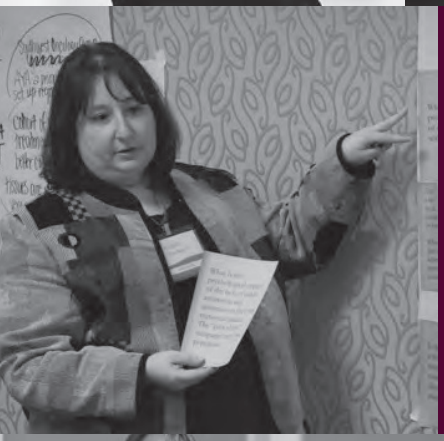

YOUNG SURVIVAL COALITION

RESEARCH AGENDA

EXECUTIVE SUMMARY & RECOMMENDED PRIORITIES

YSC Mission

Young Survival Coalition (YSC) is the premier organization dedicated to the critical issues unique to young women and breast cancer. YSC works with survivors, caregivers and the medical, research, advocacy and legislative communities to increase the quality and quantity of life for women diagnosed with breast cancer ages 40 and younger.

YSC Vision Statement

To set the standard and be the foremost influencer of issues and resources focused on young women affected by breast cancer, and to ensure that the needs of this population are met.

YSC YOUNG SURVIVAL COALITION®
Young women facing breast cancer together.

YSC RESEARCH PRIORITIES

Each year, approximately 13,000 women under the age of 40 are diagnosed with breast cancer, and more than 1,000 will die of the disease.[1] There are currently 250,000 women living in the United States today who were diagnosed with breast cancer under age 40.[2] A recent paper suggested that the incidence of metastatic breast cancer at the time of initial diagnosis is rising in women under the age of 40.[3]

Young women face greater mortality rates and an increased risk of metastatic recurrence.[4,5,6] Breast cancer in young women tends to be more aggressive with more lymph node involvement, as well as larger and higher grade tumors.[4,5,6,7] Triple negative breast cancer, a particularly aggressive form, is more common in young women and especially prominent in young African-American women.[8] In addition to these secondary characteristics, studies indicate that young age in and of itself is predictive of aggressive disease. [7,9,10]

Young women face unique issues as a result of their diagnosis. They are more likely to be single and dating, starting a career, raising young children, or possibly starting a family.[11,12] Cancer treatments might cause infertility issues, premature menopause, and sexual dysfunction.[13,14,15,16] Young breast cancer survivors have a higher prevalence of unique psychosocial issues, including anxiety and depression.[16]

Yet breast cancer in young women is rarely studied. Many studies, especially in the metastatic setting, set criteria that exclude younger women. It is not understood why young women are more likely to be diagnosed with more aggressive forms of breast cancer. Other than in the use of differing hormonal therapies based on menopausal status, we do not know whether young women need to be treated more aggressively or differently than women over 40. There is much work to be done. However, before questions can be answered, we must determine which questions are the best ones to ask.

YSC led the effort to identify and prioritize these research questions in order to improve the lives of young women diagnosed with this disease, and with hopes of preventing the future diagnosis of our sisters, nieces, daughters and granddaughters. The YSC research priorities discussed in this paper evolved out of an intense collaboration of scientists and advocates called The Research Think Tank (RTT). The RTT was attended by more than 50 advocates and scientists who have been focused on investigating breast cancer in young women. The goal of the RTT was to identify the most pressing research priorities that would improve and extend life for young women affected by breast cancer. To read more about the RTT, please visit youngsurvival.org/research-agenda.

The YSC research priorities start with metastasis and treatment, the two areas most in need of answers and progress. YSC hopes that researchers will use this list as a guide in formulating their future research projects, and that funders will use it to guide their funding decisions. YSC recognizes the value of breast cancer research and the impact of dedicated scientists, researchers and practicing physicians who strive to end this disease. They are our partners in this fight, and progress depends on their guidance and assistance.

YSC is willing to work with researchers who conduct studies on the issues identified below. The YSC process for reviewing and vetting such studies, as well as YSC's anticipated levels of assistance, can be found on page 14. This assistance may include YSC reaching out to our constituents to educate them about research trials in general, the importance of trial participation, and information about specific research projects actively enrolling. YSC currently has a database of more than 100,000 constituent contacts; website engagement of more than 168,000 visits in 2013; 18,000 registered users on our community boards; 31,000 followers on Facebook and more than 5,500 followers on Twitter. YSC is also exploring creative and innovative ways to work with the research and research funding communities to advance the research priorities identified on the following pages.

