



Y-ME National Breast Cancer Organization
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24-hour Y-ME National Breast Cancer Hotline

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*Interpreters available in 150 languages

www.y-me.org



There's Still Time to Send a Y-ME Holiday Card

The new Y-ME Greeting Card Shop is now available at www.y-me.org! Family and friends can purchase a personalized, quality, ink-on-paper greeting card right on the Y-ME Web site. Simply select from a wide range of card designs, then type in a personal message and even upload the perfect digital photo or handwritten note. Custom cards will then be professionally printed for only \$3.25. The

customized card is then packaged in a quality envelope and elegantly addressed and stamped for First-Class Mail. The best news is that not only will the card be a Y-ME sponsored card with logo, organization information and Hotline number, but \$1 of each card purchase will benefit Y-ME's programs and services. In addition to holiday cards, all-occasion greeting cards are now available year 'round. 

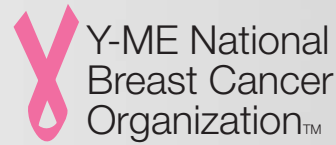
The mission of Y-ME National Breast Cancer Organization is to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.

mission





Lifeline



A Quarterly Publication of Y-ME National Breast Cancer Organization

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Guidance for Family and Friends of Breast Cancer Survivors

Can you be a cancer survivor without actually having been diagnosed with cancer? Please read on because this is not a riddle; this is the experience of every individual who has ever supported a loved one through cancer. According to the American Cancer Society, more than 217,000 people are expected to be diagnosed with breast cancer this year. Family members and friends will be at their side, helping them navigate the maze of details that accompany a cancer diagnosis—finding an oncologist, understanding treatment options, furnishing health updates to others and managing side effects. When you support a loved one through cancer, you will likely experience a conflicting range of emotions, including disbelief, denial, anger, relief, worry and even guilt.

You Are Not Alone

According to the American Cancer Society, three out of every four American families will have at least one family member diagnosed with cancer. Fears of mortality, changing family roles, having your own needs met, and uncertainty about saying the right words at the right time can easily surface when someone you love is diagnosed.

“There is certainly a feeling of inadequacy,” states Alison Mayer Sachs, an oncology social worker and the coordinator of cancer

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A Candid Conversation on Sexuality, Intimacy and Fertility

Some of you may have heard of Ruth Handler who created “Nearly Me,” a company that produces and distributes breast replacements and post-mastectomy swimwear, after she was diagnosed with breast cancer and underwent a mastectomy. Her efforts helped pave the way for a deeper understanding of the breast cancer experience. What you may not know is that Ruth was also the legendary entrepreneur who invented the Barbie Doll in 1959. For decades, Barbie, the ubiquitous, statuesque icon of early girlhood, mirrored the social and political landscape of changing times; often, her very existence invited controversy. Nevertheless, few will deny that Barbie still reigns as queen on every young girl’s wish list and, for many of us, she was our first encounter with body image and sexuality.

Our views about sexuality are extremely complex, and they incorporate a wide range of physical, psychological, social, religious and cultural perspectives. Despite our diverse characteristics, sexuality plays an important role in everyday life; especially for women. From early on, we are bombarded with overt and subliminal messages about what is physically attractive, how we should behave, what we should wear, and how we should look. Although concerns about sexuality, physical intimacy and fertility may not take center stage when you are first diagnosed with breast cancer—whether you are single or engaged in an intimate relationship—you may find yourself dealing with these issues at some point during your cancer experience.

Sexuality and Body Image

While current research suggests that approximately 50 percent of women who have been treated for breast cancer experience long-term sexual dysfunction, other studies indicate that many women who undergo breast conservation procedures or mastectomy do not experience persistent sexual difficulties. In fact, many researchers and healthcare professionals concur that the primary predictors of good sexual health after breast cancer may have more to do with a positive body image and satisfaction with sex and relationships prior to the cancer diagnosis.

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message from margaret



Dear Readers,

It is with great sorrow that I announce the recent passing of Ann Marcou, Y-ME's co-founder. Although it is sad that we have lost such a remarkable woman, we are happy that Ann's legacy lives on every day in the mission and spirit of Y-ME.

When I began working at Y-ME, I learned that Y-ME co-founder Mimi Kaplan had passed away in the early 1980s, but that Ann was still living in the Chicagoland area. I was excited to meet her, and one of my greatest joys was getting to know Ann during the last year and a half. Ann's strength and vision that resulted in the establishment of Y-ME and the 24-hour Y-ME National Breast Cancer Hotline never left her over the years, and she still remains an inspiration to me as I lead the organization.

In the next issue of *Lifeline*, we will celebrate the life of Ann Marcou with a tribute that will highlight her accomplishments and emphasize the enormous impact she had on people touched by breast cancer across the country. If you would like to learn more about Ann in the meantime, or would like to make a tribute gift in her memory, visit our Web site at www.y-me.org. We could easily dedicate all of *Lifeline's* content to Ann Marcou, but we know that she would want us to continue with the mission of Y-ME and focus on the information and support needed by those touched by breast cancer.

To that end, we bring you an issue that focuses on intimacy and the breast cancer experience. From the cover story to *Ask the Doctor*, we're addressing the subject with information and practical tips for coping with problems that arise in communication, intimacy and fertility. Family and friends, as well as patients, can benefit from the articles.

Although fewer men are diagnosed with the disease than women each year—nearly 1,500 vs. nearly 216,000—male breast cancer is a topic that should be discussed. On page 12, you can read about the differences and similarities between diagnoses in men and women, and look at an update on Senator Edward Brooke, whom we featured last year.

