



BREAST CANCER
INFORMATION AND SUPPORT
THINK TANK

Sharing and Planning Together

APRIL 17 – 18, 1999

WORKSHOP REPORT SUMMARY

July 2000

BREAST CANCER INFORMATION AND SUPPORT THINK TANK

WORKSHOP REPORT SUMMARY

TABLE OF CONTENTS

SECTION I - INTRODUCTION	3
Ontario Breast Cancer Information Exchange Partnership.....	3
Background.....	3
Aim and Objectives of the Think Tank.....	4
About this Summary	4
Think Tank Planning Group	5
The Think Tank	5
Participants	5
Format.....	5
SECTION II - PRIORITIES FOR ACTION	6
SECTION III - EVALUATION OF THE THINK TANK	7
SECTION IV - NEXT STEPS	12
FINAL COMMENT	12
APPENDICES	13
APPENDIX A	14
Coalition of Stakeholders list	
APPENDIX B	15
List of Think Tank Participants	
APPENDIX C	19
Readings	
APPENDIX D	20
Program	
APPENDIX E	
Priorities for Action	(separate document)

SECTION I - INTRODUCTION

Ontario Breast Cancer Information Exchange Partnership

The Ontario Breast Cancer Information Exchange Partnership is a coalition of organizations who have a stake in the dissemination of information about breast cancer. The coalition emerged from the Ontario Breast Cancer Information Exchange Pilot Project (OBCIEP), originally established in 1993. The evolution to a coalition model occurred when the original stakeholder organizations represented on the OBCIEP Advisory Panel stated, during a strategic planning session, the need for the function of information exchange to continue and to build on the work of the past five years.

During the initial five-year funding period, OBCIEP responded to the specific needs of Ontarians by facilitating easy access to state-of-the-art, user-friendly information about breast cancer, and serving as a catalyst for co-operative activity regarding the exchange of information about breast cancer. Representatives from 30 stakeholder organizations across the province, with input from their own networks, guided the OBCIEP initiatives in those areas in which Ontario's breast cancer community lacked a concerted, organized effort. These areas included: dialoguing with organizations involved in providing breast cancer information, sharing information about existing resources, responding to the needs of women and health care professionals, and identifying and filling information gaps. Since its inception, the OBCIEP etched a distinct role in Ontario's breast cancer community.

The new coalition has 38 member organizations and is committed to ensuring information about breast cancer is available to all people in Ontario. By providing a neutral forum for networking and information exchange, co-operative, co-ordinated problem-solving is fostered and action concerning issues related to breast cancer information dissemination can be taken.

The primary role of the OBCIEP is to assist organizations, involved in the dissemination of breast cancer information, to respond to the information needs of their clients. This is accomplished by sharing information about existing breast cancer resources through our newsletter, web site, and various communication tools used by our members. Without duplicating the efforts of others, we also develop information resources for women, their families and health care professionals to fill identified gaps. In addition, our activities involve the evaluation of current dissemination strategies to ensure that people can easily access quality, up-to-date information when they need it.

Whatever the activity, the philosophy remains the same: the development and dissemination of information about breast cancer should be guided by those directly affected by the disease. The strategic direction is set by a Coalition of Stakeholders consisting of 38 cancer and breast cancer organizations from across Ontario. Of all the organizations that are involved, over half are grassroots and breast cancer survivor-directed groups (see Appendix A).

Background

In 1999, it is estimated that 7400 women in Ontario will be diagnosed with breast cancer and 2100 are expected to die from their disease (National Cancer Institute of Canada, 1999). The impact of breast cancer upon a woman and her family and friends can be profound, creating a myriad of challenges. If women are to cope successfully with these challenges, access to breast cancer information and support is critical. To make informed decisions about breast cancer, women, their families and friends, as well as their health care providers, all need easy access to the right information offered in a helpful format at the time it is needed, regardless of where they live in the province.

