

JUDGES & LAWYERS BREAST CANCER ALERT



Vol. 20 No. 1

Editor: Martha L. Golar, Esq.

February 2015

— 2015 SPRING SYMPOSIUM —

BREAST CANCER; UPWORTHY IDEAS

DATE: Tuesday, March 10, 2015
TIME: 6 - 8 PM
PLACE: New York County Lawyers' Association
14 Vesey Street
New York, New York

MODERATOR

Hon. Jennifer Schecter, Past Co-President, JALBCA

OPENING REMARKS

Jamie Sinclair, Co-Chair, NYCLA Committee on Women in the Law

INTRODUCTION OF SPEAKERS

Hon. Richard Lee Price, Chair, Law-Related Education,
New York County Lawyers' Association

SPEAKERS

Devra Davis, Ph.D., Founder and President of Environmental Health Trust
Mary Ann Massie, MD, Attending Psychiatrist,
Memorial Sloan Kettering Cancer Center

SPONSORS

NYCLA Committee on Women in the Law
Women's Bar Association of the State of New York

SYMPOSIUM CO-CHAIRS

Hon. Barbara Jaffe and Karen Blaustein, Esq.

Open to the public without charge. Refreshments will be served.



Last fall, litigators Alison Greenberg and Virginia (Ginger) Trunkes represented JALBCA in attending the National Breast Cancer Coalition’s (NBCC) bi-annual “Project LEAD [Leadership, Education, & Advocacy Development] Workshop” in Washington, DC. Launched in 1991, NBCC is a grass-roots organization which has mobilized a nationwide network of organizations and political activists to give breast cancer a meaningful voice in Washington, DC, state capitals, laboratories and health care institutions. Among other accomplishments, it increased federal funding for breast cancer research, including procurement of \$2.89 billion for the Department of Defense Breast Cancer Research Program.

NBCC created Project LEAD’s science training program to educate breast cancer activists in the fight against breast cancer, due to an ever-evolving scientific and political landscape. As part of the training, students receive crash courses taught by esteemed faculty on topics such as:

molecular biology; the science of cancer and, specifically, breast cancer; epidemiology; risk factors; features of clinical trials; the impact of research on clinical practice; and improving critical appraisal skills in reading and interpreting health information in the media. The purpose of the program is to prepare graduates to engage in and influence the wide range of national and local fora where breast cancer decisions are made by “bringing to the table” an educated consumer perspective and critical thinking skills. Below, Alison and Ginger relate what they learned at the training and offer suggestions for JALBCA in moving forward.

NBCC has set a deadline of 2020 for a cure and/or prevention of breast cancer. NBCC acknowledges that this is a lofty goal, but believes that advocates’ successes in the past several decades have made this goal necessary. That is, NBCC believes that substantial strides have been made in the fight against breast cancer, including creating awareness, increasing the percent-

age of women who obtain annual screenings, pinpointing the DNA mutation BRCA1 and BRCA2 as creating a high risk for breast cancer, galvanizing politicians and obtaining funding for a plethora of research projects on possible links to breast cancer, whether it be lifestyle or genetics, or both.

NBCC is pleased that with remarkable scientific innovations and with the fact that individuals afflicted with advanced breast cancer have been living longer. Indeed, scientific breakthroughs have successfully targeted mutations such as “Estrogen Receptor Positive” and “Her-2 Amplified”, and have led to now commonly-used targeted therapies such as Tamoxifen and Herceptin. For many, these therapies are more tolerable than other types of treatment, and, significantly, their role in extending lives cannot be overstated.

Nonetheless, NBCC is frustrated because science has not eliminated the disease entirely or significantly reduced the overall metastatic rate. Nor is NBCC satisfied with the current

approach to breast cancer awareness, including the focus on early screening. NBCC wants to encourage its supporters and the overall community fighting breast cancer to focus on finding a cure.

The Project LEAD Workshop highlighted that “breast cancer” is extremely complex: it is a heterogeneous disease with at least six or seven subtypes. The molecular profile of the particular subtype may have the most profound impact on overall survival. For some subtypes, targeted therapies are extremely effective. For others, different treatments are being studied and pursued. At a minimum, in view of the disease’s complexity and unpredictability, NBCC strongly advocates against “one size fits all” treat-

ment following a diagnosis of breast cancer. In light of all of these intricacies, NBCC urges that a greater proportion of resources be allocated to scientific research which will cure breast cancer.