RECOMMENDED RESEARCH PRIORITIES

Research priorities are grouped by topic area, with the pregnancy and fertility group priorities combined. The research priority is listed in bold, colored text, followed by a short paragraph that provides context.

You will also find a list of the scientists and advocates (A) who participated in each work group.

METASTASIS

Do young women have different risk factors to develop metastatic breast cancer than older women, and how can those at greatest risk be identified?

Identifying which young women are at highest risk for metastatic disease will allow physicians to personalize their care, sparing those who will not develop metastasis from harsh or unnecessary treatments.

What causes metastasis in younger women (post-adjuvantly, at presentation, dormancy) and how can it be prevented? Is there a difference between younger and older women?

Young women face greater mortality rates and an increased rate of metastatic recurrence.[4,5,6] But very little definitive and substantive research exists with regard to breast cancer metastasis in young women. In particular, we do not know why some breast cancers can remain hidden or inactive and then re-emerge years or decades later. It is also not known if factors in the metastatic microenvironments of young women may be unique and contribute to the increased rate of metastatic recurrence. Generally, young women and older women with metastatic breast cancer are treated similarly, but it is not clear whether they should be.[18]

How can the psychosocial needs of young women with metastatic breast cancer and their families be better met?

Young women living with metastatic breast cancer have unique psychosocial needs and concerns. In the early fall of 2013, based on a priority recommended by the RTT metastasis work group, YSC launched a comprehensive survey of young women diagnosed with metastatic breast cancer to identify the source of their psychosocial stressors and strategies that could be used to assist them. Preliminary results were presented in poster format at the Advanced Breast Cancer (ABC2) conference in Lisbon. Final results and manuscript are being prepared.

METASTASIS

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Ms. Roz Kleban
Dr. Larry Norton
Ms. Joy Simha (A)
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Dr. Linda Vahdat

TREATMENT

Are there specific factors in the tumor microenvironment of young women with breast cancer that contribute to worse prognosis, alter treatment response and increase risk for local recurrence, distant relapse, and decreased overall survival?

Young women generally have denser breasts[19] (a higher ratio of breast/connective tissue to fat tissue) and a different tumor microenvironment[20] than older women. Although we know that high mammographic breast density is a marker for increased risk of developing breast cancer,[21,22,23] it is not clear how higher breast density and/or specific factors in the tumor microenvironment of young women may impact systemic treatment response. It is not known whether breasts with a higher or lower percentage of breast/connective tissue provide a tumor microenvironment that facilitates breast cancer growth and progression.

In what contexts should younger women with breast cancer receive more aggressive treatments?

The mindset of many oncologists is to treat young women diagnosed with breast cancer more aggressively than older patients. It is not clear whether this strategy is justified and, if so, in what circumstances.

What are the optimal chemotherapy and targeted therapy regimens for each tumor type in young women? In what contexts should neoadjuvant chemotherapy be considered in young women?

Optimal chemotherapy and targeted therapy regimens for young women are not known. Most trials performed to-date do not break down results by age. At best, they distinguish between pre and post-menopausal patients, but not age. A need exists to evaluate young age onset breast cancer separately or as a predetermined subset of major treatment trials, to avoid the greater than/less than 50 division from historical studies. In addition, at the 2012 San Antonio Breast Cancer Symposium, a meta-analysis found that young breast cancer patients tend to benefit more from neoadjuvant chemotherapy than older women.[24] More research is needed to confirm this finding and to determine whether this applies to all young women or only those with certain subtypes of breast cancer.

When is ovarian suppression (GnRH agonist or oophorectomy) appropriate in the treatment of young women with ER+ disease? Is inducing menopause in young women a valid treatment approach?