The holiday season, for many, is a time to gather with loved ones and remember the aspects of our lives for which we are thankful. Personally, I am grateful that I became friends with Ann Marcou and had the opportunity to experience her mentoring presence. Without Ann, and her friend Mimi, we would not be able to offer the incredible free-of-charge programs and services that we do today. Our community of breast cancer survivors and those who love them started 26 years ago with 13 women meeting over coffee, and has expanded to include thousands touched by the disease. With this kind of network, truly no one has to face breast cancer alone.

Sincerely,

A handwritten signature in black ink that reads "Margaret C. Kirk". The signature is written in a cursive, flowing style.

Margaret C. Kirk
Y-ME CEO

A Candid Conversation on Sexuality, Intimacy and Fertility

Body image concerns for all breast cancer survivors are prevalent, though several findings suggest that women who undergo breast conservation surgery have more positive feelings about their bodies and appearing in the nude. Other studies indicate that women who had mastectomies did not demonstrate any significant problems with sexual and emotional adjustment. What is important to emphasize is that every breast cancer experience is unique, and can have a distressing impact on you and your feelings of attractiveness and desirability, even if you don't display the physical manifestations associated with cancer and ensuing therapies.

Why and Where Did My Libido Go?

Treatments for breast cancer—including chemotherapy and radiotherapy—and side effects like nausea, fatigue, pain and hair loss may affect your body image, lower your sex drive or cause discomfort during sex. Moreover, chemotherapy can propel some women into early menopause, generating the sudden onset of symptoms that are supposed to appear gradually during a transitional phase of the life cycle.

“The most difficult thing for me was that I was completely not prepared for being kicked into menopause,” recalls Denise, a 49-year-old breast cancer survivor who was diagnosed with invasive breast cancer last year. “I was not prepared for menopause, for the hot flashes—which I thought were a side effect of chemo—and for vaginal dryness. My libido totally decreased.”

In addition, if you are receiving hormone replacement therapy (HRT) to alleviate menopausal symptoms, you usually need to stop HRT after a breast cancer diagnosis, particularly if your cancer is sensitive to estrogen and/or progesterone. Linda, a 59-year-old breast cancer survivor, started taking hormones after she underwent a hysterectomy in her mid-40s. She was unable to continue hormone therapy after she was diagnosed with breast cancer and it did influence her sex drive. Linda is an active volunteer with Y-ME San Diego and ABCAP, a breast cancer advocacy organization in Alaska. To this day, her outreach efforts include teaching women to become self-advocates and encouraging the medical community to develop sexual enhancement alternatives for women for whom hormone replacement therapy is no longer a viable option.

Treatment protocols for breast cancer also utilize hormonal therapies. One of the most common is tamoxifen, a selective estrogen receptor modulator (SERM), which inhibits estrogen-stimulated cancer cell growth and may prevent abnormal growth in healthy cells. Side effects of tamoxifen treatment, which can involve intense hot flashes and night

sweats, often mimic those of menopausal symptoms. The effect of tamoxifen on sexual functioning remains inconclusive though recent studies conducted by Mortimer and colleagues suggests that tamoxifen, whether taken alone or concurrently with chemotherapy, may negatively impact sexual intercourse. Again, it's important to reiterate that each experience is unique and many women can and do regain improved sexual functioning anywhere from six months to one year after breast cancer treatment.

Medicines given to treat various symptoms can also lead to a loss of interest in sex, as well as difficulties in attaining an orgasm. “Some of the medicine used to treat depression greatly affect sexual function, as do pain medications,” says Judith Paice, Ph.D., R.N., a pain management specialist with Northwestern University Medical School in Chicago. “The opioids can cause suppression of testosterone and other hormones which then causes problems with sexual function—all of these work hand in hand.” Dr. Paice judiciously includes questions about physical intimacy in her assessment process and notes that people are appreciative when she brings it up, but she also states that many health care professionals are hesitant to broach the subject for fear of offending, upsetting or embarrassing their patients.

The Emotional Rollercoaster

A breast cancer diagnosis is often accompanied by an avalanche of emotions that can change from moment to moment. Fear may certainly be one of them—anxiety concerning the prognosis, apprehension about pain and treatment and concerns about family, friends and the future. You and your partner may also confront immediate or subsequent worries about body image and sexual relations. A series of questions will likely surface for both of you—*Will treatment disfigure me? How will I cope with losing my breast from surgery or my hair from chemo? Will I still want sex and will I still be sexually attractive? Will she still want sex? Can I touch her? Will I hurt her more if she's already in pain—* before and after treatment. All too often assumptions are made and direct communication avoided when it is most needed to clarify respective feelings and needs.

If you are single and dating, you may be even more keenly aware of subsequent alterations in your appearance and how it will affect potential relationships.

Sharon was 30 years old when she was diagnosed with a very serious and rare form of inflammatory breast cancer. Her first marriage ended after her diagnosis and she was suddenly confronted with being single *and* coping with aggressive cancer treatments. “I did date and I found that it

A Candid Conversation on Sexuality, Intimacy and Fertility

was very challenging,” Sharon recalls. “Not only was I a breast cancer survivor, but I still had cancer, was stage four and I had to tell [people] that I had a mastectomy and stage four cancer.” Sharon met her future husband on a blind date and immediately felt a connection to him. “I told him that I had breast cancer on our third date...I was prepared for it to end my relationship with him because, in the past, it did.” However, the relationship did not end; they were engaged last Christmas, subsequently married, and Sharon says that it has been an incredible experience to have someone in her life who loves her unconditionally. She has also created a series of “intimacy” seminars to help other women cope with the emotional and practical concerns of breast cancer and intimacy.