Despite the growth and development of the Ontario breast cancer community during the past five years, easy access to information support remains elusive for many women diagnosed with breast cancer in the province. This is especially the case for women belonging to visible minority groups and women living in rural and outlying regions of the province. Women say they do not always know where to obtain relevant, user-friendly information nor are they always able to access a support group. Existing information and support programs are not seemingly accessed by these women.

Canadian women are becoming more outspoken about the inadequacies surrounding the availability and access to breast cancer information and support. These inadequacies need to be addressed through collaborative initiatives that make use of, and build upon, existing resources and networks. Consensus needs to be gained regarding what information and support priorities are best served through collaborative initiatives in the provinces and who will assume responsibility for the leadership of such initiatives. An action plan for Ontario regarding breast cancer information and support is required as a discussion tool. Such a tool will help organizations comprehend the roles they might play in the fight against breast cancer. It is essential that such a plan be developed collaboratively and involve the widest range of stakeholders as is possible.

In the fall of 1998, the OBCIEP assumed leadership for the process of developing an Ontario Action Plan for Breast Cancer Information and Support, utilizing a think tank workshop format. Although this project topic area is larger than the mandate of the OBCIEP, the coalition is in an excellent position to provide the necessary expertise. Many coalition members participate in the provision for both breast cancer information and peer support. Additionally, there are members with strong workshop planning and facilitation skills.

Aim and Objectives of the Think Tank

The ultimate aim of holding the Think Tank was to enhance the accessibility to breast cancer information and support in the province of Ontario. The specific purpose of the Think Tank was to provide a forum where a full range of stakeholder organizations could design a provincial plan for breast cancer information and support. The Think Tank took the format of a two-day workshop that was designed to achieve the following:

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

The primary product from the Think Tank is an action plan for the province concerning breast cancer information and support. It is anticipated this tool will be a critical one as we build community capacity around breast cancer information and support over the next several years in Ontario. Additionally, the model of the Think Tank and action plan may be a useful reference for other provinces to use in their goal setting processes.

This Think Tank was made possible through a grant provided by Health Canada with the assistance of the Ontario Breast Cancer Information Exchange Partnership and the Toronto-Sunnybrook Regional Cancer Centre. The views expressed herein do not necessarily represent the official policy of Health Canada. Additional unrestricted education grants were also received from Eli Lilly Canada and Pharmacia and Upjohn.

About this Summary

The purpose of this summary report is to share the action plan developed as a result of the discussion at the Think Tank held on April 17 and 18, 1999, in Toronto. It highlights the priorities identified during the session and specific suggestions to mobilize action in the areas discussed.

Think Tank Planning Group

The Planning Groups for the Think Tank was composed of representatives from various OBCIEP member organizations:

- Ontario Breast Screening Program
- Canadian Breast Cancer Foundation (Ontario)
- Canadian Cancer Society (Ontario)
- Willow Breast Cancer Support and Resource Services
- Ontario Breast Cancer Network
- Public Health Department, Metro Toronto
- Cancer Care Ontario
- Toronto Regional Cancer Centre

The Planning Group shaped the selection of topics, the invitations to speakers and the format of the workshop itself to ensure the objectives were achieved. They also shaped the invitation list to ensure that a wide cross-section of stakeholder organizations participated in the Think Tank, representing various disciplines, professions and those with personal experience with breast cancer. It was important for the success of the Think Tank that participation went beyond the membership of the OBCIEP.

The Think Tank

Participants

The Think Tank was held in Toronto on April 17 and 18, 1999. It was attended by 120 individuals from agencies or organizations involved in prevention, screening, diagnosis and treatment, supportive care, and palliative care. Both institutional (e.g., hospital, cancer clinics, screening programs, etc.) and community-based (e.g., visiting nursing, Canadian Cancer Society, etc.) organizations were represented. The specific participants are listed in Appendix B.

Format

The two-day Think Tank was designed to achieve both the educational and the developmental objectives.

