Workshop: Research Opportunities to Address Breast Cancer in Young Women

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Organized by:

Canadian Breast Cancer Foundation

Institute of Cancer Research of the Canadian Institutes of Health Research

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Canada

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Workshop: Research Opportunities to Address Breast Cancer in Young Women

Executive Summary

Background

Breast cancer incidence increases with age and is primarily a disease of post-menopausal women. However, about 1500 cases (7%) of breast cancer are diagnosed each year, in Canada, in young women aged 40 years or less. Breast cancer in this age group, tends to be more advanced at the time of diagnosis and also more aggressive and resistant to treatment. Prognosis is therefore generally worse for the under 40 group than for older women. Added to this are the many unique challenges associated with a diagnosis of breast cancer during the child-bearing years such as pregnancy associated breast cancer; loss of fertility; early career disruptions; care of young children amid the complex reactions of family, friends and partners; and the shock of facing an unexpected cancer diagnosis at such a young age.

Although breast cancer research, in general, is relatively well funded in Canada, only about 8% of the funding supports projects focused specifically on young women with breast cancer and this funding has mostly been focused on research on BRCA positive breast cancer with family history and little research has focused on sporadic forms of breast cancer in young women. Currently the biology of breast cancers in young women is poorly understood and it is unclear to what extent breast cancer in women under 40 represents a disease that is fundamentally different from breast cancer in older women.

The Canadian Breast Cancer Foundation (CBCF) and the Institute of Cancer Research (ICR) of the Canadian Institutes of Health Research (CIHR) have joined forces in the development of a strategic funding opportunity to support innovative and transformative research targeting breast cancer in young women 40 years of age or less. Both organizations are committed to encouraging Canadian researchers working in the field to combine their expertise in ways that will add value to the solid base of breast cancer research currently funded through open competitions, such as operating grants. It is anticipated that an improved understanding of both the biological and psychosocial parameters associated with breast cancer in young women will improve the clinical outcomes for this vulnerable population. CBCF and ICR have committed an initial $6 million over five years to support this initiative and additional funds may be sought through partnerships.

Consultation Workshop

On September 13th and 14th, 2012, CBCF and ICR co-hosted an invitational workshop, in Montreal, to seek input and advice from the research community and women previously diagnosed with breast cancer. The workshop was planned by CBCF and ICR staff in consultation with an expert organizing committee. Workshop pPaarticipants were selected from across Canada to represent multidisciplinary expertise in cancer research and cancer control. and included Participants also included women at high risk of, or previously diagnosed with, breast cancer at a young age. The workshop covered the following themes: risk prevention and screening; genomics; molecular oncology; therapeutic research; and psychosocial-survivorship research. The workshop was comprised of a blend of scientific presentations to set the scene and provide an overview of the current research landscape and small breakout sessions to solicit the input and ideas of the broader research community. The workshop steering group and participants are listed in Appendix 1.

Key Workshop Findings

Workshop participants were asked to consider innovative funding mechanisms and tools that would provide added value over research currently supported through investigator-initiated programs, such as operating grants. An essential consideration was the feasibility of a given approach within the anticipated time lines and the funding envelope of $6 million over five years. Ideas that emerged included:

- Increased support for breast cancer-focused operating grants;
- Support of pilot projects and seed grants to generate momentum or to implement knowledge translation strategies;
- Support of team grants to focus expertise on specific research questions related to the biology of - breast cancer in young women or the unique psychosocial issues experienced by these women; and
- Creation of a national network of collaborative research hubs focused specifically on young women with breast cancer across the spectrum, from prevention to palliation.

Although not unanimous, a large number of participants expressed enthusiasm for the idea of creating a national network/consortium that would capitalize on Canadian strengths and establish a critical mass of researchers in hubs of expertise supported by a central administrative structure. Such a network would harness existing core facilities, such as tissue/cell banks and standardized databases and registries linked to population based cohorts. It was felt that breast cancer in young women, with an incidence of about 1500 new cases a year, faces the same clinical research challenges as a rare disease but that targeted research could reveal new insights into breast cancer in all age groups. The Canadian health care system and the existence of well-established tumour banks and population-based cohorts, combined with the collaborative Canadian culture were felt to provide an ideal environment for this type of national approach. A consortium approach has proven to be highly successful in addressing pediatric rare diseases, including pediatric cancer,creating a precedent for a similar approach for breast cancer in young women.

Next steps...