Resetting the Biological Clock

If you are a woman of childbearing age with breast cancer, you may be concerned about your ability to conceive. Chemotherapy and radiation treatment may cause damage to the ovaries and can result in menstrual irregularities, temporary or permanent infertility. Nonetheless, many women do regain reproductive capacity after treatment has been completed, although research has suggested that older women have a higher risk of developing complete ovarian failure.

When Darlene, a Y-ME Hotline peer counselor, was diagnosed with invasive ductal carcinoma at 32 years of age, her son was 18 months old and she knew she wanted more children. She did experience irregular menstrual cycles during and after her chemotherapy regimen. “Throughout it all, I had a dream in my heart that I wanted to have another child,” Darlene recalls. “Even during treatment when I was possibly my sickest.” Although her periods returned to normal within six months of treatment, she and her husband waited, concerned about recurrence. Four years after diagnosis, encouraging words from her oncologist urging her to “live her life” spurred her to action and she got pregnant with her second son within a year.

Furthermore, the good news is that fertility preservation options do exist for breast cancer survivors and can be initiated prior to the start of chemotherapy. In addition to the widely accepted medical practice of embryo freezing, experimental methods include egg and ovarian tissue freezing, as well as the promising development of alternative hormone stimulation protocols utilizing tamoxifen and aromatase inhibitors to minimize estrogen levels.

Lindsay Nohr Beck is founder and executive director of Fertile Hope, a national nonprofit organization dedicated to providing the latest research and information on fertility and preservation options for cancer survivors and their families. She stresses that there is a lot people can do to preserve fertility.

“Many people think that if they didn’t bank eggs or freeze embryos, they’ve missed the boat, especially if they experience premature menopause,” she says. “But there are a lot of options before, during and after treatment.” Lindsay also draws a clear distinction between infertility and premature ovarian failure—damage sustained to eggs and ovaries can still cause difficulty conceiving even if your menstrual flow resumes and appears normal years later. Thus, immediate and appropriate family planning is important.

Moving Towards Intimacy

As breast cancer survivorship rates continue to increase, many patients, their loved ones and their healthcare teams are focusing on these important quality of life issues. So what can you and your partner do now to adapt to the changes in your body and create an environment where physical and emotional intimacy can flourish?

Les Gallo-Silver, an oncology social worker and director of clinical programs for CancerCare in New York, suggests that partners need to cultivate their listening skills. “You must listen to what is said and what is not said. Sometimes the woman you love with breast cancer is going to want to be alone, leave her alone. Sometimes the woman you love will want to be with you, be with her. If you don’t know which time, ask.” He also offers some very practical tips for women: seek a cosmetologist evaluation to help you adjust your makeup, if you wear it, to changes in skin texture and hair loss; take control of your hair loss—if you can’t bear to have a short haircut or hair removed suddenly, shop for a wig before your hair is gone to match texture and color; throw away your long T-shirt and wear something colorful—something that makes you feel beautiful—to bed; and keep a personal diary or journal to help you begin to articulate your inner feelings.

Dr. Paice also stresses the importance of communication. If you can’t discuss your feelings with your partner, talk to your physician, nurse or seek the assistance of a sex therapist. Many breast cancer survivors find support groups to be an invaluable source of support and shared information. The Y-ME National Hotline (1-800-221-2141) and Men’s/Partner’s Match program also provide a confidential outlet to discuss your feelings about intimacy-related issues. To learn more about the Match program, see page 15.

During or after breast cancer, intimacy may take on an entirely new dimension. Learn to touch, hold hands, experiment, be together and simply try to relax. You may rediscover yourself and romance and sex in very different and fulfilling ways. ✧

Q

Is it safe to become pregnant after completing treatment for breast cancer?

A For women who are planning on having a child but have yet to give birth, a breast cancer diagnosis can raise a number of questions. Among them are, “Will the hormones of pregnancy increase the risk of my cancer coming back?” and, “How long must I wait after completing treatment to have a child?”

According to breast cancer surgeon Jeanne Petrek, M.D., it is important for a woman to allow herself enough time to regain the nutritional and metabolic health she needs to meet the demands of a pregnancy. Dr. Petrek, who serves as director of the Evelyn H. Lauder Breast Cancer Center at Memorial Sloan-Kettering Cancer Center, says that a key consideration is making sure that any aggressive disease that may have been underestimated does not come back. Although there is no guarantee that the patient will remain cancer free, this is why doctors suggest waiting two or more years before becoming pregnant. It would be even better to wait five years, she says, if indeed a woman has that kind of time available. Often she does not.

Dr. Petrek suggests that a woman consider those factors that govern her long-term health when considering a pregnancy. For instance, what was the stage of her cancer when it was diagnosed? Were her lymph nodes free of cancer at that time? What is her prognosis now?

Another concern is that doctors don’t know exactly whether there is anything unique about one breast cancer versus another. Dr. Petrek explains that a woman may have had chemotherapy, but maybe the treatment merely damaged the cancer cells. Could they, perhaps, be dormant and come to grow again from the pregnancy? What is unknown at this time is how to identify women in whom pregnancy is safe and women in whom it is not safe. “At present, there is no way to know,” she says.

Dr. Petrek says that these concerns are theoretical because many pre-menopausal women—perhaps the large majority—do go on to safely become pregnant after breast cancer. The problem is that no long-term prospective studies have been completed at this time to provide solid answers for women. All past studies are retrospective and, she believes, scientifically weak. She has little confidence in these findings.

Meanwhile, a study led by epidemiologist Beth Mueller, Ph.D., a member of the Public Health Sciences Division at the Fred Hutchinson Cancer Research Center, and published in the journal *Cancer* in 2003 (Vol. 98, No. 6; pages 1131-1140), appears encouraging.