The first morning was devoted to plenary sessions aimed toward informing participants about the current status of knowledge regarding prevention, screening, treatment and supportive care in breast cancer. This was an important initial step in this workshop. There were a wide range of stakeholder organization representatives and the range of knowledge about breast cancer and existing services was varied. The presentations of the first morning provided the basis or foundation for the subsequent discussions and ensured that everyone present had a common starting point or frame of reference for the dialogue about an action plan. It was also anticipated that the update would provide representatives with information they could take back to their respective organizations.

An exhibition area was also provided for the participants. Stakeholder organizations were invited to present posters or table-top displays outlining their programs and resources. This gave the Think Tank participants an

opportunity to learn about new resources that are available as well as network and make new contacts with one another. It was anticipated the exhibition would also contribute to the education of the attendees.

Additionally, a collection of supplementary readings were prepared for the Think Tank participants. They included articles on carcinogens in the environment, the influence of diet and exercise on breast cancer, improved screening methods, drug therapy, quality of life issues, and information needs of families. A complete list of supplementary readings is included as Appendix C. It was hoped that this material would assist the participants in their reports to their respective organizations.

The afternoon of the first day and morning of the second day were devoted to small group session discussions. Each group had 10 to 12 participants who had selected a topic area of their choice and an appointed facilitator. The broad discussion topics were primary prevention, screening and early diagnosis, treatment and decision-making, and rehabilitation and survivorship. The preliminary program is attached as Appendix D. Each group discussed a single broad topic area but focused on the following questions:

- Celebrate Success (What's worked well?)
- Challenges and Gaps (What's your experience?)
- Priorities for Action (What needs to happen?)
- Identify Expertise (Where are the skills?)
- Resources (What's needed?)
- Areas for Collaboration (What can we do together?)
- Mobilization (How do we work together?)
- Actors (Who takes the lead for what?)

The written material from all of the discussion groups was collated for a Think Tank Newsletter following the initial discussions on the first afternoon and after the second discussion group in the morning of the second day. These newsletters were distributed to the Think Tank participants to aid in the subsequent discussions.

On the final afternoon, a plenary discussion was held to review the strategies and action steps that had been proposed in the small groups. Clarification was sought and additional comments were noted for incorporation into the final report of the action plan. The process during this session was aimed toward garnering agreement about the identified strategies because they would form the basis of the action plan.

SECTION II - PRIORITIES FOR ACTION

The major points of discussion raised during the Think Tank are condensed in Appendix E. The discussions focused on:

- Prevention
- Early Detection
- Diagnosis
- Treatment
- Rehabilitation
- Palliative Care

Issues raised under “Identified Priorities” represents the views of the Think Tank participants captured during small group discussions and plenary dialogue. The OBCIEP Joint Advisory Group has taken an additional step to categorize the priorities and, where possible, identify existing resources, action steps, and suggest organizations or bodies that would assume leadership and/or responsibility for the issues identified. In some

cases, such as endeavours in improving professional education, a number of different programs are already underway so the list as presented is not meant to be exhaustive.

The summary chart is presented to the OBCIEP coalition members and Think Tank participants for feedback and comments.

SECTION III - EVALUATION OF THE THINK TANK

Evaluation of the Think Tank was conducted by asking the participants to complete an evaluation form. The evaluation covered all aspects of the Think Tank. A total of 63 (52%) of the Think Tank participants returned an evaluation form. The summary of the responses is presented in Table 1 and Table 2.

Overall, the Think Tank participants who responded in the evaluation rated the Think Tank as "excellent" or "good" in the precoded sections of the evaluation. In addition, all participants wrote extra comments, although not for every question.

Participants described the plenary presentations as interesting and informative. They found the information was useful later in the small group discussions. The presentations were seen as providing a good mix of speakers and topics, with the survivor presentations highlighted as important. In the words of the participants:

- *all speakers were very pertinent, enjoyed and learned from all sessions*
- *[the presentations] provided common content for rest of the week-end*
- *food for thought! even hearing information previously known was valuable in that new meanings are always being gained by individuals*

The major concerns expressed about the presentations focused on the length of the sessions being too long and the lighting in the room making it difficult to see slides and overheads.

