community contact process (get set, get known, get going) to use in program planning.

**ACCOMPLISHMENTS**

- Recruited and trained community contacts in all communities with a CCPN site, which resulted in expansion of existing programs, program support from existing infrastructure, avoidance of duplication, and promotion of collaboration and on-going sustainability.

- Targeted Acontacts@ from each Regional Health Authority thereby ensuring equitable access to training and resources throughout the province.
- Activities involved in the training workshop provided valuable information regarding the designated communities and their challenges and assets.

**KEY LEARNING POINTS:**

- Success of program implementation linked to community resources/support
- When Acontacts@ return to their community and attempt to enact their role
- On-going support of Acontacts@ by host organization essential, time-consuming, and long-term
- Hosting a conference over a weekend and negotiating with several conference facilities can save considerable money.
- The contacts require considerable resources when they return to their community (books, pamphlets, exhibit materials) therefore, this requires budgeting

**CHALLENGES:**

- Ensuring sustainability requires on-going support and dedication of resources (training, de-briefing, collaboration, communication and dissemination strategies, program planning, development and evaluation)
- Ensuring province-wide representation challenging given the vast geographic and cultural diversity of Manitoba.

**CONTACT NAME AND E-MAIL:**

Kathy Thomson - Director, Breast Cancer Centre of Hope  
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**Project title: Development of Northern Strategies for Providing Breast Health/Breast Cancer Information and Support**

**Goal:** To consult with Aboriginal women in Nunavut and the NWT on effective and appropriate ways to provide breast health/breast cancer information and support in northern communities.

**Objectives:** To organize and facilitate two or more community focus groups; based on the results, to recommend information and support strategies.

**Results:** Six focus groups were held in five NWT or Nunavut communities, with a total participation of 45 Dene/Metis or Inuit women.

Participants said they prefer to receive information verbally, preferably one-on-one from a local health care provider. The second most recommended way is by video, including Aboriginal language versions. Information on community radio in English and in Aboriginal languages, were also recommended. Pamphlets can be helpful if they are short and simple, with vocabulary that is appropriate for the north. Pamphlets should make use of pictures and culturally appropriate graphics.

Participants felt that there is general support for survivors and their families from within the community. It should be noted however that there were no breast cancer survivors among the participants.

**Recommended strategies include:**

Provide community nurse-practitioners and other interested persons with resources for breast health/breast cancer education and information in their community, including a resource kit, a northern video on BSE and screening mammography, a northern plain-language pamphlet and audiotaped information for community radio stations. Materials should be in all NWT Aboriginal languages. Provide training for community nurse-practitioners and others in CBE(nurses), BSE, and orientation to screening mammography. Provide opportunities for interested breast cancer survivors to link with other survivors and to identify what is needed for peer support. Develop and promote an NWT breast health/breast cancer resource centre.

**Follow-up:** The NWT Breast Cancer Information Project has since developed and distributed a breast cancer information manual for northern health centres, a plain language breast health pamphlet in all NWT/Nunavut Aboriginal languages, set up an information resource centre, and begun working on information audiotapes and a possible video proposal.

For more information contact the Project Coordinator at (867) 920-6177 or by email at [cranbery@internorth.com](mailto:cranbery@internorth.com)

## **Community Capacity Building Project 1998/9**

### **Project Title:**

Breast Cancer Information and Support Think Tank: Sharing and Planning Together

### **Partners:**

Ontario Breast Cancer Information Exchange Partnership B Coalition of 38 cancer and breast cancer organizations.

### **Goal:**

To develop an Ontario Action Plan for Breast Cancer Information and Support, utilizing a think tank workshop format.

### **Objectives:**

To hold a two day think tank/workshop that was designed to achieve the following:

- a) to inform the Think Tank participants about the current status of knowledge concerning prevention, screening, treatment and supportive care regarding breast cancer, and
- b) to identify current issues regarding accessibility to breast cancer information and support, rank priorities for collaboration and develop strategies for action.

### **Accomplishments:**

One hundred and twenty stakeholders in breast cancer information and support attended the Think Tank. A wide range of agencies and organizations, both institutional and community based, were involved. The dialogue was excellent and produced many ideas about strategies for action about breast cancer information dissemination and support.

### **Key Learning Points:**

- The past five years has seen progress in the area of disseminating information about breast cancer and providing support. However there is still a great deal that needs to be done.
- Two factors contributing to the success of the think tank were:
  - a) the inclusion of a wide range of participants and
  - b) providing plenary presentations of current information about breast cancer at the beginning of the think tank. The presentations provided a common frame of reference for the subsequent discussions.

### **Challenges:**

The major challenge emerging from the Think Tank is communicating the ideas from the sessions in such a way so as to mobilize action.

### **Activities:**

The main activity following the Think Tank is the distribution of the Think Tank report and mobilizing various agencies and organizations to act upon the recommendations.