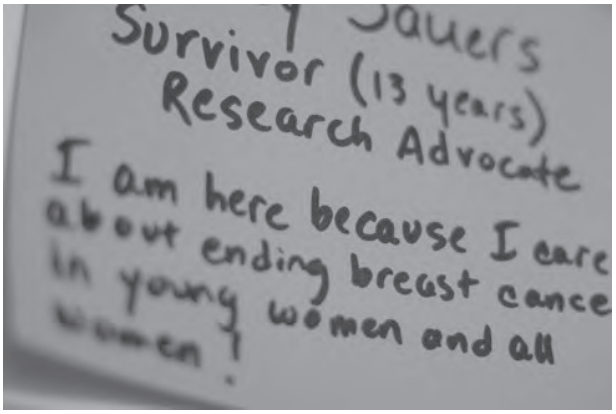
We know that chemotherapy suppresses estrogen biosynthesis and may cause chemotherapy-induced amenorrhea. Research has shown that this chemotherapy-induced amenorrhea correlates with improved survival outcomes in young ER+ patients.[25] Separate from chemotherapy, it is not clear if young women should undergo ovarian suppression, i.e., induced menopause, either during or after treatment as a way of preventing cancer recurrence.[26,27,28] There are currently two trials (SOFT and TEXT) with pending results that should provide guidance to help determine if ovarian suppression as adjuvant therapy in young women is beneficial.

In the long-term, which surgical option (mastectomy or lumpectomy with radiation) provides the best overall survival for young women? Does local recurrence impact survival in young women?

Although the proportion of local relapses in young women with breast cancer is higher for those who undergo lumpectomy versus mastectomy,[29,30,31] studies to date have found no difference in distant recurrence-free survival.[30,32] Further research is needed to determine whether local relapses in young women negatively impact long-term and overall survival. Long-term consequences of radiation performed in conjunction with lumpectomy also need to be evaluated,[10,33,34,35] particularly for young women with a family history of breast cancer.[36]

How can we identify young women who may be candidates for endocrine therapy alone, versus combined adjuvant or neoadjuvant chemotherapy with endocrine therapy? What is the optimal type/duration of endocrine therapy in young women?

Chemotherapy in young women may cause long-term and/or late-appearing side effects, including secondary malignancies such as leukemia.[10,37] Young women suffer greater chemotherapy toxicity and have higher rates of secondary malignancies, compared to their older counterparts.[10,16,37] Sparing young women with ER+



disease from chemotherapy, in appropriate circumstances, could minimize or alleviate these issues. We need to define and determine those circumstances.[38] While recent research has shown the benefit of extending tamoxifen usage to 10 years, optimal use of this or other endocrine therapy in young women has yet to be determined.[44]

TREATMENT OF BREAST CANCER IN YOUNG WOMEN

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Ms. Tracy Leduc (A)
Ms. Debra Madden (A)
Dr. Ann Partridge
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Ms. Elizabeth Wohl (A)

PREGNANCY & FERTILITY

Why does the risk of breast cancer increase during the postpartum period (up to a minimum of five years after giving birth)? Why are women with breast cancer diagnosed during this time period at higher risk of metastasis and death?

Approximately 30% of breast cancer patients are diagnosed during the postpartum period (up to five years after giving birth), and these diagnoses carry a greater risk of metastasis and death.[39,40,41] Recent research shows that this period of higher risk definitely extends to five years post-birth, and the risk appears to remain elevated up to 10 years post-birth.[39] Understanding why there is a greater risk of breast cancer during that time period, and why it is more deadly, could lead to different treatments and possible prevention of postpartum diagnoses.

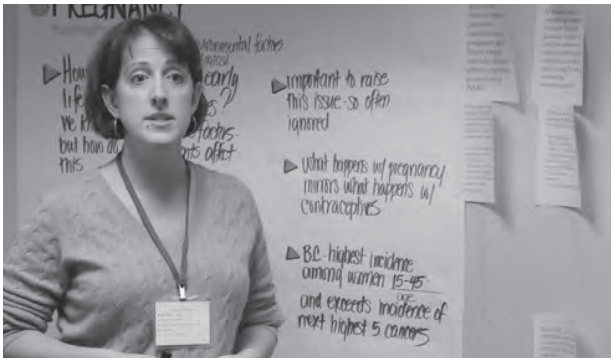
Is pregnancy after breast cancer safe to the mother and child and does safety differ by tumor subtype? What is the optimal timing, particularly for women with ER+ disease who would otherwise undergo extended endocrine therapy?