This study retrospectively followed 438 women in Seattle, Detroit and Los Angeles. The women were younger than 45 years of age with primary invasive breast cancer, who gave birth after diagnosis. In addition, 2,775 comparison women,

matched on the basis of a number of criteria, were identified with breast cancer—but without births after diagnosis.

“The results of this study may provide some reassurance to young women with breast carcinoma in that subsequent childbearing is unlikely to increase their risk of dying,” says Dr. Mueller. “I can assure women that we conducted the study as carefully as possible, using the tools and data available at that time.

“It is reassuring that we did not observe an increased risk of mortality and that our results appear to be consistent with those from many other studies—including some studies using other designs,” continued Dr. Mueller.

Although Dr. Mueller did not observe an increased risk for women who had births 10 months or more after their breast cancer diagnosis, relative to the control group who did not have children since diagnosis, she cautions readers to be careful not to over-interpret the results. She says that their finding of a decreased risk of dying may be due to what she calls a “healthy woman bias.” She explains that women who are healthier, or have a better prognosis, may be more likely to attempt pregnancies after diagnosis.

“Although we attempted to control for this, by using the data available about the severity of the women’s disease at diagnosis, we had limited knowledge about their health status afterwards,” she says.

Both researchers look forward to large population-based prospective studies in the years ahead, which would provide the best assessment of the question of an individual woman’s safety to proceed with pregnancy. Dr. Petrek, in fact, is currently recruiting women for two such trials to shed light on these and other quality-of-life questions, but her studies are just beginning, and her findings a long way off.

In the meantime, Dr. Petrek suggests that a woman who wishes to have a child confer with her family as well as with her health care providers—particularly a medical oncologist and a high-risk obstetrician. Dr. Mueller agrees and adds that each woman has a different situation regarding her own health status, social support and desire for offspring.

“One’s decision may incorporate several factors including family cancer history, the presence of a supportive family and/or partner, and whether or not she already has children,” she says. “Ultimately, every woman faced with this scenario makes a personal decision based on her own situation.”

“If there is any question,” Dr. Petrek adds, “adoption is a great way to go.”

profiles in encouragement

pam johnson

This is the first installment of a new column that will spotlight a different Y-ME Hotline peer counselor in each issue. We would like to share with you a glimpse into the lives of the many wonderful survivors who staff our 24-hour Hotline as we acknowledge their commitment to ensuring that no one faces breast cancer alone.

Pam Johnson is our newest Hotline peer counselor from Tennessee. Diagnosed at age 47, Pam learned that she had ductal carcinoma in situ (DCIS), yet the mass lacked clean margins. Opting for a mastectomy with the TRAM flap reconstruction, Pam met this challenge with courage and soon after began rebuilding her life.

Pam first entered the world of outreach in the breast cancer community by fitting mastectomy bras for



breast cancer patients at a medical establishment. Looking to explore other opportunities, she interviewed for an administrative job in a doctor's office. During the course of this interview, however, Pam discovered that her heart lay with helping breast cancer patients directly and not through administrative work. As the interviewer and Pam discussed this realization, the interviewer referred Pam to Y-ME National Breast Cancer Organization. This was truly Y-ME's gain, in addition to Pam's.

When Pam is not answering calls on the Hotline, she finds enjoyment in activities such as taking exercise classes to de-stress, going to the movies, shopping and bicycling with her husband. She has been married fourteen years and has two children and three grandchildren. When asked about her work on the Hotline, Pam states that she gets most out of hearing, "I am so glad I talked to you!"^Y

Interested in becoming a peer counselor? Call 312-294-8514 to find out how you can join us.

Who Am I?

I am a woman with intelligence, grace and dignity.
I am a woman of compassion, strength and sentiment.
I am a woman with cancer and forever will be seen that way.

Cancer cannot remove my intelligence,
It can strip away my dignity and grace if I let it.
It has made me more determined to live.

I am now a stronger, smarter woman who will fight this disease.
I fight for myself and others.

I am me and I love who I was, am and will be in spite of this disease.

Pamela K. Embury
©9/23/2004

Continued from cover

Guidance for Family and Friends of Breast Cancer Survivors

support services at the Eisenhower Lucy Curci Cancer Center in Rancho Mirage, California. “There is also the feeling that there are words out there, and if they only knew what the ‘magic words’ were, they could make the patient feel better. Caregivers need to give themselves permission to not know the right answers, to just listen.”

There is also a profound feeling of helplessness, of not knowing what to do as you struggle to comprehend your own feelings and, at the same time, provide reassurance and support.

If a woman has undergone a mastectomy, the trauma of losing a breast can be paramount. It is very important for both partners to acknowledge and support each other through the loss and understand that a grieving process is healthy and normal.

As time and treatment progress, many caregivers also function as a vital intermediary between family and friends. Leonard Thomas has supported his wife, Toya, through two bouts of breast cancer. They both praise their wonderful network of supporters who have volunteered time and assistance to help Toya deal with her chemo regimen. Conversely, Leonard has had to frequently monitor phone calls—at times turning the ringer off—so that both he and Toya can get some much-needed respite from well-intentioned callers.

As cancer care continues to transition to an outpatient environment, there is also greater home nursing responsibility placed on family and friends. The burden of care can take a significant and unexpected toll on caregivers.

California resident Roxanne’s mother-in-law has metastatic breast cancer and now lives with her and her husband. Daily activities consist of managing her diet and medication dosage; helping her cope with side effects, which include lymphedema and pain; and ferrying her to and from frequent doctors visits.

“We are gratified to be able to do this for her at this stage of her life,” says Roxanne, “but we honestly had no idea of the level of stress that it would introduce into our lives.” They are currently exploring options to develop an extended support network.