In the coming weeks, CBCF and ICR will consider the insights from the workshop outcomes and formulate a joint funding opportunity and the launch of a Request for Applications.

Workshop Report

Background

In Canada, roughly 7% of breast cancers occur in women under the age of 40 and breast cancer is the leading cause of cancer deaths in this age group. If caught in the very early stages, the five year survival rate for women aged 20-39 is almost 90%. However, diagnosing breast cancer in women less than 40 years of age can be challenging. Due to the relatively low incidence of cancer in this age group and the fact that younger women generally have denser breast tissue resulting in lower mammography sensitivity, routine breast cancer screening is not performed in this age group in the absence of major risk factors.

Also, young women and their physicians do not expect to find a breast cancer at such a young age and so diagnosis may be delayed. In addition, breast cancers in young women tend to be more aggressive and less responsive to treatment. Although a breast cancer diagnosis is devastating at any age, in young women it is compounded by the fact that they must deal with an array of unique challenges, such as loss of fertility, diagnosis during pregnancy, childcare, early career disruptions and an increased risk of a second breast cancer.

There are also the complex reactions of family, friends, partners and a forced acknowledgement of their own mortality at a very young age. The biology of breast cancers in young women is poorly understood and it is not known whether the disease is part of the normal spectrum of breast cancer or whether, in young women, breast cancer is a distinct disease that may require alternative prevention and control strategies.

Canadian Breast Cancer Research Funding

Based on statistics provided by the Canadian Cancer Research Alliance, breast cancer research in Canada is relatively well funded with a total investment of $575 million from 2000 to 2009. However, of the 2033 projects funded during this period only 8% were focused specifically on young women, with most of those related to genetic/familial factors, such as BRCA1/2 expression. The major funders of Canadian breast cancer research are the Canadian Institutes of Health Research (CIHR) and the Canadian Breast Cancer Foundation (CBCF). CIHR funds breast cancer research through its suite of open competitions and also the CIHR Institute of Cancer Research (ICR) manages an additional $3 million a year designated specifically to breast cancer research. Currently these funds support excellent breast cancer operating grants in the CIHR open competitions, but ICR is also committed to investing in targeted initiatives that will build on existing funding to strengthen research outcomes and impact. CBCF and ICR have agreed to combine forces to address the unique challenges related to breast cancer in women diagnosed at or before 40 years of age through the launch of a strategic research initiative. Each organization has committed $3 million over five years to support this joint endeavour.

Consultation Workshop

The first step was to convene an expert multidisciplinary organizing committee to identify a wide range of participants, including women previously diagnosed with breast cancer, to take part in a consultation workshop. The organizing committee worked with CBCF and ICR staff to set the workshop goals and objectives and plan the workshop agenda. Organizing committee members also played an important leadership role in the organization and management of the workshop. The participant list and organizing committee members are listed in Appendix 1.

The workshop took place in Montreal on September 13th and 14th , beginning with a networking reception and dinner that included two keynote presentations, on the evening of September 14th followed by a full day of scientific presentations and small breakout group discussions on the second day (see Agenda, Appendix 2).

Workshop Objectives

The workshop objectives were to:

- Explore the unique profile and needs of young women, 40 years of age or younger, with breast cancer;
- Identify, within the context of the current Canadian research funding landscape, gaps and opportunities that could be addressed through strategic funding; and
- Provide advise to CBCF and ICR on the design of appropriate research programs that would provide added value to the research conducted through operating grant funding and support strategic research endeavours of high impact

Workshop Presentations Day 1

Dr. Malcolm Pike

Dr Malcolm Pike from the University of Southern California Cancer Centre and Memorial Sloane-Kettering Cancer Centre in the US gave an informative plenary presentation on the first evening entitled: "Hormonal Contraception: A neglected opportunity of potentially achieving a major reduction in breast cancer risk". The presentation focused on the epidemiology of breast cancer; known risk factors such as age at menopause and menarche; parity; and hormonal therapy. The success of oral contraceptive use in serendipitously reducing the incidence of endometrial and ovarian cancer was highlighted. With respect to prevention strategies for breast cancer, a case was presented for exploring alternative hormonal interventions to reduce breast density and cell proliferation.