The safety of pregnancy after breast cancer is a controversial issue that needs a resolution. While some recent research suggests that pregnancy is safe and may even confer a slight protective effect from subsequent breast cancer, this needs to be confirmed.[42,43] And if confirmed, guidance is needed on how long after a breast cancer diagnosis a young woman should wait before becoming pregnant—and whether pregnancy recommendations differ by tumor subtype. This is particularly important to young women with ER+ disease who may be placed on endocrine therapy for five to 10 years, during which the risks of infertility increase.[13,44]

What are fertility options for young women diagnosed with breast cancer? How likely are they to result in healthy children? What is their impact on long-term outcomes in younger breast cancer patients?

There has long been a concern about an increased exposure to estrogens during fertility preservation treatments[45,46] with limited current research suggesting that fertility preservation is safe.[47,48] Larger and long-term studies to confirm these findings are needed.[47,49] Work is also needed in the development of non-hormonal fertility options, which are currently labeled "experimental."[50] In addition, the efficacy of various fertility preservation methods in achieving live births and healthy children after breast cancer is not known.

Which breast cancer treatments cause infertility? How do additional risk factors such as age and ovarian reserve modify risks of infertility from cancer treatment? Can drugs be developed that lessen the impact on fertility? Chemotherapy can damage the finite ovarian reserve, resulting in higher risk of infertility.[15] The Fertile Hope website provides a risk calculator that uses a patient's cancer type to create a chart showing the risk of amenorrhea at various ages with different chemotherapies.[51] High, intermediate, and low risk of infertility are listed. Several common breast cancer drugs including Herceptin, paclitaxel, and docetaxel are listed as having unknown impact, and data on even newer drugs are not available. In addition, it has been suggested that BRCA mutations may impact fertility in general, as well as post-chemotherapy fertility.[52,53,54] Is it possible for clinical trials of new breast cancer treatments to measure impact on fertility? There is a need for further work and clarity in this area.



FERTILITY

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PREGNANCY

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Dr. Susan Love
Dr. Jose Russo
Dr. Irma Russo
Dr. Julia Tiernan (A)
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QUALITY OF LIFE & SURVIVORSHIP

How can long-term or late-appearing physical side effects from breast cancer treatment be reduced or prevented in young women?

Because younger women have a longer life span, there is more time and opportunity for long-term and late-appearing side effects to occur, including cardiotoxicity, premature bone loss, neurocognitive disorders, secondary malignancies, etc. YSC is a partner in the Dr. Susan Love Research Foundation's HOW (Health of Women) study, which seeks to catalog and understand the harms of breast cancer treatment. However, it is also necessary to know how to reduce or prevent the occurrence of these side effects.

What evidence-based interventions could be used to decrease the risks of depression, anxiety and other psychosocial and emotional issues in young breast cancer survivors?

Studies have shown that young women diagnosed with breast cancer have higher rates of depression, anxiety and other psychosocial issues than older women.[16,17] These problems persist long after treatment ends.[17] Awareness of this phenomenon is needed, as well as the development, dissemination and implementation of effective interventions.

How can we increase awareness, screening and interventions on improving the sexual health of young women diagnosed with breast cancer, including issues relating to early menopause and the safety of potential hormonal interventions?

Studies have shown higher rates of sexual dysfunction in young breast cancer survivors.[13,16] For treatment of symptoms related to estrogen deprivation, e.g. vaginal dryness, hormone therapy with estrogen may be prescribed. However, estrogen use may be inappropriate for certain breast cancer survivors.[55] More studies are needed to assess safety.

QUALITY OF LIFE

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Ms. Nikki Oliver (A)
Ms. Jean Rowe (A)
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RISK FACTORS

Are there modifiable risk factors that can prevent early onset breast cancer?

The causes or risk factors of breast cancer in young women versus older women may not be the same.[56] A family history of breast or other cancer[57] and exposure to chest radiation[58] are known to be risk factors for early onset breast cancer. Research on other potential causes such as alcohol, obesity[59,60] and parity are not clear and have yielded conflicting results.[60,61] Much work remains in this area so that we can learn how to prevent breast cancer in young women.

Are there specific environmental exposures (in utero, childhood, adolescence and beyond) that increase the risk of early onset breast cancer?

Environmental factors such as chemical carcinogens, plastic and growth hormones (used to boost production of meat and dairy products, among others) are frequently cited as potential causes of cancer. There may be "windows of susceptibility" such as puberty, during which women's breasts are particularly sensitive to certain environmental exposures.[62,63,64,65] But which, if any, of these environmental exposures increase the risk of breast cancer in young women?

What are the unidentified genetic risk factors that contribute to the risk of early onset breast cancer?

