

Women At Risk

Dear Friends,

This year, Women At Risk celebrates 18 years of enhancing the lives of women and families affected by breast cancer. We thank you for supporting our life-saving programs even during these difficult economic times.

I am thrilled to announce the appointment of Dr. Kathie-Ann Joseph as WAR's Medical Director. Dr. Joseph was the first Women At Risk Breast Surgery Fellow and has served as our Acting Medical Director for the past 15 months. We are excited for this opportunity to work more closely with her in the future.

I am also happy to report that the High-Risk Program is now up and running at Weill Cornell Medical Center. This expansion will allow us to reach more high-risk women and increase the amount of data available to researchers through our High-Risk Registry. In an effort to increase benefits for women participating in our high-risk program, we are set to begin distributing high-risk resource packets to those enrolled in the registry and are introducing a support group specifically for women who are at high risk for breast cancer.

In November, we hosted our Laurie Bass Sklaver Annual Symposium, which this year focused on "Survivorship: The Next Frontier in Breast Cancer." More than 200 people gathered to listen to our panels of doctors and survivors address the physical, emotional and social issues associated with breast cancer survivorship. You can read more about the success of this event on page 5.

Finally, I'd like to extend a special thank you to Patti Kenner who opened her home to host an evening of "Cocktails and Conversation" this February. This event was held in conjunction with Ellen's Run, a breast cancer organization based on the East End of Long Island. The evening offered attendees an opportunity to learn more about the work of both groups and to hear updates on current breast cancer research.

We hope you enjoy reading about the latest work of Women At Risk, and we thank you, as always, for your continuing support and commitment to our cause. I hope to see all of you at Women At Risk's 18th Annual Luncheon on May 11th.

Bonnie Pressman, *President*

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Please Join Us!

Women At Risk's Eighteenth Annual Luncheon

MONDAY, MAY 11, 2009 • WALDORF=ASTORIA HOTEL, NEW YORK CITY

KEYNOTE SPEAKER

Hoda Kotb
Co-Host, Fourth Hour of
"Today" and Correspondent,
"Dateline NBC"

HONORING

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Director of Legal Assistants,
White & Case, LLP
Immediate Past President,
Women At Risk

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Susan and Alan Fuirst

For more information,
call (212) 305-4486.

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Visit Women At Risk's website at

www.womenatrisknyc.org



The WAR board and staff mourn the passing of our long-time board member and friend, Steve Agins. The following article, written by friend and fellow board member, Lynda Wertheim, is a tribute to Steve's tireless commitment to the work of Women At Risk.

The Man Who Sat Among the Women

by Lynda Wertheim

Getting a spot on Steve Agins' dance card was quite a feat. If he wasn't meeting with a fellow car lover about a racing event, or pitching a proposal for new PR business with his partner and Women At Risk board member, Sally Sherwood, or floating down the Amazon with his wife, Ronne, or entertaining his grandchildren ("the kidlets"), Steve was challenging Women At Risk to find unique ways to fulfill its mission.

I first met Steve as a voice in the background during a phone call I had with his wife. Newly diagnosed, I could hear his supportive tone and kind words echoing in the background as Ronne prepared me for what I might encounter along the breast cancer journey. Though Steve was the quintessential PR pro, he could easily have become a voiceover personality. His vocal cadence, tone and enthusiasm transcended the words he spoke.

Steve's combination of intelligence, sensitivity and personal experience made him an invaluable resource for husbands of women diagnosed with breast cancer. Having coached his wife through surgery, chemotherapy and radiation, he gladly accepted my request to provide support, empathy and hope to other spouses whose wives were undergoing treatment. An active participant in Women At Risk's Strategic Planning Task Force, Steve spearheaded creative communication efforts to reach the women served by the organization. Steve's instinctive ability to blend words with graphics earned Women At Risk the prestigious *Communicator Award* from the International Academy of the Visual Arts for the premier edition of "Women At Risk Today," the first comprehensive summary of the organization's accomplishments. Steve also lobbied vigorously to enhance the website and create an online

newsletter to streamline the delivery of late-breaking news about Women At Risk, breast cancer research and the many programs and research projects we support.

In 2007, Steve worked with the Dinner Committee to recognize the important role men play in the lives of women who go through treatment for breast cancer. Steve was personally familiar with the theme of the dinner dance: "Celebrating the Men Who Stand With the Women." Steve knew what it was like to stand by Ronne, to encourage the Women At Risk board to take calculated risks and to change the lives of the people to whom he offered guidance.