Alicia Tait

Mrs. Tait spoke of her personal experiences as a young woman diagnosed with stage 3, grade 3 triple negative breast cancer that was not BCRA1 or BCRA2 positive, at the age of 23, shortly after giving birth to her first child. The presentation focused on how the diagnosis changed her life and introduced tremendous uncertainty in planning for the future. After six rounds of chemotherapy and 30 rounds of radiation, Alicia is now cancer free but questions remain as to the appropriate interventions to mitigate the risk of a second breast cancer. Alicia described some of the unique challenges experienced by young women with breast cancer and emphasized the importance of the support she received from her immediate family, especially her mother who is herself a breast cancer survivor.

Workshop Presentations & Discussions Day 2

Members of the workshop organizing committee gave short overview presentations in each of the following five theme areas:

- Risk prevention and Screening
- Genomics
- Molecular oncology
- Therapeutic Research
- Survivorship and Psychosocial Research

The presentations were followed by small breakout discussions, led by the organizing committee members, to expand on the information presented and identify opportunities to advance current research through additional strategic research investment. Groups were asked to identify topics, areas and approaches that would be transformative in nature and deliver outcomes of high impact. The genomics and molecular oncology themes were combined into one breakout group.

Risk Prevention & Screening – Norman Boyd

In order to prevent breast cancer, it is first necessary to understand the key risk factors. The presentation covered many of these risk factors (Table 1), focusing in on cumulative breast density as a potentially modifiable risk factor and predictor of breast cancer incidence.

Table 1. Early life and risk factors for breast cancer

Inherited genetic variants Placental weight Birth weight Growth in adolescence Height and weight – *both associated with breast density and age at menarche. Being overweight before menopause decreases risk; but increases risk post-menopause*	Age at menarche Radiation exposure – *higher risk the earlier in life you are exposed* Tobacco and alcohol use – *increase risk especially if exposed at a young age* Oral contraceptives – *may increase risk slightly depending on contraceptives and length of exposure*

Breast cancer incidence increases with age but breast density decreases with age. Magnetic resoance and mammography studies measuring percentage water content have shown 50% density in the 15-19 age range as compared to about 15% by age 80. By calculating cumulative breast density – the amount of time women are exposed to dense breasts over their lifetime, it is possible to predict breast cancer risk, suggesting that breast density might be a principle cause of age-specific incidence. However, there is limited information on whether changing breast density changes risk or whether there are any safe interventions for reducing breast density, especially in younger women. The genetic variants associated with cumulative density are also unknown, as are the potentially modifiable environmental factors associated with cumulative density. In the design of prevention strategies, the challenge is to identify young women with dense breasts and optimize the acquisition of risk information.

Breakout Group Discussion

Discussions during the breakout session highlighted the need for more studies on the influence of behavior, lifestyle, diet, and artificial pregnancy on breast cancer risk. Other topics introduced were the potential for breast cancer vaccines, and surveillance and screening in young women with an emphasis on increased breast awareness. The need for more research focused on pharmacological interventions, perhaps in partnership with Canadian generic drug companies, was also highlighted, as was the potential role for advanced imaging technologies in diagnosis and risk characterization. In terms of existing Canadian strengths for conducting prevention research, the group identified:

- Provincial cancer registries – except in Quebec
- Provincial cancer treatment services
- Provincial screening programs – some are underutilized
- Other administrative databases, such as perinatal databases linked to cancer registries
- Ongoing cohort studies – however most start recruiting at age 45 so they are not useful for studies on young women, unless you could enroll the children of the enrolled adults or begin a cohort of high school-age boys and girls.

Genomics – William Foulkes

Breast cancer in women under 40 is relatively rare with a 1:250 risk and therefore the population of young women with breast cancer in Canada is small with only about 1500 new cases diagnosed each year. Breast cancer risk rises exponentially with age until menopause, such that around the age of 40, the incidence of breast cancer increases dramatically. It is not clear what causes this change but for young women, at least, gene-environmental factors do not seem to play a significant role. Breast cancer risk increases 25 fold in a young woman who already has breast cancer making breast cancer itself the biggest risk factor in this population. Most genetic research has focused on BRCA1 and BRCA2, the two most important breast cancer susceptibility genes, even though mutations in these two genes account for less than 10% of breast cancers in most Canadian populations in women diagnosed under 40.

Canada has considerable strength in genomics research through its internationally competitive genome centres. The availability of next generation sequencing capabilities mean that it is now possible to look for both rare and common susceptibility genes through whole exome and whole genome sequencing. Although, there is little genomics research focusing specifically on the under-40 population or on genomic changes and mutations that might differentiate between younger and older women, there are many studies on the types of breast cancer that are more commonly seen in younger women, such as high grade, triple negative tumours. More research is needed on gene interactions as well as tumour-stromal interactions, to determine whether breast cancer in young women is distinct from that in older women, even when one takes into account the breast cancer phenotype itself.