Alison and Ginger both found the Workshop to be extremely informative about the disease, its lexicon, the efforts to find treatments and a cure, and the political aspects of how to approach breast cancer. They also valued meeting breast cancer activists, many of whom are fighting the disease themselves. Alison and Ginger encourage JALBCA to continue supporting NBCC and to host fora about the different views regarding the significance and efficacy of early screening. There has been much discussion on the sub-

ject, including by Dr. Daniel Kopans, a professor of radiology at Harvard Medical School and senior radiologist in the department of radiology, breast imaging, at Massachusetts General Hospital in Boston, who along with our own Dr. Larry Norton, believes in the life-saving potential of screening. The knowledge gained at the Project LEAD Workshop left Alison and Ginger with the belief that these issues require greater dialogue at JALBCA.

Alison Greenberg is with Fensterstock & Partners LLP and Virginia Trunkes is with Ganfer & Shore, LLP. They met at 60 Centre Street as adversaries on an order to show cause and later became good friends.

— SAVE THE DATES —

Upcoming CancerCare Program

Workshop: **Update on Triple Negative Breast Cancer**

Date: Tuesday, March 3, 2015

Time: 1:30 – 2:30 pm, EST

Lecturers: **Melinda L. Telli, MD**, Assistant Professor of Medicine, Division of Oncology, Stanford University School of Medicine

Lisa A. Newman, MD, MPH, FACS, Professor of Surgery, Director, Breast Care Center, University of Michigan, Comprehensive Cancer Center

Steven J. Isakoff, MD, PhD, Massachusetts General Hospital Cancer Center and Harvard Medical School

Allison Nilsen, MSW, Coordinator, Women’s Cancers Program, CancerCare

Registrants can listen in live over the phone or online as a webcast. A listing of featured programs is available by calling 1-888-337-7533, 24 hours a day, 7 days a week. You can also listen to previous workshops on the CancerCare website by logging on to www.cancercare.org/podcasts.

Upcoming NYU Cancer Program

Webinar: **Reconstructive Surgery Options for Women with Breast Cancer**

Breast reconstruction can help restore the look and feel of the breast after mastectomy. Learn the facts about the many surgical options available.

Date: Friday, March 6, 2015

Time: 1- 2 pm

Lecturers: **Deborah Axelrod, MD, FACS**, The John and Elaine Kanas Associate Professor of Surgical Oncology, Laura and Isaac Perlmutter Cancer Center

Jamie Levine, MD, Associate Professor, Department of Plastic Surgery, NYU

This program is in collaboration with SHARE. RSVP is required for all events.



Since 2005, JALBCA has made grants to SHARE, a nonprofit organization that offers support, information and the benefit of experience to women diagnosed with breast and ovarian cancers and their caregivers. SHARE's services include a helpline staffed by volunteer peers, support groups, and seminars on both the treatment of cancer and living with the disease. SHARE was founded in 1976, and all services are free of charge.

JALBCA funds launched SHARE's Metastatic Breast Cancer (MBC) Support Group program in 2007 which:

- offers 3-5 educational programs which are SHARE's most highly attended programs



- provides dedicated Helpline support to women living with MBC
- publishes a quarterly newsletter with 1,200 subscribers
- participates in Count Us, Know Us, Join Us
- is a founding member of The Metastatic Breast Cancer Alliance
- facilitates six telephone support groups each month

SHARE offers more educational programs and support services for the MBC community than any other breast cancer organization. These are some of its recent programs:

- On January 7, 2015, SHARE began a new telephone support group for young women living

with MBC with eight women attending. This group is facilitated by a young woman who is living with the disease.

- The first evening group of 2015, "Living with Uncertainty", held on January 8, was attended by 11 callers.
- An additional evening telephone group will be added in February 2015, bringing the total number of group sessions to nine each month.

What SHARE MBC group participants say:

- The group helps me feel I'm not alone with this awful disease and horrible prognosis.
- It's comforting to me to know that everyone in the group worries about results from scans and tests and those come around very, very often.
- I feel the facilitator and the other women are sincerely concerned about me.

On behalf of the staff, volunteers and Board of Directors, SHARE's Executive Director, Jacqueline Reinhard, extends their deep appreciation for JALBCA's generous and continued support.

— THE-OPTIMAL-LYMPH-FLOW™ —

Enhancing Lymphedema Risk Reduction using an e-Health Approach

Even with modern medical advances, lymphedema (*i.e.*, the accumulation of lymph fluid in the affected upper limb or body) remains a major health problem affecting thousands of breast cancer survivors since no current surgical or medical interventions can provide a cure. More than 50% of women report multiple distressing symptoms related to fluid accumulation even years after cancer treatment. The abnormal accumulation of lymph fluid or lymphedema after breast cancer treatment is a result of obstruction or disruption of the lymphat-

ic system associated with cancer treatment (*e.g.*, removal of lymph nodes and/or radiotherapy), influenced by patient personal factors (*e.g.*, obesity or higher body mass index (BMI)) and triggered by factors such as infections or trauma.