Steve may no longer sit at our board meetings, but Women At Risk will be a long-term beneficiary of his many talents. ■

Women At Risk

*is grateful to the following businesses who
partnered with us this past October for
Breast Cancer Awareness Month*

**Giella
Grandview
Great Stuff
Lot84
Olive and Bette's
The Salon
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*If you or someone you know is
interested in creating a business promotion
with WAR, please contact Kavita Desai
at 212-305-4486.*

Research using WAR's High-Risk Registry published in Surgical Oncology Journal

By Lydia Chiu

Breast cancer risk factors have been studied mainly among women between the ages of 40 and 65. However, according to the Surveillance Epidemiology and End Result Cancer Statistic Review, women between the ages of 70 and 75 have the highest incidence rate. This statistic highlights the need for more research specific to risk factors among women in extreme age groups, 35 or younger or 70 or older. Researchers recently examined the established breast cancer risk factors in these extreme age groups using data from Women At Risk's High-Risk Registry, and the findings from the study were published in the January 2009 issue of the *Annals of Surgical Oncology*. The study expanded on previous research presented at the Miami Breast Cancer Conference in 2007 which focused solely on younger women. Researchers involved in the study included Jennifer Chun, M.P.H., WAR's Medical Director Kathie-Ann Joseph, M.D., M.P.H., WAR's former breast surgery fellow Ben Pocock, M.D., Mahmoud El-Tamer, M.D., Laura Klein, M.D., and Freya Schnabel, M.D.

According to existing literature, established factors associated with increased risk for development of breast cancer include, but are not limited to, history of atypical ductal hyperplasia (ADH), atypical lobular hyperplasia (ALH), lobular carcinoma in-situ and a strong family history of breast cancer (FHBC). Eighty-two women in the

High-Risk Registry were 70 years of age or older. Among these women, 52 (63%) had a strong FHBC, 27 (33%) had a history of LCIS, 20 (24%) had a history of ADH, and 5 (6%) had a history of ALH. Six (7%) of these 82 women went on to develop breast cancer. None of these risk factors (FHBC, LCIS, ADH, ALH) were significantly associated with development of breast cancer among women 70 years or older. One hundred and ninety-nine women within the High-Risk Registry were 35 years of age or younger. Only three of these 199 women went on to develop breast cancer. All three women had a strong family history of breast cancer, suggesting an association between strong family history of breast cancer and increased risk.

These findings suggest that the significance of established risk factors associated with the development of breast cancer may vary by age. Among women 35 years of age or younger, a strong family history of breast cancer seems to be the strongest predictor of risk. Among women 70 years or older, established risk factors seemed to lose significance, which may be due to the influence of age on risk. Studies which examine the prognostic significance of established risk factors impact how clinicians screen for and prevent the development of breast cancer. More studies must be conducted in these extreme age populations in order to create better risk-assessment models for women 35 and younger and women 70 and older.

Helping Women Help Themselves

October 25, 2008
Free Screening Day
Statistics

- 92 women received breast screenings
- 100 women received cervical screenings
- 40 women received colorectal screenings

With your support, Women At Risk is able to help provide these life-saving services free of charge.

Thanks to the volunteers who made this day a success!

If you are interested in volunteering for a Free Screening Day, please contact Lisa Held at (212) 305-3269.

High-Risk Program Announcements

WAR is pleased to announce our successful expansion of the High-Risk Program to Weill Cornell Medical Center. If you or anyone you know is interested in enrolling in the High-Risk Program at Weill Cornell Medical Center, please contact Rhonda Theodore at (212) 821-0635 or rtm9001@nyp.org.

Women At Risk is also happy to announce our new peer-led High-Risk Support Group. This support group will be co-sponsored by FORCE (Facing Our Risk of Cancer Empowered), a non-profit organization whose mission is to improve the lives of individuals and families affected by hereditary breast and

ovarian cancer. Any woman who is at high risk for breast cancer is welcome to come share and receive resources, information and emotional support.

The support group will meet in the Stacey Garil Womack Resource Library on the 10th floor of the Herbert Irving Cancer Center (Room 1035). The Cancer Center is located at 161 Fort Washington Avenue between 166th and 167th Streets. The group will meet on the third Wednesday of every month from 6–7:30 p.m. For more information or to RSVP to a meeting, please contact Lisa Held at (212) 305-3269 or lhheld@womenatrisknyc.org.

This issue of Women At Risk's newsletter is made possible through the generous support of The Larry and Jane Scheinfeld Foundation.

Support Groups

The Women At Risk Support Group for Women with Breast Cancer

Dealing with breast cancer? You are not alone. Come to our peer-led support group to meet other survivors, exchange information, and help one another through this journey. New patients may join at any time.