As far as the small group sessions, participants described them as productive, an excellent opportunity to network and a wonderful opportunity for sharing voices. Participants liked the mix of survivors and health care professionals. Many participants commented on how the facilitator made a difference to the group experience. In a few groups, participants reported one person tried to monopolize and push a personal agenda, which they found frustrating. Examples of participants' comments include:

- *a little difficulty in keeping the group on topic and focused, but good exchange of ideas*
- *encouraged by how diverse backgrounds were and how we were still able to agree and come to a mutually agreeable action plan*
- *an excellent variety of perspectives*
- *we had an excellent group and I feel we came up with a lot of good ideas*

Those who commented on the newsletter or written group summaries thought it was helpful to have the written information. The newsletter provided the participants with a sense of what all the small groups had discussed and that decreased the necessity of having lengthy verbal reporting to the large group.

Participants commented that they liked having the package of supplementary readings. The only concern cited about them was that the packages were given to the participants at the time of registration. Participants would have liked to have had them before the Think Tank. There were a number of suggestions for improvement should the Think Tank be held again in the future. Many of these comments were focused on conference administration (e.g., name badges, registration procedures, etc), conference venue (e.g., need darker room to see slides) and more breaks (e.g., have sessions shorter).

Overall, participants who completed the evaluation especially liked the opportunity to interact and network with other survivors and stakeholders from all sectors. Brainstorming and the exchange of ideas were welcomed. Another highlight for participants was the presentation of a play based on research about information needs of women with metastatic breast cancer entitled, "Handle with Care". The following examples reflect comments many of the participants wrote concerning what they liked best about the Think Tank:

- *the opportunity to dialogue as part of the conference was most valuable both in terms of knowledge sharing and connection in an intimate way. Thank you. And the play was excellent.*
- *opportunity to meet and mix with a cross-section of women in Ontario - patients, survivors and health care professionals*
- *meeting all the participants and learning about what is happening throughout the province*
- *meeting people, sharing ideas, great idea to do this, everyone had similar agendas*

Many women mentioned how much the mix of people contributed to the dialogue and how co-operation can happen. As an example:

- *[I liked the] synergy of participants. I hope that it can be maintained and harnessed to move the Action Plan forward*
- *co-operation, communication, strides forward in limited time - amazing!*

Participants wrote about being tired at the end of the Think Tank. This made it hard to engage in the final discussion about the Action Plan. Many were convinced an action plan was an important step to take. They emphasized, however, that there needs to be feedback to participants about the Action Plan and there needs to be follow-through. Participants were startled by the gaps that still exist regarding breast cancer and felt there was a need for action to implement the recommendations. For example:

- *very important for the plan to be HEARD by the powers that be. Must be acted upon to make change happen*
- *all those ideas need to be completely, on an on-going basis, synthesized; each part needs to be acted upon*

Finally, many women indicated they would return home feeling they would make use of the information from the Think Tank and continue to advocate for change. Many expressed a desire for continued networking.

- *[I will] use the summaries for discussion and hopefully draft a "community action plan" within our Breast Cancer Support Group*

- *[we need to] continue to network for information and support services availability.*

Table 1 Responses by Participants of Conference Activities (N = 63)