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## **Towards ideal toll-free breast cancer information and support service(s) - Phase 1**

- Partners:** Breast Cancer Action Saskatchewan  
Canadian Breast Cancer Foundation  
Canadian Breast Cancer Network  
Canadian Cancer Society  
Fondation quebecoise du cancer  
The Hope Breast Cancer Information and Resource Centre  
North West Territories Breast Health/Cancer Action Group  
Reseau quebecois pour la sante du sein  
Willow Breast Cancer Support and Resource Services  
Health Canada
- Goal:** Working collaboratively to define ideal toll-free service(s) for breast cancer information and support in order to respond to the needs of callers.
- Objectives:** To clarify a common vision for the toll-free service(s).  
To describe Aideal@ provision of information and support.  
To conduct an environmental scan of existing breast cancer information and support services.  
To identify strategic directions, prioritize implementation alternatives and develop an action plan.
- Accomplishments:**  
The final report, *Interactive models for the provision of breast cancer information and support by telephone*, March 1999, in English and French. The report outlines optional interactive models for the provision of information and support by telephone. The models are based on a review of relevant research literature, discussion with representatives of organizations participating in the project and a focus group of individuals with breast cancer.
- Key learning points:**
1. Partner organizations learned to work together cooperatively for a common goal.
  2. Core elements of an ideal 1-800 service were identified.
- Challenges:** Short timelines for a large project involving many players.  
Identifying areas where organizations can collaborate effectively.
- Activities:**
1. Description of the Aideal@service.
  2. Several models outlined as options.
  3. Proposal for phase 2 of the project submitted.
  4. Identification of evaluation issues.
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## **Responding To Diversity Phase I Willow Breast Cancer Support & Resource Services**

Partners: Special thanks to the organizations who organized focus group discussions: Davenport Perth Neighbourhood Services, Malton Neighbourhood Services, Peel Sisters of Colour, Queen West Community Health Centre, St. Stephen's Community House. Researchers from the Portuguese, Italian, Chinese and Black communities carried out the research.

Goal: An exploratory research project on how best to meet the information and support needs of women from diverse ethno-cultural backgrounds experiencing breast cancer.

Objectives: Seven key objectives were set for project including:

- Determine if existing service delivery models of peer survivor support are appropriate for community members;
- Find out where women are going, or are likely to go to obtain breast cancer information and/or support;
- Determine how best to inform people about Willow services;
- Determine if there are any barriers to existing peer support services.

Accomplishments:

- Published and distributed research findings which included 18 key findings, 8 in issues relating to service; 8 pertaining to outreach and publications; 2 pertaining to research.
- Participation of 72 individuals in 49 agencies in questionnaire
- Participation of 65 women in 5 focus groups
- Development of 9 key recommendations for Willow
- Establishment of a pilot project with the Hispanic Development Council

Key Learning:

- Findings support the existing confidential peer-support, survivor-driven information delivery model followed by Willow for women from all cultures
- Peer information and support is a welcome and valued service model
- Use of peer support groups for breast cancer survivors is perceived as an appropriate support service model in most ethno-cultural communities.
- English-French recorded telephone message is a definite barrier to service.
- Print material on breast cancer generally requires significant literacy skills; this limits the effectiveness of existing material
- Real concern about lack of breast cancer awareness within ethno-cultural communities and lack of resources for their communities.

Challenges:

Strong links between Willow and community organizations are needed for effective community education and outreach; Direct links with staff workers in ethnic organizations are highly important; Actively involving women from ethnic communities in work of Willow is seen as essential; Annual budget for diversity initiatives required; Current Willow promotional video is ineffective and inappropriate for women from diverse ethno-cultural groups.

Activities:

Carried out March 1999: Survey questionnaire distributed by fax to immigrant-serving organizations throughout Ontario; Personal interviews of front-line staff working with ethno-cultural populations; Series of five focus groups; Publication of findings and distribution of report summary to all participating agencies.

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## **Peer Support and Facilitator Training: Regional Workshops Willow Breast Cancer Support & Resource Services**

Contact: Chris Sinding, [willow1@web.net](mailto:willow1@web.net)

### Partners:

- Breast Cancer Action - Saskatchewan
- The Hope Breast Cancer Information and Resource Centre in Manitoba
- Northwest Territories Breast Health/ Breast Cancer Action Group
- Breast Cancer Infolink Prairies / Northwest Territories

### Goals

- To pilot a model for delivering peer support and facilitator training workshops outside of Ontario
- To strengthen community capacity to respond to the range of information and support needs of women with breast cancer
- To build the foundation of an integrated approach to the provision of peer support services, regardless of location in Canada
- To increase the ability of women involved in community-based breast cancer activities to assume leadership in achieving these outcomes.

### Objectives, Activities and Accomplishments

- To provide a peer support/ facilitator training workshop, for women active in or interested in becoming active in providing support and information via telephone or breast cancer support groups.
  - *Two workshops entitled Supporting Women with Breast Cancer were held, one in Winnipeg March 12 - 14 and one in Regina March 19 - 21.*
- To involve approximately 20 women in the workshop, from communities and groups in Saskatchewan and the Northwest Territories.
  - *In total, 41 women participated, from Saskatchewan, the Northwest Territories, Manitoba and Ontario.*
- To share information, resources and materials between regions and across the country.
  - *Information, resources and materials developed all across Canada were shared. Over the course of the weekend women signed up to receive information about resources that were on display or to receive the resource itself. Mountains of photocopying ensued.*

### Key Learning Points

- Collaborative planning considerably increased the relevance of the workshop to local women
- The attentive logistical support provided by partner groups saved the project money, saved Willow the headache of organizing at a distance, and contributed to the comfort of all involved
- Sufficient funds allocated for travel - and the commitments of women in urban centres - meant that women from rural communities and communities at a distance from Regina and Winnipeg were able to attend this workshop.

### Key Challenges

- New to us at this workshop was the participation of women who are not active in self-help groups but are rather providing support one-on-one, often by phone. Both logistical and program challenges emerged; details available on request.