We know that BRCA1 and BRCA2 mutations significantly increase the risk of a woman developing breast and other cancers at a young age, and that younger women diagnosed with breast cancer are more likely to harbor these mutations.[66,67] However, we also know that BRCA is not the only genetic link.[68] More work is needed.

IDENTIFICATION OF RISK FACTORS

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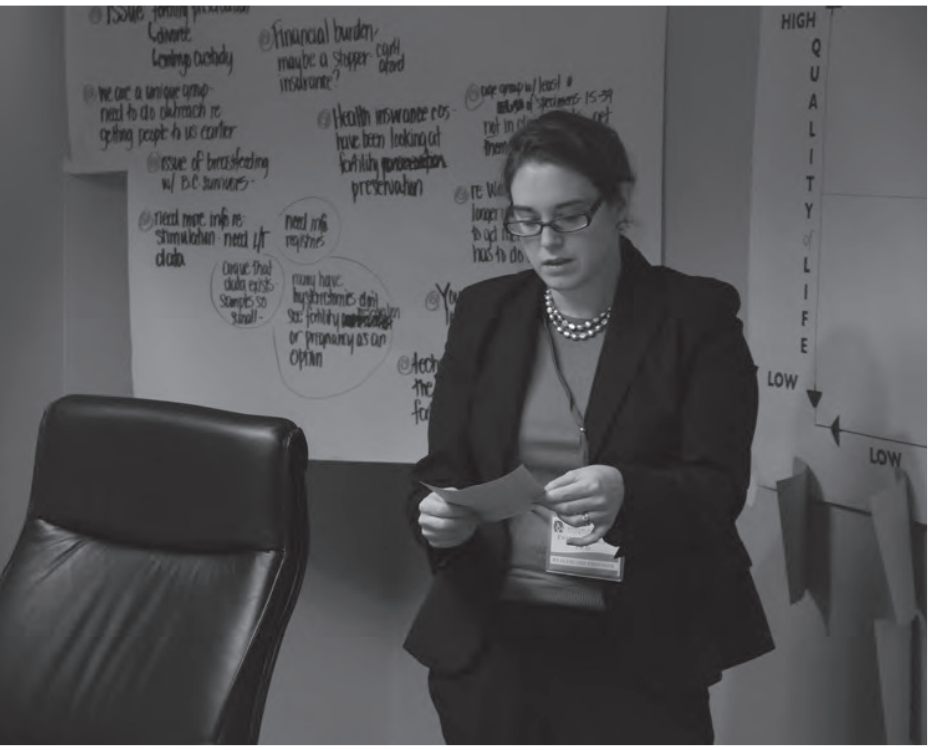
RESEARCH
THINK TANK


Financial burden
HIGH
QUALITY of LIFE
LOW
LOW


TREATMENT
METASTASES
FERTILITY
Top Research Priorities:


YOUNG SURVIVAL COALITION
RESEARCH
THINK TANK
Driving the Agenda on Breast Cancer in Young Women


Current State of the Research
What we know and need to know
PREGNANCY

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COLLABORATION WITH THE RESEARCH COMMUNITY

YSC does not perform or fund clinical research. We recognize that progress on our Research Agenda can only be made through the efforts of the cancer research community, specifically scientists, researchers, practicing physicians and other nonprofits. YSC is willing to work with and assist researchers who conduct studies that fall within our research priorities.

OUR REVIEW PROCESS AND STANDARDS

Because YSC is a nonprofit with finite resources, we cannot assist on every study or grant opportunity presented to us—as much as we would like to!
To submit your request, complete the form at youngsurvival.org/research-agenda. Provide details about your study, how it fits within the YSC research priorities, and a description of the assistance you are seeking.

A YSC staff person will respond to your request within three weeks, describing our decision and availability to assist. Our decision will be based on the following considerations:

- Does the proposed research clearly fall within the YSC research priorities and focus on young women?
- Are the study/research design and concepts sound and based on existing theory or evidence?
- Will results of research be shared with YSC?
- Timing of request – how quickly are YSC actions required and can we assist in the time needed?
- Effort level – what is being requested and does YSC have the bandwidth to assist?