Coping as Companion and Caregiver

What can you do to help yourself and your loved one deal with cancer? Here are some tips to help you optimally manage the cancer experience:

Keep the lines of communication open. Actively listen and be mindful of what you say. In particular, Sachs advises people not to tell a cancer survivor “I know how you feel,” as they likely *don’t* know how someone feels unless they have had that particular cancer. She also suggests that caregivers be more directive when asking someone what they need, such as rephrasing “What can I do for you?” to “What are the things you hate doing most?” and offering to take on an unpopular task.

Accompany your family member or friend to all medical appointments. You will become more knowledgeable and you can also serve as an important conduit for information. Take notes, tape-record consultations, help your companion prepare questions and seek out treatment options for her diagnosis.

Be proactive and educate yourself. The Thomas’s

Continued on page 13



ShareRing Network

Looking for an interactive way to learn more about breast cancer? ShareRing Network is for you!

This **free** monthly one-hour teleconference features a breast cancer related presentation by a medical professional. A question and answer session follows, and then participants are divided into small groups. Volunteers moderate the telephone discussion.

Teleconference Schedule

January 19, 2005

7:00 p.m.-8:00 p.m. CST

Speaker: Lynne Staley, writer and educator who specializes in grief and loss on:

Topic: Grieving After Breast Cancer

February 16, 2005

7:00 p.m.-8:00 p.m. CST

TBA

March 16, 2005

7:00 p.m.-8:00 p.m. CST

Speaker: Lynn M. Phillips, C.L.T., C.M.T., certified lymphedema therapist, Equilibrium Lymphatic Health Center

Topic: Prevention and Treatment of Lymphedema

TO REGISTER:

Visit www.y-me.org or call 1-800-221-2141 to sign up.

Pre-registration is required and dial-in instructions will be given at that time.

Questions may be directed to sharering@y-me.org or 1-800-221-2141.

ShareRing Network transcriptions are now available! Visit www.y-me.org today.

Breast Cancer Advocates Get BCRP Off the Ground and Keep It Running Smoothly

What began as a program to fund research on breast cancer screening and diagnosis for military personnel and family members has developed into the second largest financial supporter of breast cancer research in the world, largely because of the efforts of people like Rosemary Locke.

“The strategy and leadership for the \$210 million, the Institute of Medicine recommendations, and the Department of Defense (DoD) Breast Cancer Research Program (BCRP) belong to the National Breast Cancer Coalition and the advocates from organizations who made it happen. Y-ME played a crucial role in identifying the DoD funding source, but the combined efforts of the coalition resulted in the successful program we have today.” *Rosemary Locke*

The funding of research targeting a specific type of cancer was uncommon in the early 1990s when Locke, a breast cancer survivor and Y-ME activist, along with a team of advocates led by the National Breast Cancer Coalition (NBCC), lobbied aggressively to increase appropriations for the newly founded Department of Defense Breast Cancer Research Program (DoD BCRP). Y-ME and other advocacy organizations supported the grassroots movement to convince Congress of the necessity of such funding, and their hard work soon paid off (see box on page 9).

“In 1992, the proposed DoD budget for breast cancer research was \$25 million, and nobody seemed to know how the money was going to be allocated,” Locke says. *“In the space of a short summer of lobbying that year, the funds increased to \$210 million, and we were able to move to the next step—focusing attention on the administration of the program and the management of the money.”*

Not long after the advocates set the wheels in motion, a National Academy of Sciences Institute of Medicine committee recommended an annual investment strategy and a two-step process for the review of research proposals, plans that were quickly adopted by BCRP administrators.

The implemented review process identifies and awards proposals that focus on innovative breast cancer

research, the translation of laboratory science into clinical practice, and training (see box on page 9). All proposals are evaluated first by a scientific peer review panel and then by an integration panel that conducts a programmatic review. Both panels are made up of consumer advocates (breast cancer survivors or their family members) and scientists (researchers and medical doctors).

Margaret Volpe, a breast cancer survivor and board member at Y-ME National Capital Area, served as a consumer advocate on a scientific peer review panel for two years. *“During the review process, consumers usually concentrate on a lay abstract and statement of the work, whereas scientists focus on the technical data in the proposal. The scientists listen carefully to our comments, and most of them really appreciate what we have to say. For many, it is an eye-opening experience because it is the first time they worked with advocates and heard how a patient might react to the proposed research,”* she says.

For Volpe, reading the entire proposal, including the researcher’s resume and list of published articles, was

“Many Y-ME volunteers and staff—those who are breast cancer survivors or patients—have served as peer or programmatic reviewers over the years. Additionally, many of us have actively advocated with Congress to include the funding in the Defense Appropriations bill. This advocacy is not limited to the National Breast Cancer Coalition’s ‘Lobby Day,’ but rather, many of us have called members of both the House and Senate to urge signing on to the ‘Dear Colleague’ letter, which is circulated annually to encourage that funding be included in the Appropriations bill.” *Margaret Volpe*

critical to the process. *“I wanted to award someone because of a commitment to breast cancer research and not for trying to get research funds. I felt it was especially important to support pre- and postdoctoral fellows who are truly interested in breast cancer research,”* she says. *“Scarce resources should be spent on research that most benefits breast cancer patients, including prevention, detection, treatment and follow up, and to improve quality of life.”*

Volpe explains that consumer advocates participating in scientific peer review are typically asked to evaluate about 15 proposals. Numerical ratings and other comments, she says, are forwarded to the integration panel for programmatic review.


Breast cancer survivor and Y-ME National Board member Karin Noss has a long history of review panel participation as a consumer advocate. After serving on six scientific peer review panels, she became a programmatic reviewer and has served on five integration panels since 2000.