It was suggested that, ideally, we need to coordinate genomics research across Canada to identify important mutations that could lead to the identification of those at increased risk as well as therapeutic targets. Significant progress in this area could be made if the right samples were collected at the time of diagnosis and made available to researchers through a national network. The Canadian health care system and the existence of well-established tumour banks and population-based cohorts, combined with the collaborative Canadian culture presents an ideal environment for national studies.

Molecular Oncology – Sandra Dunn

This presentation expanded on the genomics theme by focusing on the types of tumours most frequently found in young women. For example, 34% of breast cancers in young women are considered to be triple negative as compared to 17% in older women. Basal–like carcinomas in young women can be particularly aggressive and are associated with a poor prognosis. Recent research in the area of young women points to activation of the signaling pathways unique to this patient population thereby providing new opportunities for developing targeted therapies. The challenge is to develop targeted therapies and use molecular diagnostics to stratify patients according to their particular tumour subtype. Such studies will enable the identification of high risk groups and lead to the development of more effective "personalized" treatments. As it is metastatic disease that kills patients, it is important to identify the drivers of disease progression and cancer recurrence for all cancer patients, including young women. The more we understand the biology of breast cancer, through studies on tumour heterogeneity, the role of inflammation and gene expression profiles, the more all breast cancer patients will benefit, including young women.

Existing Canadian strengths identified for genomic and molecular oncology research included:

- Molecular diagnostics (nanoString, TMA, circulating tumour cells)
- Deep sequencing, genomics, bioinformatics, drug repositioning
- Molecular genetics
- Models of tumour progression
- Targeted therapies/ high content screening
- Normal and cancer stem cell biology
- Population-base cohorts (980 triple negative breast caner patients in BC)
- Personalized medicine approaches, including clinical trials
- Quality of life – web based support

Breakout Group Discussion for Genomics and Molecular Oncology

Discussions during the combined genomics and molecular oncology breakout session focused on a consortium approach that would bring together the necessary infrastructures such as tissue/cell banks and sequencing capabilities with patients and their families. Given that the number of young women with breast cancer is low, this kind of approach would create a critical mass for studies on genomics, epigenetics, therapeutics, the role of the tumour microenvironment and the immune system, and drivers of tumour progression.

The young women population represents a biological extreme in that the disease differs in many respects from breast cancer in older women, e.g. tumours tend to be less heterogeneous and develop at an accelerated rate. Therefore the study of this subpopulation might represent a unique opportunity for developing new insights into the biology of breast cancer. As there are only about 1500 cases of breast cancer in the under-40 group per year in Canada, it would be feasible to set a target of collecting at least 50% of all these cases into a common database.

This would enable the collection of tumour tissues, including fresh tissue, and provide an opportunity for xenograft transplantation studies. A control population could be derived from the relatives, especially the sisters, of young breast cancer patients. The Canadian health care system and the existence of well-established tumour banks and population-based cohorts, combined with the collaborative Canadian culture presents an ideal environment for these kinds of national studies.

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Breakout Group Discussion for Genomics and Molecular Oncology (continued)

A unifying theme in this breakout group was that people did not want a typical CIHR operating grant competition. This problem requires a unique approach and is an opportunity to draw Canadians together to tackle a rare problem. They suggested creating a Consortium (also termed Research Magnets, Centres for Excellence or Research Hubs). There was discussion around organizing Consortium members either regionally or by research objectives. It could be envisioned as a series of interconnected hubs across the country, perhaps organized around the five theme areas of the workshop or around specific research questions.

The group felt that the population of young women with breast cancer would be an ideal resource for increasing our understanding of breast cancer in more general terms and that a concerted, national effort would represent a truly unique and innovative approach. It was suggested that the feasibility of this model could be established by first supporting pilot/demonstration projects. A third model might be that the Consortium could be highly multidisciplinary and would engage pathologists and surgeons in addition to the research community (including trainees), and non-scientific community i.e patients and their families.

The downside of this model is that it has been tried before through CCSRI and was not particularly successful. The main reason was that it is very difficult for individuals with very different areas of expertise to communicate and that physical separation further dilutes the potential synergy. This is why it was felt that thematic spokes to the Consortium wheel might work better. The ultimate success of the consortium would depend on the identification of strong leaders willing and able to unite the community around a common cause.