LEVELS OF ASSISTANCE AVAILABLE

If your request is granted, YSC may be able to assist in the following ways:

- Signing on as collaborator of research submitted to granting/funding agencies, with the precise nature of YSC efforts to be decided jointly between researcher and YSC
- Provide a letter of support regarding the importance of your study (and YSC's involvement, where applicable)
- Recommend educated advocates to assist in design, review or oversight of your study
- Share your research and study results on Facebook, Twitter, our e-newsletter and blog
- Publicize the study or trial through Facebook, Twitter, our e-newsletter and webpage to aid in participant accrual

If you have any questions, please contact us at research@youngsurvival.org.

REVIEWERS/CONSULTANTS

We thank the following individuals who reviewed and provided input into the drafts of our research priorities:

Dr. Virginia Borges, Director, Young Women's Breast Cancer Translational Program, University of Colorado Cancer Center

Anna Cluxton, MBA, Breast Cancer Survivor and Advocate, Former President of YSC Board of Directors, Chair of the RTT Fertility Group

Kim Hagerich, Breast Cancer Survivor and Advocate, Chair of the RTT Treatment Group

Jennifer Ivanovich, MS, Research Assistant Professor, Genetic Counselor, Director, Young Women's Breast Cancer Program, Department of Surgery, Washington University School of Medicine

Roz Kleban, LCSW, Clinical Supervisor and Program Coordinator at Evelyn Lauder Breast Center at Memorial Sloane Kettering Cancer Center

Tracy Leduc, Breast Cancer Survivor and Advocate, RTT Treatment Group member

Dr. Kutluk Oktay, Professor of Obstetrics and Gynecology, Cell Biology & Anatomy, Medicine and Pathology, New York Medical College

Dr. Ann Partridge, Founder and Director, Program for Young Women with Breast Cancer at Dana Farber Cancer Institute, Co-Chair of RTT

Ann Marie Potter, MA, OTR, Breast Cancer Survivor and Advocate, RTT Quality of Life Group Chair

Shoshanna Rosenberg, ScD, MPH, Postdoctoral Research Fellow, Harvard School of Public Health/ Dana-Farber Cancer Institute

Nancy Sauers, Breast Cancer Survivor and Advocate, RTT Risk Factors Group member

Joy Simha, Breast Cancer Survivor and Advocate, Co-Founder of YSC and Co-Chair of RTT, Former President of the YSC Board of Directors

Dr. Patricia Steeg, Deputy Chief, Women's Malignancies Branch, Center for Cancer Research, National Cancer Institute

Dr. Irene Su, Assistant Professor of Reproductive Medicine, University of California, San Diego

Dr. Alexander Swistel, Associate Professor of Clinical Surgery, Weill Cornell Medical College

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Young Survival Coalition's Research Think Tank would not be possible without the significant contributions of Ann Partridge, M.D., MPH and Joy Simha, YSC Co-Founder. These two women have demonstrated the utmost commitment and compassion to improving the quality and quantity of life for young women with breast cancer. Their willingness to collaborate and engage in this project has resulted in a framework where educated advocates and medical experts worked together as part of an innovative approach to develop a relevant and implementable research agenda on young women with breast cancer.

ANN PARTRIDGE, M.D., MPH

Associate Professor of Medicine, Harvard Medical School

Director, Adult Cancer Survivorship Program

Dana-Farber Cancer Institute and Brigham and Women's Hospital

Ann Partridge, M.D., MPH, is a medical oncologist and clinical researcher focused on improving the care and outcomes of patients with cancer, with a particular focus on breast cancer. She is the former Clinical Director of the Breast Oncology Program, founded and directs the Program for Young Women with Breast Cancer, and currently serves as Director of the Adult Cancer Survivorship Program at Dana-Farber/Brigham and Women's Cancer Center. Dr. Partridge has published numerous manuscripts and lectures both nationally and internationally on the care of women with breast cancer, and issues of cancer survivorship and young women with breast cancer, in particular. She has received several awards and grants including an American Society of Clinical Oncology (ASCO) Improving Cancer Care Grant, LIVESTRONG Survivorshop Award and the Tracey Starr Breast Cancer Research Fund Award, and she serves as a Susan G. Komen for the Cure Scholar. She also serves on several committees, including as Chair for the Center for Disease Control and Prevention (CDC) Advisory Committee on Breast Cancer in Young Women and Chair of the YSC Medical Advisory Board.