How participants heard about Think Tank Conference			
• invitation by mail/fax			41
• word of mouth			5
• posting on OPHE weekly bulletin			-
• other			18
Plenary Sessions			
(1) Prevention, Screening & Early Diagnosis		(2) Breast Cancer Treatment, Treatment Decision-making and Rehabilitation & Survivorship	
• Excellent	26	• Excellent	23
• Good	30	• Good	34
• Fair	5	• Fair	2
• Poor	-	• Poor	-
Small Working Group Discussions			
<u>(1) Saturday, April 17 (2:15 p.m.)</u>			
(a) Rating of working group sessions		(c) Sufficient time (1.5 hrs) for discussion of theme	
• Excellent	26	• Yes	54
• Good	30	• No	5
• Fair	5		
• Poor	-		
(b) Participants received selection of choice		(d) Printed summary of small group sessions helpful	
• Yes	56	• Yes	57
• No	4	• No	2
<u>(2) Sunday, April 18 (9:00 a.m.)</u>			
(a) Rating of working group session		(b) Participants received selection of choice	
• Excellent	35	• Yes	53
• Good	17	• No	9
• Fair	6		
• Poor	2	(c) Sufficient time (1.5 hrs) for discussion of theme	
		• Yes	56
		• No	5
Full Group Discussion on Creating an Action Plan, Sunday, April 18 (1:30 p.m.)			
(a) Felt a need for Action Plan for Breast Cancer Information and Support			
• Yes	50		
• No	-		
(b) Action planned as a result of conference			
• Individually			27
• Organizationally			28
• Locally			14
• Provincially			12

Table 2 Logistics and Overall Impressions of Conference (N=63)

(a) Rating of conference venue:	
• Excellent	25
• Good	32
• Fair	5
• Poor	1
(b) Rating of meals/other refreshments:	
• Excellent	44
• Good	17
• Fair	2
• Poor	-
Rating of delegate package and supplementary readings provided:	
• Excellent	27
• Good	28
• Fair	2
• Poor	1
(d) Rating of event logistics (i.e. pre-conference and during conference):	
• Excellent	19
• Good	25
• Fair	8
• Poor	1

SECTION IV - NEXT STEPS

The Breast Cancer Information and Support Think Tank generated many ideas for action during the two days of discussion. The ideas are presented in the preceding pages of this report for information and, hopefully, action. It is anticipated the ideas will provide input for planning breast cancer activities across the province by any number of organizations or groups. Some parts of the report will have more relevance to some agencies or organizations more than others. It is anticipated each agency will review the ideas and select ones to pursue based on the agency's mandate and willingness to take leadership.

As the Think Tank drew to a close, participants reviewed the priorities for action which had been generated during the Think Tank. General discussion was held to clarify wording of the priorities and to determine if anything of importance had been omitted from the list. Participants then engaged in a simple voting procedure to indicate the ideas they thought ought to be pursued in the immediate future (i.e., next six months). The result of that vote is presented below.

Primary Prevention

- hold an initial meeting to discover what is happening across the province; provide communication to the Breast Cancer Prevention Coalition and invite collaboration with other groups/ OBCIEP and Willow become linked to the mandate; use existing networks
- co-ordinated efforts to disseminate information

Screening and Early Detection

- coalition of existing groups – develop a provincial body to oversee (called Ontario Breast Health Program) – collaboration, standards, consistent, access, availability, evaluation, advocacy
- legislate all mammography facilities to become CAR accredited
- more and better and less invasive diagnostic tools

Treatment and Decision-making

- funds for cancer patients facing economic barriers (e.g. government cutbacks have hurt, cost of drugs prohibitive)
- equitable funding for all cancer centres to ensure equity in programs of supportive care

Rehabilitation and Survivorship

- there should be an organization which co-ordinates information and support; provides a neutral ground for open discussion with all partners and ensures no duplication; promotes shared problem-solving and opportunities for collaboration, identifies gaps, facilitates partnerships, finds funds for projects

FINAL COMMENT

The Ontario Breast Cancer Information Exchange Partnership hosted the Breast Cancer Information and Support Think Tank. The Partnership has collated the material from the two-day discussion and produced this report. The report will be circulated widely in anticipation of stimulating actions that will ultimately improve access for Ontarians to information and support surrounding breast cancer.