Therapeutic Research – Karen Gelmon

Young women present with breast cancers of all sub-types but in different proportions compared to older women. They are also more likely to be diagnosed with late stage disease, often because their general practitioner doesn't take them seriously when they first present with a lump. Young women also have special issues such as pregnancy associated breast cancer, preservation of fertility, and an increased risk of local/distant relapse that create challenges when designing clinical trials. For example, although 45-50% of breast cancers in young women are endocrine positive it has proven difficult to develop an optimal endocrine therapy for this group that encourages compliance, preserves fertility and does not result in short-term and long-term adverse effects. It is also possible that young women may be more resistant to radiation therapy and many opt for bilateral mastectomy rather than radiation and regular mammograms. There are, however, many ongoing national and international clinical trials, studying topics such as tumour heterogeneity; tamoxifen with or without oopherectomy in pre-menopausal women; and neoadjuvant therapy for triple negative tumours. The way of the future, however, will be through adaptive clinical trials such as the US-based I SPY 2 trial, which applies a personalized medicine approach by evaluating which new drugs are most effective with which types of breast cancers and which early indicators of response (tumor analysis prior to surgery via magnetic resonance imaging (MRI) images along with tissue and blood samples) are predictors of treatment success.

In addition to the Canadian strengths mentioned earlier, Canada also has strong expertise in clinical and translational research and clinical trials organization, although better links are needed between the clinic, pathologists and patients. Increased funding for clinician scientists and a stronger focus on translational research is required. One way of achieving this could be through the creation of a national network for therapeutic research.

Breakout Group Discussion

Discussions during the breakout session reinforced the special issues facing young women and the influence this has on their recruitment into clinical trials. Endocrine trials are particularly complex in this group of patients and tolerance of hormones in young women tends to be poor. In addition, because they receive chemotherapy at a young age, they have many more years ahead of them to deal with the potential adverse long-term side effects and this is an aspect that requires more research. However, young women are generally motivated to participate in trials and it may be possible to align their special interests with other trials.

Again, the concept of a national network/consortium was raised as an approach suited to this particular demographic with their functionality in the modern electronic era. Such a network could function as a centre of excellence, serving as a conduit for standards of care and guideline development, with hubs of research and national and provincial coordinators to ensure patient accrual. The network would include central repositories and clinical trials capacity, potentially linked to international efforts.

Survivorship & Psychosocial Research – Karen Fergus

Young women diagnosed with breast cancer face many unique challenges, including:

- The shock of a cancer diagnosis at such a young age and a premature confrontation with mortality;
- The possibility of premature menopause with loss of fertility;
- Decreased or impaired sexual function accompanied by body image and dating concerns;
- Care of young children amid the complex reactions of family, friends and partners;
- Loss of age appropriate goals and expectations and early career disruptions; and
- A feeling of being sidelined and isolated which is accentuated by social comparisons.

Although support groups for people with cancer have existed for many years, until recently there were few, if any, groups specifically for young adults with cancer, including young women with breast cancer. Given their special needs, the emergence of support groups and organizations/programs such as Young Adult Cancer Canada and PYNK, a breast cancer program for young women run out of the Sunnybrook Odette Cancer Centre in Toronto, are an important resource for this group of cancer patients. Additional Canadian resources include national consultations such as that documented by the "Nothing Fit Me" report, and studies dealing with age and fear of recurrence ("Young and Worried"); the impact of breast cancer in young women on their relationships with their Mothers; issues related to self esteem, dating, and new relationships ("Wearing my heart on my chest"); and studies of pilot interventions such as an online skills and support program post-treatment ("Moving forward after breast cancer"). In addition, many support and information programs originally designed for older women can be adapted to fit the special needs of the younger population, especially with respect to diet, exercise, and fear of recurrence.

Despite the challenges young women face, they are generally resourceful, informed and support seeking. They are also comfortable with technology and open to a wide range of modalities in terms of education, intervention and outreach. However, more research is needed to address issues such as how best to provide support to family members; how to deal with psychosocial challenges associated with fertility issues; strategies to better manage early menopause; and providing support for young women and their families when dealing with metastatic disease.