"As an Air Force officer with breast cancer, I was surprised to learn that the DoD funded breast cancer research, but when I heard about it, I decided I wanted to be involved. Friends in Y-ME and at DoD helped me to get accepted as a peer reviewer for the first time in 1997. Since that first intimidating review, I have come to appreciate the commitment of the clinicians and researchers and have been able to pass on what they have taught me to those who we help through Y-ME." *Karin Noss*

Programmatic reviewers, Noss says, determine whether the funding recommendations of the scientific peer reviewers are appropriately balanced and focused on the most pressing needs in breast cancer research. "From the advocate perspective, we try to question recommendations that may be scientifically interesting, but that may not have much overall impact on those of us who are dying of breast cancer. The goal is to look for innovative ideas that are 'high risk, but potentially high gain.' We challenge the scientists to think differently and they challenge us," she says.

At the end of programmatic review, the integration panel votes on the recommendations, Noss says, and their comments proceed up the Army chain of command for consideration. Final approval of funding is made by the Commanding General of the U.S. Army Medical Research and Materiel Command (USAMRMC). An administrative process, which includes award notification and contractual negotiation, then begins.

Colonel Kenneth A. Bertram, M.D., Ph.D., director of the Congressionally Directed Medical Research Program, says of the review process, "Through this unique public-private partnership with the consumer advocacy and scientific communities, the DoD serves as a successful vehicle for responsible change in science."

Between 1992 and 2003, the DoD appropriated nearly \$1.66 billion for the funding of breast cancer research, and more than 4,000 awards have been supported. 

Looking to get involved in Y-ME advocacy efforts? E-mail us at advocacy@y-me.org to find out what you can do.

Major Breast Cancer Research Program Award Categories:

Awards for innovation: Concept, Idea, Exploration, and Innovator

Awards for the translation of laboratory science into clinical practice: Clinical Translational Research and Breast Cancer Center of Excellence

Awards for training in breast cancer research: Breast Cancer Predoctoral and Postdoctoral Traineeships and Historically Black Colleges and Universities/Minority Institutions Partnership Training

Project LEAD[®] Training

The training course is a four-day program that provides breast cancer advocates with the basic knowledge and background to influence research and public policy processes in a range of forums. There is no charge for the course apart from travel and hotel accommodations. Most meals are provided. Scholarships are available for those in serious financial need.

LOCATION: Minneapolis, MN
DATE: August 3-7, 2005
APPLICATION DEADLINE: June 3, 2005

Visit www.stopbreastcancer.org to request applications and scholarship forms.

The training is an excellent way for breast cancer advocates to hone their existing skills and gain new expertise.

If you'd like to speak with a Project LEAD[®] graduate, call the 24-hour Y-ME National Breast Cancer Hotline at 1-800-221-2141 between 9 a.m. and 5 p.m. on weekdays.

on the side: depression

The holiday season is joyous for most people, but for breast cancer patients, along with their friends and families, it may be a particularly distressing time. Holidays, and other important dates, are “markers” of the future and patients may be understandably fearful of the future. Such markers underscore how different life has become for these women. As they sit with their families around the dinner table, women may ask themselves, “Will I be here next year?” The mother who typically prepares the family gathering, but this year has no strength to do so, may feel saddened that her role has been so altered by her disease. Fortunately, these are transient sentiments. While the holidays can be an upsetting time, once they pass, the heightened anxiety and depression often do, too.

Anxiety and depression are common in all cancer patients; roughly one quarter develops major depression during the course of their illness. One study, reported at this year’s ASCO conference, found that anxiety and depression were more severe in breast cancer patients relative to patients with other types of cancer. However, Roz Kleban, C.S.W., senior social worker at Memorial Sloan Kettering Cancer Center, is skeptical. In her experience, only a tiny group of breast cancer patients suffers from true, clinical depression, where people are incapable of experiencing joy, feel helpless and hopeless, stop eating and stop sleeping. Most often, these women have advanced disease.

A hallmark sign of depression is a sense of isolation in which patients refuse to leave home and stop associating with friends and family. Sometimes, a diagnosis of cancer comes with feelings of shame and/or guilt and this causes a patient to hide from people, even people they love.

Interestingly, Ms. Kleban sees this more amongst senior patients. “It’s an older view of what cancer means.” Younger women tend to view cancer, as it ought to be, she added, as a diagnosis perhaps to be feared, but not to cause shame.

“For the most part,” Ms. Kleban continued, “We see a great deal of sadness in patients, but I wouldn’t raise it to a level of true depression. What I see most is tremendous anxiety—the feeling of being out of control which is what this illness does to people.”

What can patients do to manage their anxiety or depression? Most importantly, patients must recognize and accept what they’re feeling. Once they do so, treatment options include:

- Anti-depressant drugs, if depression is diagnosed
- Professional Counseling
- Support Groups
- Talk to someone who’s been there — call Y-ME at 1-800-221-2141

It is quite common to give patients anti-anxiety medications, particularly the SSRIs (selective serotonin reuptake inhibitors), which can be enormously helpful. If an oncologist has not prescribed such a drug, a patient should not hesitate to request one.

Yet, women tend to be reluctant to take anti-depressant agents because they feel that they can or should pull themselves together on their own. Some women view depression as a comment on their character as opposed to a comment on what’s going on in their bodies, Ms. Kleban pointed out, but this is a mistake.

Support groups are wonderful ways to help patients lessen the feelings of loneliness and isolation. Again, it is older patients who are less amenable to counseling and support groups and drawing these women in can be a challenge. If you have a question about depression, want to talk or are interested in finding a support group, call Y-ME at 1-800-221-2141.