Symptoms related to the accumulation of lymph fluid following breast cancer treatment are debilitating late complications that impact the breast cancer survivors' quality of life as well as create a tremendous burden on the health care system. Persistent distress-

ing symptoms related to fluid accumulation are considered stressful complications since it is perceived as a constant reminder of cancer and exerts tremendous limitations on daily living. Distressing symptoms related to lymphedema can instigate fears and induce feelings of loss of control. Nonetheless, in clinical practice the risk for lymphedema and managing symptoms related to lymph fluid accumulation are still under-recognized and under-treated.

The-Optimal-Lymph-Flow™ is part

of the continuum of an eight-year ongoing collaboration to advance the science on lymphedema risk reduction and symptom management among breast cancer survivors and serves as a focal platform to garner the talents from across disciplines at New York University (NYU). This collaboration involves the NYU College of Nursing, NYU Cancer Center, NYU School of Medicine (surgery, pathology, and biostatistics), NYU Rusk rehabilitation, NYU Polytechnic School of Engineering, and NYU Asian Center. Low cost and pragmatic self-care strategies for lymphedema risk reduction and symptom management may hold great promise for improving patients' quality of life. Grounded in research-driven self-care behavioral strategies, The-Optimal-Lymph-Flow™ is a patient-centered educational and behavioral program focusing on self-care strategies to lessen the symptom burden by promoting lymph flow and maintaining optimal BMI, which targets a compromised lymphatic system and BMI, that are risk factors for lymphedema and

symptoms related to lymph fluid accumulations. Its underlying premise is to empower, rather than inhibit, how breast cancer survivors live their lives by emphasizing "what to do," rather than "what to avoid." It features safe, feasible and easily-integrated-into-daily-routine self-care strategies that include muscle-tightening-breathing, muscle-tightening-pumping exercises, and large muscle exercises to promote lymph flow and drainage, shoulder mobility exercises to promote shoulder function, as well as general instructions to encourage nutrition-balanced (more vegetables and fruits) and portion-appropriate diet (feeling 75% full for each meal) to strive for maintaining optimal BMI. The efficacy of The Optimal Lymph-Flow™ has been demonstrated in a recently published study of 140 patients who received the face-to-face nurse-delivered program. Findings of the study demonstrated that over 90% of patients improved their limb volume at 12-month follow-up.

A technologically-driven delivery model is needed to universally expand

the accessibility of The Optimal Lymph-Flow™. The web-based The Optimal Lymph-Flow™ platform has been developed and can be used on computer, iPhone, iPad, or other smart phones. The web-based platform includes information about lymphedema, diagnosis and measurement of lymphedema, lymphatic system, risk of lymphedema, risk reduction for optimal lymph flow, and self-care for an optimal life. The platform also contains 8 Avatar videos that provide step-by-step instructions for The-Optimal-Lymph-Flow™ exercises to optimize lymph flow and promote shoulder and limb mobility. Based on the pilot evaluation of the system, patients love the web-based system, especially the avatar technology that demonstrates the complicated lymphatic system and illustrates the physiological functions of each exercise and detailed step-by-step instructions for each exercise. The next step of the project is to develop electronic applications or apps that can be used by iPhone or Android phones to evaluate the efficacy of the web-based The-Optimal-Lymph-Flow™ system.

— CALENDAR/CONTACTS —

ADELPHI NY STATEWIDE BREAST CANCER

Hotline & Support Program

Adelphi University School of Social Work
Garden City, NY 11530

www.breastcancerhotline@adelphi.edu

CancerCare

275 Seventh Avenue
New York, NY 10001

www.cancercare.org

1.800.813.HOPE (4673)

ELLEN'S RUN

200 West End Avenue, Suite 12 G
New York, NY 10023

www.ellensrun.org

212.840.0916

GILDA'S CLUB NEW YORK CITY

195 West Houston Street
New York, NY 10014

www.gildasclubnyc.org

212.647.9700

MEMORIAL SLOAN KETTERING CANCER CENTER

Post-Treatment Resource Program

Educational Forums

215 E. 68th St., Ground Fl.

New York, NY 10021

www.mskcc.org

212.717.3527

Bendheim Integrative Medicine Center

1429 First Avenue (at 74th Street)

New York, NY

SHARE (*Self-Help for Women with Breast or Ovarian Cancer*)

1501 Broadway, Ste. 704A

New York, NY

www.sharecancersupport.org

212.719.0364

Speak to a survivor toll-free:

1.866.891.2392

TO LIFE!

410 Kenwood Avenue
Delmar, NY 12054

518.439.5975

110 Spring Street
Saratoga Springs, NY 12866

518.587.3820

www.tolife.org

YOUNG SURVIVAL COALITION

61 Broadway
New York, NY

www.youngsurvival.org

646.257.3025