The group meets every other Friday at 2:00 p.m. in the conference room on the Garden Level of the Herbert Irving Pavilion, 161 Fort Washington Avenue, NYC.

For exact meeting dates or more information, contact Nancy Singleton, Patient Navigator, at (212) 342-0297.

Grupo de Apoyo para las Mujeres Latinas con Cancer del Seno

El Grupo de Apoyo se reúne los 2 y 4 Jueves de cada mes

The 2nd and 4th Thursday of each month

10:00 a.m.–11:30 a.m.

Para más información, llamar a Lola Ruz-Curry al:

For more information, call Lola Ruz-Curry, at: (212) 305-9894.

Co-sponsored by Women At Risk, SHARE and Social Work Services, NYP/CUMC.

WAR hosts *Underneath it All* Services for Patients

By Lisa Held

When most women undergo breast surgery and/or chemotherapy, they are unsure of what to expect or what they will need during and after their treatment. During this period of physical and emotional turmoil, shopping for post-operative garments or wigs can be overwhelming. After her first breast reconstruction, Nancy Singleton said, “No one told me about the drains, and as I left the hospital, they pinned them to my shirt. Trying to move around with the pins was a nightmare. I finally heard about the surgical camisole from a patient on a hotline, but I had a hard time finding one.” Patients may also find it difficult to travel to shops that carry the products they need, and many of the locations that carry these products are intimidating. “Many women walk into a surgical store to buy a prosthesis or bra,” Nancy added, “and after they walk past the limbs and wheelchairs, they find that no one there can fit them properly.”

Underneath it All, a one stop shopping service for women who have had any form of breast surgery or who are undergoing chemotherapy, is an exception. Located on Manhattan’s Upper East Side, *Underneath it All* is committed to understanding each woman’s needs and assists and advises each customer on purchase decisions in a warm, compassionate and private environment. Christina Faraj, a fitter from *Underneath it All*, noted that women are initially hesitant to visit the shop because they don’t know what to expect and feel like they are going to yet another appointment. “But soon,” she said, “when they take a look around and we fit them in a fabulous bra, their spirits are instantly uplifted, and by the time they leave, there is a hug involved.” Their range of products includes breast forms in a variety of shapes, sizes, contours and skin tones, mastectomy bras, mastecto-

my swimwear with matching cover-ups, post-surgery camisoles and an entire feminine lingerie collection. The store’s proprietors, Carol Keanne and Christina Faraj, are both certified fitters and will meet with women individually to help fit breast forms and bras.

For women experiencing hair loss, *Underneath it All* also carries a complete line of wigs, and patients can be seen by a hairstylist to recreate the hairstyle they’re familiar with or to try something new. Hats, turbans, scarves and other accessories are also available.

In November, Christina visited the Women At Risk Breast Cancer Support Group. Armed with a bag of mastectomy bras, breast forms and lingerie, she explained *Underneath it All*’s available services, and women were amazed by the quality and range of products. They were especially surprised by the number of products their insurance would likely cover. Most insurance companies now cover the costs of breast forms, mastectomy bras and most wigs for cancer clients. Coverage does not stop at the first fitting but extends beyond and often covers replacements as well. “The women at the support group were thrilled to hear about the insurance coverage,” Christina commented, “It was really fun to see their reaction to the fun bras in colors, lace and styles updated from what they know of as the more ‘matronly’ looking bras that were available in the past. They were also thrilled to see the variety of lighter-weight breast forms available to them now.”



Christina Faraj and Carol Keanne, from *Underneath it All*, display their products in the Stacey Garil Womack Resource Library.

As a result of the need demonstrated at the support group, *Underneath it All's* certified fitters will now be holding fittings and shopping services in WAR's Stacey Garil Womack Resource Library. The Resource Library is located on the 10th floor (Room 1035) of the Herbert Irving Pavilion at 161 Fort Washington Ave. The services will be offered on select Fridays once a month, and women are welcome to stop by to browse available products, receive personalized fittings,

and inquire about insurance coverage. *Underneath it All* will also make surgical camisoles available at all times through Women At Risk's Patient Navigator, Nancy Singleton. For exact dates or times or for more information, contact Nancy Singleton at nsingleton@womenatrisknyc.org or (212) 342-0297. For information on specific products or insurance coverage, contact Christina Faraj at *Underneath it All* at (212) 717-1976. ■



Paula Roberts and Dr. Jon Levenson at the Laurie Bass Sklaver Annual Symposium.