Over the years, the tenor of the public has helped change attitudes toward cancer and that has certainly benefited patients. Years ago, breast cancer patients received more pity than support and this only reinforced their feelings of dread. “No patient, young or old, wants pity,” Ms. Kleban stressed, “they need positive support.” And these days, the community at large is much more likely to provide those supports. ❧

**Roz Kleban is the recent recipient of the Susan G. Komen Foundation Professor of Survivorship Award for her commitment to furthering the understanding of the complex issues of long-term survivorship of breast cancer.*

depression

The Verdict on Soy: Still Deliberating...

When it comes to measuring the beneficial effects of soy intake in the lives of breast cancer patients, the jury remains out. Both sides of the debate do find common ground in acknowledging the need for more human studies before concluding that any hypothesis regarding soy holds credence. At this time, it's best to use a cautious approach when incorporating soy into your diet. "I think it's very important that women don't rush and join the bandwagon, until they look at all the evidence. Research is very important; that's why I promote research in this area," explains Electra Paskett, Ph.D., associate director for population sciences, Ohio State University Comprehensive Cancer Center.

According to Kaayla T. Daniel, in the May/June 2004 issue of *Mothering* magazine, "The soy industry's own figures show that soy consumption in China, Indonesia, Korea, Japan and Taiwan ranges from 9.3 to 36 grams per day. That's grams of soy food, not grams of soy protein alone."

Soy's ability to lower levels of triglyceride, a fatty acid, may result in the lowering of cholesterol which strengthens heart health and reduces coronary disease. The soluble fiber contained in soybeans interferes with the absorption of cholesterol. Soy has also been shown to deliver essential nutrients to the body such as calcium, zinc, iron, phosphorus, magnesium and the B vitamins. When it replaces animal proteins in the body, soy may assist the body in retaining calcium, which animal proteins cause to be leached from the bones and excreted by the body. Therefore, soy protein may guard against bone loss.

Soy contains a powerful phytoestrogen called isoflavones, or isoflavonoids, which bear estrogen-like properties and actions in the human body. These are the components of soy that give pause to people concerned about breast cancer.

Reduction in menopausal symptoms, such as hot flashes, is also attributed to soy. Providing a complete protein, which is rare for a food not derived from animals, soy may indeed promote certain aspects of health in human beings.

In considering the effects of soy in women as it relates to breast cancer, it is critical to understand that longer exposure

to estrogen throughout a woman's lifetime, including her years of menstruation, increases her chances of developing breast cancer. Taking this conclusion a step further to the realm of soy in a woman's diet, it is necessary to note that soybeans and soy foods are rich in phytoestrogens, or plant estrogens. Although they are natural sources of estrogen, they are still estrogen. Soy contains a powerful phytoestrogen called isoflavones, or isoflavonoids, which bear estrogen-like properties and actions in the human body. These are the components of soy that give pause to people concerned about breast cancer.

According to Mark Messina, Ph.D., in his article entitled, "Should Women with Breast Cancer Eat Soy?" he states that, "... early on it was established that at low concentrations, genistein, the main isoflavone in soybeans, actually stimulates the growth of estrogen-receptor positive (ER+) breast cancer cells in vitro. The growth of ER+ breast cancer cells is stimulated by estrogen."

Nancy Oliveira, a medical writer for *CancerSource.com*, wrote, "The human hormone estrogen has both beneficial and harmful effects in the body. In women, estrogen protects the bones and heart and is vital for childbearing. However, years of exposure to high levels of estrogen may raise the risk for breast and uterine tumors." Oliveira goes on to explain with greater detail, "Certain cells, especially in the breast and uterus, are sensitive to estrogen receptors that interact with the hormone. Estrogen stimulates cells in these areas to multiply, which can increase the risk for tumors."

Other researchers and physicians hold an overabundance of soy in the diet of westerners accountable for a whole host of other diseases, including thyroid, digestive and reproductive problems. All of these assertions add fuel to the debate over the status of soy. While definitive conclusions are still lacking due to the inadequate pool of studies of soy in human subjects, one thing is clear: physicians often recommend that women with ER+ breast cancers or those on the drug tamoxifen limit their intake, especially of soy supplements, until further research indicates otherwise. ⁸

Confused about soy or another aspect of nutrition?
Call the Y-ME Hotline at 1-800-221-2141 and get the facts
from a trained peer counselor.

Male Breast Cancer: A Rare But Real Disease

“If a man notices a lump or bump in the breast, he will likely dismiss breast cancer as a possible cause,” says William J. Gradishar, M.D., Feinberg School of Medicine and the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL. “Although such an abnormality could be totally benign, it needs to be evaluated, and that goes for men, as well as for women.”

Male breast cancer is rare, accounting for less than 1 percent of all breast carcinomas. In the United States, approximately 1,300 men are diagnosed with breast cancer each year and

Family history also plays a strong role: about 20 percent of men with breast cancer have a close female relative who has had the disease. Diagnosis occurs most often between 60 and 70 years of age.

about 400 men die annually of the disease. But, unlike the observed increase in female breast cancer in the U.S. and Europe since the 1960s, the incidence of male breast cancer has remained stable during the same period.

Gradishar explains that male breast cancer usually presents as a firm painless mass in the subareolar region of the breast. The second most common presentation, he says, is a mass in the upper outer breast quadrant. Other early findings may include nipple retraction; skin dimpling or puckering; redness or scaling of the nipple or breast; and abnormal swelling or lumps in the breast, nipple or chest muscle. Although nipple discharge is not a common presenting feature of male breast cancer, it may represent an underlying malignancy, Gradishar says.

Risk factors for male breast cancer include Klinefelter’s syndrome (a condition that results from the inheritance of an additional X chromosome), estrogen excess, radiation exposure, liver disease and mutations in the *BRCA2* gene. Family history also plays a strong role: about 20 percent of men with breast cancer have a close female relative who has had the disease. Diagnosis occurs most often between 60 and 70 years of age.

