



# The Development of a Research Agenda Focused on Breast Cancer in Women 40 Years of Age and Under.

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 Young Survival Coalition (www.youngsurvival.org)



## Introduction

The Young Survival Coalition (YSC) is the only international, nonprofit network of breast cancer survivors and supporters solely dedicated to the critical concerns and issues unique to young women (YW) affected by breast cancer. It is a strategic goal of YSC to increase the amount of quality research on young women, to define the greatest research needs for young women with breast cancer and to advocate these needs to doctors and researchers.

## Background

There are nearly 250,000 women in the United States under the age of 40 currently living with breast cancer (BC). [1] Among women aged 15-34 years, breast cancer is the number one cause of cancer death. [2] Breast Cancers that are diagnosed in younger women are generally more aggressive and result in lower survival rates. [3,4] Although there is cause for optimism regarding advances in the prevention, diagnosis and treatment of breast cancer among the general population, the situation for young women remains less certain and is complicated by a series of special concerns and questions, coupled with a lack of population specific research data.

## Methods

The YSC organized a Medical Research Symposium on Young Women and Breast Cancer. Leading researchers, scientists and practitioners representing a variety of specialties assembled together with YSC

leadership to discuss what we know and what we need to know about YW who are at risk or who have been diagnosed with Breast CA. Each speaker surveyed current research on YW in his/her field including existing studies, unanswered research questions and further research needed.

### Participants Included/Topics Discussed:

Ira Bleiweiss, MD, (Pathology), Miriam Levy, MD, (Diagnostics and Screening), Anne Moore, MD, (Medical Treatment), Jeanne Petrek, MD, (Ovarian Function), George Raptis, MD, (Risk Assessment and Recurrence), Ruby Senie, PhD, (Epidemiology), Ulana Suprun, MD, (Diagnostics and Screening)

## Results

A white paper was compiled that summarized the results of the meeting. From this paper a list of issues that needed to be researched was extracted. The list was presented to the YSC Medical Advisory Board (MAB). With help from the MAB a research agenda was created with both short and long term goals.

### YSC Medical Advisory Board

Deborah Axelrod, MD, Leslie Bernstein, PhD, Ira Bleiweiss, MD, W. Archie Blyer, MD, Ernie Bodai, MD, Judy Garber, MD, MPH, Aron Goldhirsh, MD, Laurie Goldstein, MD, Clifford Hudis, MD, Kathryn Kash, PhD, Roz Kleban, MSW, Thomas Kolb, MD, Minetta Liu, MD, Susan Love, MD, Edward Luce, MD, Kathy Miller, MD, Anne Moore, MD, Larry Norton, MD, Kutluk Oktay, MD, FACOG, Olufunmilayo Olopade, MD, Ann Partridge, MD, MPH, Edith Perez, MD, Bert Petersen, MD, Irma Russo, MD, Jose Russo, MD, Lillie Shockney, RN, George Sledge, MD, Richard Stevens, PhD, Eric Winer, MD, Karrie Zampini, CSW, Randi Zinberg, MS, CGC

## Ranked Research Agenda (3-5 years)

Categories	Priority Research Area
<b>Identification of Factors that Increase Risk of Breast Cancer in Young Women (YW)</b>	<ul style="list-style-type: none"> <li>Genetic Factors (gene mutations and family history)</li> <li>Prospective epidemiological studies</li> <li>Environmental, physical, &amp; lifestyle factors</li> <li>Pre-natal and In-utero exposures</li> <li>Role of disease (chronic and infectious), as well as auto immune deficiencies</li> </ul>
<b>Fertility and Pregnancy</b>	<ul style="list-style-type: none"> <li>Prevention of damage to and preservation of ovarian Function</li> <li>Risk of pregnancy subsequent to a breast cancer dx on recurrence/development of new primary</li> <li>Understanding the mechanism of CT on the ovaries</li> <li>Effect of fertility preservation procedures on breast CA risk</li> <li>Breast cancer during pregnancy</li> <li>Long-term/late effects of CT exposure in utero on health of child</li> </ul>
<b>Screening and Diagnosis</b>	<ul style="list-style-type: none"> <li>New screening modalities, both radiological and other Methods</li> <li>Improving current diagnostic modalities e.g. mammography, ultrasound and MRI</li> <li>Identification of other cancers and diseases that correlate with early-onset breast cancer</li> <li>Access to care and other socio-economic factors that affect screening and timely diagnosis</li> <li>New diagnostic modalities for occult metastases</li> </ul>
<b>Quality of Life and Survivorship</b>	<ul style="list-style-type: none"> <li>Sexuality issues, include loss of libido &amp; safety of estrogen supplements</li> <li>Long-term prospective studies on both recurrence and psychosocial issues e.g. depression/anxiety, childbearing, marriage</li> <li>Effect of treatment on cardiac health, bone-density and other chronic conditions</li> <li>OB/GYN follow-up post treatment</li> </ul>

## Ranked Research Agenda (8-12 years)

Categories	Priority Research Area
<b>Pathology</b>	<ul style="list-style-type: none"> <li>Genomic &amp; proteomic makeup of tumors</li> <li>Tumor registries for YW</li> <li>Heterogeneity of breast cancer</li> <li>Prognostic differences between genetically predisposed and sporadic Breast Cancers.</li> </ul>

## Ranked Research Agenda (8-12 years) - Cont'd

Categories	Priority Research Area
<b>Adjuvant and Metastatic Treatment (systemic and surgical)</b>	<ul style="list-style-type: none"> <li>Tailored treatment strategies for tumor and patient characteristics, both CT and hormonal</li> <li>Development of more effective and less toxic treatments</li> <li>Development of local interventions to treat early stage breast cancer and prevent recurrence</li> <li>Patient decision-making process: lumpectomy vs. mastectomy</li> </ul>
<b>Advocacy and Awareness</b>	<ul style="list-style-type: none"> <li>Physician attitudes and actions toward YW presenting with symptoms of breast cancer</li> <li>Barriers to participation in clinical trial by YW at risk for or diagnosed with breast cancer</li> <li>Role of medical school education for primary care physicians and ob/gyns in educating about breast cancer in YW.</li> <li>Level of information shared by physicians with patients on all aspects of treatment and side-effects e.g., fertility, pregnancy, fatigue</li> </ul>
<b>Reconstruction</b>	<ul style="list-style-type: none"> <li>Safety of pregnancy after reconstructive procedures, e.g. TRAM and DIEP</li> <li>New methods of reconstruction</li> <li>Role of society's expectation of video on YW's decision-making</li> </ul>

### Current YSC Research Collaborations:

SOFT/TEXT/PERCHE trials, Screening breast ultrasound in high risk women (ACRIN 6666) tomosynthesis and BC, Baylor study of chemotherapy induced amenorrhea and secondary health effects, University of Connecticut study of breast cancer risk in women 40 and under. In 2003 the results of the Dana Farber web based fertility study done in collaboration with YSC was presented at a session of the SABCS.



Diagnosed at Age 32



Diagnosed at Age 28



Diagnosed at Age 22