Women At Risk's Laurie Bass Sklaver Annual Symposium Addresses Breast Cancer Survivorship

By Lisa Held

“There are more than two million breast cancer survivors in this country, and that number is growing every day,” Dr. Anne Moore stated at Women At Risk's 2008 Laurie Bass Sklaver Annual Symposium. As the early diagnosis and effective treatment of breast cancer advances each year, more women are confronted with the challenge of figuring out what it means to be a “survivor.” While most women expect breast cancer to end with their treatment, they find that after treatment they enter a new phase of the breast cancer experience often referred to as “survivorship,” and this phase presents entirely new emotions, challenges and triumphs.

On November 13, 2008, more than 200 people gathered at the Symposium to address what Women At Risk called “Survivorship: The Next

Frontier in Breast Cancer.” The symposium focused on the physical, emotional and social issues faced by breast cancer survivors and their families and featured presentations by Dr. Anne Moore, Dr. Jon Levenson, and Ms. Paula Roberts. The evening was moderated by Dr. Kathie Ann Joseph, Women At Risk's Medical Director.

Dr. Moore opened the program by discussing the physical issues survivors may encounter. She pointed out that “many patients feel lost in transition between being a cancer patient and a cancer survivor,” and it's important to pay attention to them after their treatment and to create a formal plan for follow-up care. Immediate issues after treatment may often include fatigue, “chemo-brain,” effects of estrogen-deprivation, the possibility and fear of recurrence and issues of fertility and pregnancy. Dr. Moore reviewed common lifestyle changes often helpful in combating the effects of treatment and preventing recurrence. While she showed that research often varies on each of these components, she concluded with three basic post-treatment guidelines.

Survivors should:

- Resume exercise as soon as possible after

The Stacey Garil Womack Resource Library

Staffed by breast cancer survivors and offering confidential one-on-one support.

HOURS OF OPERATION:

Monday–Thursday from 10 a.m.–4:30 p.m.

Friday from 10 a.m. to 1 p.m.

Bilingual support is available on Wednesdays and Thursdays from 1 p.m.–4:30 p.m.

Women At Risk on the Web

Check out the newest way to stay up-to-date regarding Women At Risk news, announcements and programs!

Women At Risk now has a blog at www.womenatrisknyc.blogspot.com.

Visit our blog periodically to receive information on upcoming events, hear personal stories from women who have or are at high risk for breast cancer, and learn about groundbreaking research studies we're funding. You can also sign-up to receive e-mail updates from WAR!

Visit our main website at www.womenatrisknyc.org.

The difference is you...

Thank you to all of our volunteers who make a difference every day in Women At Risk's Resource Library:

Helene Bland
Clare Cooper
Marianne Glasel
Renee Goodman
Rita Heller
Laura Minella
Joanne Parent
Karen Small
Helen Tarr
Angela Vallaro

Women At Risk is grateful to:

The Friends and Family of Laurie Bass Sklaver

The Greater NYC Affiliate of Susan G. Komen for the Cure

Sanofi Aventis

For their generous support of the 2008 Symposium.

treatment and maintain some level during the treatments.

- Watch their diet and attempt to maintain a healthy weight.
- Limit their alcohol intake to small amounts reserved for special occasions.

In addition to paying attention to the long-term physical care of breast cancer survivors, "addressing psychosocial needs should be an integral part of quality cancer care," acknowledged Dr. Jon Levenson. Dr. Levenson noted that while the majority of women do remarkably well during and after treatment, most experience distress at some point, and a quarter to a third of women express or exhibit problems that warrant further assessment. Therefore, systematic screening for distress is critical and important. Dr. Levenson identified several factors associated with optimal adaptation to survivorship and dealing with these stressful emotions.

These factors include:

- Active participation in one's care.
- Use of a social support network
- Finding a sense of purpose and meaning in one's life.

Dr. Levenson also mentioned that although many survivors experience emotional distress, most manifest remarkable resilience and some even find benefit from the cancer experience. Women have reported increased self-esteem, greater interest in and commitment to personal and family health and the ability to "not sweat the small stuff" anymore, allowing them to live more fulfilling lives.

Finally, Ms. Paula Roberts addressed the challenges survivors face in their social world after treatment. They are often transitioning back into family roles and making important decisions regarding child bearing, dating or other family

issues. They may also be confronted with workplace and insurance issues. "Family, coworkers and friends can all play an important role," in supporting these women, Ms. Roberts noted, "but cancer survivors may need to talk to other survivors outside the family environment." Support Groups are one way to address this, and Patient Navigation programs that guide women and their families through the clinical process and ensure quality of care may also "take the sting out of feeling totally overwhelmed and alone," Ms. Roberts added.