APPENDICES

Appendix A	OBCIEP Coalition of Stakeholders List
Appendix B	List of Participants
Appendix C	List of Readings
Appendix D	Think Tank Program
Appendix E	Priorities for Action (separate document)

APPENDIX A

Ontario Breast Cancer Information Exchange Partnership

Coalition of Stakeholders

Alliance of Breast Cancer Survivors
Bayview Support Network, Toronto
Breast Cancer Action Ottawa
Breast Cancer Action Kingston
Breast Cancer Prevention Coalition, Brantford
Breast Cancer Research and Education Fund, St. Catharines
Breast Cancer Support Services, Burlington
Canadian Association of Nurses in Oncology
Canadian Breast Cancer Foundation
Canadian Breast Cancer Network
Canadian Cancer Society – Ontario Division
Cancer Information Service
Centre for Health Promotion, Toronto
College of Physicians and Surgeons of Ontario, Toronto
Connecting Rainbows, Stouffville
Hospice Association of Ontario, Toronto
Living with Breast Cancer Huron-Perth, Stratford
Marvelle Koffler Breast Clinic, Mount Sinai Hospital, Toronto
Ministry of Health, Public Health Branch, Toronto
Ministry of Health, Women’s Health Bureau
North York General Hospital Breast Diagnostic Centre
Ontario Breast Screening Program, Toronto
Ontario College of Family Physicians, Toronto
Ottawa Regional Women’s Breast Health Centre
Peterborough Breast Cancer Support Group
Sarnia Living with Breast Cancer
Sudbury and District Breast Cancer Support Group
Sunnybrook Health Sciences Centre, Toronto
Supportive Cancer Care Research Unit, Hamilton
Thunder Bay Breast Health Coalition
Timmins Breast Screening Coalition
Toronto-Sunnybrook Regional Cancer Centre
University Health Network – Princess Margaret Hospital
Waterloo Region Breast Health Network
Wellspring, Toronto
Willow Breast Cancer Support & Resource Services, Toronto
Wings Breast Cancer Support Group, Thornbury
Women’s College Hospital, Toronto

APPENDIX B

Breast Cancer Information & Support Think Tank: *Sharing & Planning Together*

List of Participants

Susan Barber Community Care Access Centre York Region	Toronto Public Health
Cris Barrett Sunnybrook & Womens College Health Sciences Centre, Women’s College Campus	Jean Chapman Canadian Cancer Society
Meryle Berge Breast Cancer Education & Research Fund	Carol Conliffe Cancer Care Ontario South Region
Margaret Blatherwick Guelph–Wellington Breast Cancer Support Inc.	Pat Crockford Connecting Rainbows Breast Cancer Support Group
Joyce Bonneau Canadian Auto Workers (CAW) Women’s Committee	Dauna Crooks Supportive Cancer Care Research Unit Hamilton Regional Cancer Centre
Laura Brawn Bayview Support Network	Marg Czaus Centenary Health Centre
Lucienne Bushnell Ontario Breast Screening Program	Deborah Davis Canadian Forces
Brenda Caldwell Interlink Community Cancer Nurses	Cathy DeGrasse Ottawa Regional Women’s Breast Health Centre Ottawa Hospital Civic Campus
Jane Campbell Bayview Support Network	Eunice Derowin Wings Support Group Georgian Bay Breast Cancer Support Group
Brigid Campbell-Nash Community Care Access Centre Simcoe County	Lorna Dobi Ontario Breast Screening Program
Filomena Carvalho Immigrant Women’s Health Centre	Diane Ford Ottawa Regional Cancer Centre
Maureen Cava	Elaine Forde Centenary Health Centre

Kathy Fowle
Canadian Auto Workers (CAW)
Women's Committee

Gail Foy
Georgian College

Susan Gillies
Hastings-Prince Edward Counties
Breast Cancer Support Group

Gord Glendon
Ontario Cancer Genetics Network
Cancer Care Ontario

Raylene Godel
OBCIEP, Project Design & Dissemination
Group

Dorothy Goldin Rosenberg
Women's Network on Health and the
Environment

Deborah Gordon
Etobicoke Breast Cancer Support Group

Sally Gyton
Bayview Support Network

Joanna Hakenberg
Cancer Information Service

Joel Heitin
Canadian Breast Cancer Foundation

Robyn Henighan
Peterborough Breast Cancer Support Group

Valerie Hepburn
Canadian Breast Cancer Foundation

Doris Howell
Interlink Community Cancer Nurses

Sarafina Hui
Immigrant Women's Health Centre
Rosanne Jabbour
St. Joseph's Health Centre