JOY SIMHA

Co-Founder & Former Board Member, Young Survival Coalition

Board Member, National Breast Cancer Coalition

Joy Simha, diagnosed with breast cancer in 1994 at the age of 26, is one of the three Co-Founders of the YSC. She was the first President of YSC and served on YSC's board of directors for 15 years. She represented YSC on the board of directors of the National Breast Cancer Coalition (NBCC) from 2001-2013 and now serves as its alternate. Trained through NBCC's Project LEAD®, Joy has put her science training to good use as a member of the Integration Panel of the Department of Defense Breast Cancer Research Program, and she is chair elect for 2015. She served on the CDC Advisory Committee on Breast Cancer in Young Women and as a panel member on the Institute of Medicine's Evidence Communication Innovation Collaborative. Joy comes from a career in video production and media marketing. She strives toward effective, meaningful change in the status quo for all women affected by breast cancer, in honor of her children and future generations affected by the disease.

IN MEMORIAM

Randi Rosenberg

Randi Rosenberg was one of the original founding members of YSC and the organization's third board president. She was originally diagnosed with ER+ breast cancer in 1998 at the age of 32. In 2006, Randi learned her breast cancer had metastasized to her bones. After a four-year battle with metastatic breast cancer and 12 years after her original diagnosis, Randi passed away February 15, 2010. We will continue to honor her legacy through our unwavering commitment to advocating for research studies focused on breast cancer in young women.

Randi was an instrumental part of the team that assembled YSC's Medical Advisory Board, composed of physicians and scientists concerned with early onset breast cancer. She led YSC's Medical Research Task Force and was a driving force behind the organization's 2001 Medical Research Symposium.

Attended by some of the most noteworthy figures in breast cancer research from the tri-state area, this symposium served as the catalyst for YSC's first evidence-based whitepaper, Bridging The Gaps: Current Issues In Medical Research On Young Women & Breast Cancer—A Basis For Action And Advocacy, which formulated a plan to advocate for research specific to early onset breast cancer.

During Randi's tenure as president, the organization's capacity more than doubled. She was a graduate of NBCC's Project LEAD® and represented YSC on various boards, including the National Cancer Institute's CALG-B Cooperative Group and LIVESTRONG's Young Adult Alliance (now Critical Mass), a national coalition focused on addressing cancer in young adults.

Randi leaves behind a beautiful daughter, Alexandra Marais, brothers Lee and Scott, and her mother, Roberta (Bobbi) Rosenberg.

Randi's passion and thirst for evidence-based answers, her captivating way of querying the most intelligent minds into deep debate about oncology treatment issues, and her desire to make a significant difference in the lives of all young women were key in all she accomplished.

Since the inception of the YSC Research Think Tank, we have lost four women who were part of the RTT planning team or a work group member. All four had been diagnosed with cancer and three of the four lost their lives to the disease. This publication is dedicated to their memory and is in honor of their hard work and passion for improving the quality and quantity of life for young women diagnosed with breast cancer. We honor these incredible women in alphabetical order:

Kim Casamassima

Advocate, Member of the RTT Metastasis Work Group

Kim was first diagnosed with breast cancer in 1992 at the age of 28 and then again in 2005. After her recurrence, she educated herself about her disease, attending the National Breast Cancer Coalition's (NBCC's) Project LEAD® and Quality Care Project LEAD® and becoming active with both NBCC and YSC. In 2008, Kim was diagnosed with metastatic breast cancer (MBC). She immediately devoted herself to researching the incurable disease, attending conferences, visiting doctors across the country, and performing volunteer work. She worked on the hotlines for the American Cancer Society, SHARE, and YSC, where she shared her MBC knowledge, experience and coping skills with others encountering similar circumstances. She was also active with the South Jersey Breast Cancer Coalition, Metastatic Breast Cancer Network (MBCN), Reach for Recovery, and Breast Cancer Resource Center. She served as a team leader for NBCC where she led groups of activists to meet with New Jersey senators and congress members in the annual Lobby Day meetings in Washington, DC. In 2009, she and her daughter Jessica worked with MBCN to have Oct. 13th declared Metastatic Breast Cancer Awareness Day. She and Jessica again met with legislators on Capitol Hill in May 2012. Kim tried to live a life not defined solely by her disease. She enjoyed going on long bike rides, volunteering at her children's schools, tending to her garden, baking for friends, and spending days cruising the Barnegat Bay. Kim worked as a software engineer until 2005, before devoting the rest of her life to family and community service. Kim died of her disease on July 18, 2013 at the age of 48 leaving behind a husband and two teenage children.