After the speakers answered questions, breast cancer survivors Lola Ruz-Curry, Sara Oppenheim and Carolyn Vardi spoke about their personal experiences with survivorship. Remarkably, all three women reported some positive impact breast cancer had on their lives. Lola said, "I think my cancer was a blessing because after my cancer, I changed. I take care of myself first now, and everything else comes after. I think life is beautiful, and I enjoy every single moment." Sara changed her career after surviving breast cancer and became a Patient Navigator for the American Cancer Society. Although she remarked that breast cancer is terrible and not something she would wish on even her worst enemy, she said "I was lucky to come through this horrible experience, and I decided that I wanted to give something back to people who were struggling more." The women's opinions differed on how they felt about being called "survivors." While Sara and Lola both said they liked the term, Carolyn commented, "I don't like the term because to me it means that you've gone through something, survived it and moved on. But it doesn't ever really end—the key is finding the place cancer has in your life and managing it and putting it into perspective." ■

Turn your everyday purchases into contributions to Women At Risk!

Women At Risk is now registered with One Cause, a program that turns your everyday purchases into contributions to WAR with no extra charge to you!

Here's how it works:

1. Register. Go to www.onecause.com/signup. Fill in the registration form and choose "Women At Risk" as your cause. You do not need to give credit card or other sensitive information. Registration is fast, easy, and secure.

2. Shop. Anytime you are making a purchase with a participating vendor, log in to One Cause first, and the vendor will automatically donate a percentage of your purchase to Women At Risk. There are over 700 participating vendors including Nordstrom, Macy's, Expedia, Amazon, Delta, L.L.Bean, Hotels.com, Dell and more! You can also download a One Cause Toolbar that will remind you to log in when you're shopping on participating sites or apply for a One Cause Visa which will give back 1% of all of your purchases to WAR.

3. Spread the word. Tell your friends and family about this easy way to turn your everyday shopping into support for life-saving research, education and support programs for women affected by breast cancer!

If you have questions about this program or encounter problems registering on www.onecause.com, contact Lisa Held at lheld@womenatrisknyc.org or (212) 305-3269.

Thanks to Our Donors

Women At Risk would like to thank all of its donors for their generous support. While lack of space precludes us from acknowledging each person individually, we would like to give special recognition to the individuals and companies whose cumulative gifts to WAR totaled \$500 or more in 2008. A gift to Women At Risk is a thoughtful way to honor a friend, family member or caregiver. Your contributions enable us to continue to provide vital services and fund research initiatives that benefit women at high risk for and with breast cancer.

For stock or wire transfers or to make a donation, please use the enclosed envelope or call Carolyn Trotter at 212-305-5917.

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Included in this list are donations received between January 1, 2008 and December 31, 2008. Our apologies for any inadvertent omissions.

WAR's Board Expands

Women At Risk is proud to welcome two new members to our Board of Directors. We are confident their professional backgrounds, personal experiences, and dedication to WAR's mission will greatly enhance the work we do.

Reneé Brown is the WNBA Chief of Basketball Operations and Player Relations. Prior to holding her current position, Reneé served as WNBA Vice President, Senior Director, and Director of Player Personnel. Reneé also chaired the USA Basketball Women's Senior National Team Selection Committee and served on the Executive Committee for USA Basketball for two consecutive quadrants, from 2000 to 2004, and again from 2004 to 2008. The U.S. Women's Senior National Team won Olympic gold medals at the conclusion of each of Reneé's tenures, in both 2004 and 2008. She also served as Vice President for the Senior Women's Programs from 2000 to 2004. During the 1995-96 season, Reneé served as an assistant coach to Tara VanDerveer for the gold medal-winning USA

Basketball Women's National Team in Colorado Springs. Reneé has served as an assistant coach for women's basketball teams at the University of Kansas, Stanford University and San Jose State University. She holds a bachelor's degree and master's degree in education, both from UNLV.

Jared Weiss is the founder and president of Star Power, LLC, a company which represents brands for their sports and entertainment initiatives. Prior to founding Star Power in January of 2008, Jared worked for Steiner Sports Marketing from 1992-2007. He served as the President of Steiner from 2002-2007, where he worked with, represented, and marketed many athletes including Mark Messier, Derek Jeter, Henrik Lundqvist, and others. He graduated from the University of Hartford with a BS in communications. Jared lives in Westchester with his wife and two young sons. His mother's battle with breast cancer, and her subsequent survival, inspired him to become involved with Women At Risk.



Important Update!

Don't miss out on WAR's Fall Newsletter! In an effort to reduce printing expenses, Women At Risk's Fall 2009 Newsletter will be an E-newsletter. We will not be mailing a hard copy. Please send your e-mail address to ctrotter@womenatrisknyc.org or call (212) 305-5917 ASAP to make sure you receive WAR's next Newsletter!

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