Maureen Jackman
Princess Margaret Hospital

Kausika Jeyakumar
Immigrant Women's Health Centre

Phoebe Jibunoh
Centenary Health Centre

Suzie Joannis
OBSP – Ottawa

Claudette Johnson
KFL&A Community Care Access Centre

Trudy Kamburis
Health Education Consultant

Carole Keys
Hearth Place Cancer Support Centre
Oshawa District Breast Cancer Support Group

Irving Koven
Marvelle Koffler Breast Centre
Mount Sinai Hospital

Judy Laceby
Marvelle Koffler Breast Centre
Mount Sinai Hospital

Stephanie Lanni
CCS Vaughan Living with Breast Cancer

Catherine Lemke
Canadian Breast Cancer Network

Janice Lewkin
Breast Health Centre & Thunder Bay & District
Breast Health Coalition

Sharyn Little
Oshawa & District Breast Cancer Support Group

Lavina Lickley
Sunnybrook & Women's College Health
Sciences Centre
Women's College Campus
Anita Lovin
Sudbury & District Breast Cancer Support Group

Marilyn Lundy
Saint Elizabeth's Health Care

Christine Lyons
Canadian Cancer Society

Ontario Division

Diane Manii
Ottawa Regional Cancer Centre

Meneses Maritess
Princess Margaret Hospital

Carol Matthews
Ontario Federation of Indian Friendship Centres

Katherine McAuliffe
Community Care Access Centre
Toronto

Jane McCartney
Woodstock General Hospital

Deb Mcguire
Woodstark General Hospital

Maurene McQuestion
Princess Margaret Hospital

Gaylene Medlam
Princess Margaret Hospital

Barbara (Bobbi) Moore
Burlington Breast Cancer Support Services Inc.

Judith Moore
Orangeville & Area Breast Cancer Support
Group

Zahra Moosa
Ismaili Cancer Support Network
Marg Muir
OBCIEP, Project Design & Dissemination
Group

Linda Muraca
Marvelle Koffler Breast Centre
Mount Sinai Hospital

Sharon Mytka
Middlesex-London Health Unit

Carolyn O'Connor
Northeastern Ontario Regional Cancer Centre

Patricia Ogborn
Burlington Breast Cancer Support Services Inc.

Patricia Onion
Mount Sinai Hospital

Liz Owen
Bruce-Grey Owen Sound Health Unit

Ruth Page
Dragons Abreast – Toronto

Rebekah Pinto
Women's Breast Health Centre
Ottawa Civic Hospital

Diane Pross
Ontario Breast Screening Program

Jay Quarrie
VON – Oxford

Sharon Reine
Princess Margaret Hospital

Maureen Reynolds
Cancer Care Ontario South Region

Marilyn Robinson
Princess Margaret Hospital

Wendy Rolfe
Canadian Auto Workers (CAW)
Women's Committee

Linda Ross
Ontario Breast Screening Program

Lorna Sandler
Sandler HR
Gretchen Sangster
Waterloo Region Breast Health Network

Sylvia Shedden
Ontario Breast Screening Program

Chris Sinding
Willow

Suzanne Smith
Mary Berglund Community Health Centre

Rochelle Stern
Rochelle Stern Enterprises

Mary Stewart
Breast Cancer Action Kingston

Glenys Stollstorff
CCS – Mississauga Unit

Maria Syme
Hastings-Prince Edward Counties
Breast Cancer Support Group

Carole Taylor
Community Care Access Centre for Huron

Cindy Terry
Eli Lilly Canada

Teresa Trainer
Thunder Bay & District
Breast Cancer and Support Group

Anne Trebilcock
Willow

Maureen Trudeau
Sunnybrook & Women's College Health
Sciences Centre, Women's College Campus