Debbie Molis

Advocate, Chair of the RTT Metastasis Work Group

Debbie was smart, witty, outspoken and passionate about making a difference. From the moment of diagnosis, she was a resource to other women within YSC, helping others to cope with breast cancer or sharing her knowledge about the disease online and in person in every way she could. She started the DC affiliate of YSC and educated herself about breast cancer, taking multiple Project LEAD® courses and attending conferences whenever possible. She represented the consumer perspective by reviewing grants for the Department of Defense Breast Cancer Research Program. Representing the state of New Jersey, Debbie lobbied on Capitol Hill for more funding for breast cancer research and reminded legislators of the human "face" of the disease. She was a driving force in her RTT metastasis work group, often calling medical professionals individually so that their input and insight could be obtained. She was driven to do all she could to end breast cancer—not just for her benefit, but so that other women could be spared. Debbie was also an `organizer.' She loved to get friends and fellow YSC'ers together for dinner and fun at conferences. She was the kind of person you wanted to be around and her loss is felt deeply, far and wide. Debbie died on November 23, 2013 at the age of 47 from metastatic breast cancer.

Dr. Irma Russo was a pioneer in identifying the mechanisms of breast cancer prevention and was working to develop a hormonal treatment for disease prevention using the pregnancy hormone hCG. Together with her husband, Dr. Jose Russo, she published five books, more than 200 research articles and trained and mentored more than 50 physicians and scientists. For the past 22 years, Dr. Russo worked at Fox Chase Cancer Center; first as director of surgical and clinical pathology and then as director of the molecular endocrinology section of the Breast Cancer Research Laboratory, which she founded in 1975 with her husband.

Dr. Irma Russo was passionate about involving advocates in the research process. Once she had helped train advocates in the lab, she was eager to incorporate the unique perspective of a breast cancer patient to help her to become a better researcher. She often asked advocates to participate in writing research grants and solicited their recommendations from the very beginning of the process. When YSC was looking for researchers to be a part of the RTT, the Russos were some of the first to sign on. To YSC's invitation to participate, Dr. Irma Russo promptly responded,"The risk of breast cancer in young women is a topic very dear to me, and I will be quite pleased in participating in this symposium in collaboration with scientists and advocates." Not only did the Russos `sign on,' but they participated as a part of two work groups: the Pregnancy work group and the Identification of Factors that Increase the Risk of Breast Cancer in Young Women work group. The Russos elected to spend their 45th wedding anniversary at the YSC Research Think Tank meeting because they felt so strongly about YSC's research agenda. Dr. Irma Russo passed away on June 25th, 2013 after a long battle with ovarian cancer.

Irma Russo, M.D.

Breast Cancer Researcher, Member of RTT Risk Factors and Pregnancy Work Groups

Kat's intelligent approach to problems large and small, her generous supportive nature and overall zest for life were inspiring to us all. Kat had a remarkable ability to translate the research and science of breast cancer into information that was digestible for newly diagnosed women and explained the impact of science and research findings throughout the advocacy community. She often helped to lead the dialogue among advocates, survivors and researchers—gaining the respect, admiration and appreciation of them all. Kat worked in breast cancer research advocacy full-time for various organizations including YSC, National Institute of Health, the Cochrane Collaboration, American Cancer Society, the Department of Defense Congressionally Directed Medical Research Programs, Virginia Breast Cancer Foundation, Research Advocacy Network, the National Cancer Institute and Susan G. Komen for the Cure. In 2011, YSC was honored to have Kat join its Board of Directors as a strong voice for all young women with breast cancer, particularly those who connect using social media. As a young survivor, Kat supported countless other young women through their breast cancer diagnosis using Facebook, the YSC message boards and tirelessly volunteering. Kat was funny, open-minded, engaging and she never judged. Her warmth made it easy for young women to open up, listen and exchange perspectives. As a member of the RTT Planning Committee, Kat's insight kept us focused on the important issues and her enthusiasm for the project was contagious. Kat died suddenly on September 23, 2012 as the result of a blood clot, about one week after giving birth to her fourth child. She was 37 years old.

Kathleen "Kat" Werner

Advocate, RTT Planning Committee

NOTES

YSC would like to thank our generous sponsors for their support of the work of the Research Think Tank:

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