Breakout Group Discussion

Discussion in the breakout session identified several additional challenges faced by young women with breast cancer, some of which would be equally relevant to an older population. The list included topics such as financial concerns; dealing with advanced disease and end-of-life care; managing the transition from patient to survivor along with moving from active follow-up to long term follow-up; and physical, spiritual and emotional well being, including long term overall health maintenance.

In terms of research opportunities, the group felt that unique funding models were required to support collaborative, multidisciplinary, multi-jurisdictional, translational and sustainable research designed to ensure the incorporation of research outcomes into current standards of care and programming. Other areas of opportunity included health economic studies focused on comparative effectiveness and an evaluation of the nurse navigator system as a valuable tool for this population. There is also an opportunity to take advantage of the fact that these young adults are extremely comfortable with new technologies, such as smart phones. As an example, there is an ongoing pilot project supported by Rogers and Samsung that enables post-surgical patient follow-up via smart phone. Patients enter all the data themselves, including photos of incision sites, and doctors use this information to monitor progress over long distance.

Breakout Session 2 – Strategic Research Funding Programs

For the second, afternoon breakout session, workshop participants were pre-assigned to one of three groups to ensure a broad mix of expertise and perspective in each group. The groups were asked to think about innovative funding tools and mechanisms that would provide added value over research programs currently supported through investigator-initiated programs, such as operating grants, and that would be feasible within the available budget of $6 million over five years. A wide range of ideas emerged from the three groups, including:

- Increased support for breast cancer focused operating grants
- Support of pilot projects and seed grants to generate momentum or to implement knowledge translation strategies
- Support of team grants to focus expertise on specific research questions related to the biology of breast cancer in young women or the unique psychosocial issues experienced by these women
- Creation of a national network of collaborative research hubs focused specifically on young women with breast cancer across the spectrum, from prevention to palliation

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Breakout Session 2 – Strategic Research Funding Programs (continued)

Although there was not unanimous agreement, the greatest enthusiasm was generated around the idea of a transformative collaborative national network that could address research questions related to tumour biology, response to treatment, and also the psychosocial aspects of the disease. With only about 1500 new cases a year in Canada, breast cancer in the under-40 population can be considered a rare disease. There are already precedents for national consortia in Canada focused on pediatric rare diseases, including cancer. In addition, there are other large program grants in existence that bring together several hubs of research excellence, including the recently launched CIHR Transplantation Research Program. If successful, this Program will bring together several independent sub-projects and core infrastructures under one national program studying the full spectrum solid organ and bone marrow transplantation from donor issues to improved clinical outcomes for transplant patients. Workshop participants in support of this concept envisioned the creation of a national network/consortium that could:

- Create a provincially coordinated national network of hubs of expertise with a national steering committee, standards and operating procedures that would serve as a research magnet capturing all the young women across Canada that have breast cancer
- Support a nationally standardized database linked to existing cohorts and registries - with clinical data; patient history e.g. treatment protocols; pathology; imaging; out comes; and tissue and live cell banks, etc.
- Recruit provincial/ local coordinators linked to the registry
- Pilot studies at major centres, including breast diagnostic/screening centres
- Support companion studies focused on gaps in care
- Support prospective longitudinal studies that could capture information from future generations, e.g. children and grandchildren
- Create a critical mass of expertise that would attract additional partners and potentially increase the level of funding and ensure sustainability of the program

Such a visionary program would bring together enthusiastic and motivated researchers from across the country to explore the biological similarities and differences between breast cancer in younger versus older women and determine whether breast cancer in young women is a distinct disease or part of the spectrum of the same common disease. It would also serve as a centre for addressing the unique psychosocial/survivorship issues experience by this population.

It was acknowledged that to create and sustain a national infrastructure such as this would require a clear vision, strong and effective leadership and a sound administrative structure, but that given the collaborative culture in Canada, such a vision could be feasible.

Conclusions and Next Steps

The discussions at the workshop highlighted the need and enthusiasm for strategic research funding in the area of breast cancer in young women. The participants articulated a number of areas of strength within Canada and areas of need and opportunity upon which a strategic initiative might be predicated. The next steps are for CBCF and ICR to incorporate the insights from the workshop into the creation of a joint strategic funding opportunity that can build upon the existing research strengths in the country to advance research in this area and improve the clinical outcomes for young women with breast cancer. CBCF and ICR thank all the participants for donating their time and expertise, and particularly the organizing committee and those who shared their personal experiences with the disease. We look forward to announcing a new funding opportunity in the near future.