Joanne Tuck
Women's Health Care Centre
Angela Turner
Princess Margaret Hospital

Thelma Vaz Bozanic
Peel Health

Karima Velji
Aga Khan Health Board of Canada

Lynda Vera
Breast Cancer Prevention Coalition

Susan Walker
Wellspring

Beth Ward
Willow

Eleanor Wasserman
Mount Sinai Hospital

Marina Wegener
Niagara Breast Cancer Support Group

Joanne Western
Sarnia Living with Breast Cancer Support Group

Katherine Wicks
Alliance of Breast Cancer Survivors

Jennifer Wiernikawski
Canadian Association of Nurses in Oncology

David Williams
Thunder Bay District Health Unit

Lorna Wilson
Breast Cancer Prevention Coalition

Tsai-O Wong
Trillium Health Centre – Mississauga Site

Lynn Zalany
Toronto-Sunnybrook Regional Cancer Centre

Jeanie Zinkand
Toronto-Sunnybrook Regional Cancer Centre

APPENDIX C

List of Readings

Everyday Carcinogens: Stopping Cancer Before It Starts

Background Paper for the March 26-27, 1999 Workshop on Primary Cancer Prevention
McMaster University
Hamilton, ON

Exercise and the Risk of Breast Cancer

Julie A. Napieralski, PhD,
Carole Devine, PhD, R.D.
Cornell University Program on Breast Cancer and Environmental Risk Factors in New York State, Cornell University, 1998

New Method of Diagnosing Breast Cancer

Press Release, Biofield Corp.
Geoff Watts, Christine Suggars

Improving Imaging Methods for Breast Cancer Detection and Diagnosis

National Cancer Institute, Cancer Facts - Screening
NCI - Website 1999

Providing Accurate Information to Women

About Tamoxifen Therapy for Breast Cancer: Current Indications, Effects, and Controversies
Jeannie V. Pasacreta, Ruth McCorkle
Oncology Nursing Forum, Vol. 25, No. 9, 1998

Tamoxifen—the treatment of choice. Why look for alternatives?

M. Baum
British Journal of Cancer, (1998) 78,
(Supplement 4) 1-4, 1998 Cancer Research Campaign

Raloxifene, A “designer estrogen”

Health Oasis, Mayo Clinic Website
December, 1997

Quality of Life in Breast Cancer Survivors: Implications for Developing Support Services

B.R. Ferrell, M Grant, M. Funk, et al.
Oncology Nursing Forum, Vol. 25, No. 5, 1998

A narrative analysis: A black woman’s perceptions of breast cancer risks and early breast cancer detection

Erma Jean Lawson, RN, PhD
Cancer Nursing, 21(6), 1998

Quality of life in breast cancer

Part I: Physical and social well-being
B.R. Ferrell, M. Grant, B. Funk et al
Cancer Nursing, 29(6), 1997

Quality of life in breast cancer

Part II: Psychological and spiritual well-being
B.R. Ferrell, M. Grant, B. Funk et al
Cancer Nursing, 21(1), 1998

Information Needs of Husbands of Women with Breast Cancer

MG Kilpatrick, LJ Kristjanson, DJ Tataryn, et al
Oncology Nursing Forum, Vol. 25, No. 9, 1998

Partners in Patient Education: Creating an Impact

Educational Learning Principles for Cancer Patients
Beverley Page, Education Specialist
Toronto-Sunnybrook Regional Cancer Centre

Breast cancer: the real challenge

K. Pritchard
The Lancet, Vol. 349, March 1997

Cancer Care Ontario, Ontario’s Cancer Report Card

CancerCare Ontario
April 24, 1998

APPENDIX D

Breast Cancer Information & Support Think Tank

Sharing and Planning Together

Program*

***NOTE**

Program details and other Appendices to the Report Summary are available on request.

Please contact : admin.obciep@tsrcc.on.ca or call 416-351-3815.