About the Canadian Breast Cancer Foundation

The Canadian Breast Cancer Foundation is the leading community –driven organization in Canada dedicated to creating a future without breast cancer. Our investments in innovative and relevant research and education have led to progress in breast cancer prevention, diagnosis, treatment and care. Since 1986, we have been at the forefront of a nationwide movement supporting and advocating for the breast cancer community. Join us at www.cbcf.org.

About the Canadian Institutes of Health Research

The Canadian Institutes of Health Research (CIHR) is the Government of Canada's health research investment agency. CIHR's mission is to create new scientific knowledge and to enable its translation into improved health, more effective health services and products, and a strengthened Canadian health care system. Composed of 13 Institutes, CIHR provides leadership and support to more than 14,100 health researchers and trainees across Canada.

Research Opportunities to Address Breast Cancer in Young Women: Participant List

September 13th – 14th, 2012
Le Westin Montréal

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Research Opportunities to Address Breast Cancer in Young Women: Participant List (continued)

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Workshop Organizing Committee

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Agenda

Meeting: Research Opportunities to Address Breast Cancer in Young Women
Date: Thursday, September 13th and Friday September 14th, 2012
Location: Le Westin Montréal

Workshop Objectives:

To explore the unique profile and needs of young women (40 years of age or younger) with breast cancer
To assess Canadian research funding specifically related to this demographic
To identify research areas that would benefit from strategic research programming and investment providing added value to regular operating grant programs
To identify options for research programming and investment that would promote strategic research endeavours of high impact.

Workshop Outcome:

Research programming options for a joint CBCF/CIHR strategic research initiative that will lead to improved clinical outcomes for young women with breast cancer.

Day 1 – Thursday, September 13th, 2012

St-Antoine Room, 9th Floor, Le Westin Montréal

Time	Description	Lead
16:30	Registration	
18:00	Networking Reception	
18:30	Welcome	Morag Park/ Sandra Palmaro
	Introduction to Organizing Committee	Karen Fergus
18:45	Keynote Scientific Presentation	Malcolm Pike
19:30	Dinner	
20:30	Keynote Survivor Presentation	Alicia Tait
21:15	Adjourn	
21:15 – 21:45	Organizing Committee meeting – Palais Room – 8th Floor	Organizing Committee

Day 2 – Friday September 14th, 2012

Palais Room – 8th Floor – Le Westin Montréal

Time	Description	Lead
8:00- 9:00	Breakfast - *Grand Place*	All
9:00 9:30	**Introduction** - workshop logistics, workshop objectives **Current Canadian research funding landscape** **Overview presentations:** Each presentation will be for 10 minutes plus 5 minutes for questions and will address four slides covering: the unique challenges experienced by young women with breast cancer; highlights of Canadian and international research in this area; and Canadian strengths, gaps and opportunities. - Risk Prevention and Screening - Genomics - Molecular Oncology - Therapeutic Research - Survivorship	Brian Bobechko Judith Bray Ellen Warner (moderator) Norman Boyd William Foulkes Sandra Dunn Karen Gelmon Karen Fergus
10:45	Health break	
11:15	**Breakout session 1** Participants will select (based on interest and area of expertise) one of five breakout groups based on the topics of the preceding presentations by members of the steering committee, each of whom will chair/facilitate their own breakout session. Using the slides of the presentation as a guide, participants will address the following potential questions: - What, if anything, was missing from the overview presentation? - What are we doing well and what not so well? - How can we improve – in which specific areas do we need more targeted research? - What is feasible in the Canadian context?	All

Day 2 – Friday September 14th, 2012 (continued)

Palais Room – 8th Floor – Le Westin Montréal

Time	Description	Lead
12:15	Lunch break	All
11:30	**Report Back** Each of the five groups will summarize their discussions and additions using the template provided. Presentations will be followed by question and answer session	Breakout Group Facilitators
13:45	**Breakout session 2** Participants will break into one of three predetermined groups, mixed expertise and geography, to discuss the following questions: - What are the strategic research opportunities that are unlikely to occur spontaneously through existing funding mechanisms (i.e. operating grants)? - What strategic research programs would address the identified challenges in this area and are feasible with the anticipated financial resources?	All
14:45	**Report Back** **Closing Comments**	Breakout Group Facilitators Brian Bobechko Judith Bray
15:15	Meeting Adjourned	All
15:30	CBCF & CIHR Follow-up Meeting	Organizing Committee CBCF / CIHR