Women have long been encouraged to perform self-breast examination and to undergo periodic clinical breast examination. How-to instructional pamphlets and literature stressing the importance of early detection are widely distributed by healthcare groups and breast cancer support organizations, including Y-ME, which provides brochures in English, Spanish, Chinese, Korean and Vietnamese. Many physicians provide waiting room videos to educate women

about breast health and disease, and demonstrations of proper breast-check techniques are commonly offered to women awaiting mammography.

In contrast, specific recommendations, guidelines and instructions for men are noticeably lacking, yet, Gradishar says, routine breast examination is important in this population. “Self examination in men is quickly and easily performed because of the relatively small amount of breast tissue involved, and an internist could perform a clinical exam while the patient is already in the office for a routine annual check-up,” he says. The latter would work well, he quips, because “men are notorious for not going to physicians.”

Gradishar does not recommend screening mammography in men because of the low incidence of the disease, but notes its effectiveness in distinguishing malignancy from gynecomastia (excessive development of the male breast) during differential diagnosis of a breast mass.

If a breast mass is identified, a biopsy will be performed to establish a definitive diagnosis of male breast cancer. Suspicious tissue will be removed using fine-needle aspiration, core biopsy or excisional biopsy and analyzed for cancer cells; hormone receptor status is also usually determined at the time of biopsy.

The most common type of male breast cancer is invasive ductal carcinoma. Other cancers like ductal carcinoma *in situ*, inflammatory breast cancer and Paget’s disease can also occur in men, but are rare. Lobular carcinoma *in situ* is not typically found in men.

Treatment depends on the type and stage of the cancer and may include surgery, radiation, chemotherapy or hormone therapy. Modified radical mastectomy is the standard surgical treatment for localized disease in men, and either axillary node dissection or sentinel node biopsy can be performed to determine whether metastasis has occurred. Because most male breast cancers are estrogen receptor positive, adjuvant hormone therapy using the antiestrogen tamoxifen commonly is prescribed.

Although breast reconstruction following surgery is an option, Gradishar says that it is rarely performed. “With clothes on, many men look exactly the same after mastectomy as they did before it, and scarring is usually minimal. Reconstruction is unnecessary in most cases,” he says.

As in females, outcome in males is influenced by tumor size, extent of metastasis, and lymph node involvement. If treatment begins in the same stage, male breast cancer survival rates are similar to those of females. [Y](#)

Did you know that Y-ME has a Match Program for male patients? Call us at 1-800-221-2141 for more information.

An Update on Senator Brooke



In the summer of 2003, Y-ME brought you the story of former Republican Senator Edward W. Brooke's courageous battle with breast cancer.

Brooke, the first African-American elected to the United States Senate by popular vote and a decorated World War II captain, was diagnosed with breast cancer in September 2002. The Massachusetts senator underwent a right modified radical mastectomy and the removal of his left breast for symmetry and as a precautionary measure. Chemotherapy and radiation were not recommended, but treatment with tamoxifen for five years was prescribed because of his positive estrogen receptor status.

Now, about two years later, Brooke says of his condition, "So far, so good. I've had no indication that there is anything going on in my breasts or other organs and have seen no evidence at all of a return or a spread of the cancer."

Brooke encourages doctors to routinely examine men's breasts and advises men to perform self-examination to enable early detection. "In all my years, I had never really examined my own breasts or had a doctor examine my breasts, because I was thinking that men wouldn't get breast cancer. I think all men should realize that if you have breast tissue—and men do—you can get breast cancer," he says.

The senator acknowledges and appreciates the continued strong support of Y-ME and the Susan G. Komen Breast Cancer Foundation. ♪

Continued from page 7

Guidance for Family and Friends of Breast Cancer Survivors

are long-time Y-ME volunteers and cancer care advocates, and believe that education is key to dispelling myths surrounding cancer. Moreover, being more informed will facilitate constructive discourse with everyone involved. They also suggest initiating a phone and/or e-mail "tree" to streamline communications with family members, friends and colleagues.

Lastly, seek avenues of support. Leonard helped co-found what is now the Y-ME Men's Match Program, which provides support and education to men assisting a loved one through breast cancer. The peer support he received has been invaluable.

"We are all individuals who have uniqueness about our experience and our lives, but talking to somebody who is currently doing, or has done what you're doing, is extremely helpful."

For more information about the Men's Match Program, Partner's Match Program or other Y-ME support resources, contact the 24-hour Y-ME National Y-ME Breast Cancer Hotline at 1-800-221-2141. ♪

Attention Family & Friends

We want to hear from you! Call us at 1-800-221-2141 to share your experiences and get involved with Y-ME.

Still Time to Purchase the Breast Cancer Stamp



At post offices across the country, the breast cancer stamp will be available through December 2005. So far, proceeds from the sale of the stamp have resulted in \$38.7 million for research. The goal is to raise \$50 million—let's make it happen! ♪

Lifeline Is Available Online

If you'd like to read the current issue, or back issues, of *Lifeline* online, you can do so by visiting www.y-me.org and clicking on publications. ♪

Ways You Can Support Y-ME

Support Y-ME with a Year-End Donation

As the end of another year draws near, please remember Y-ME with a year-end contribution. If you have already responded to our recent annual appeal mailing, thank you. If you are still considering a gift, please know how much we appreciate your continued support. Help Y-ME answer the call today by making a gift to support those battling breast cancer today—those who can't wait for tomorrow's cure.

84¢ of every dollar donated to Y-ME goes directly to programs and support services, including the enhanced 24-hour Y-ME National Breast Cancer Hotline and affiliate efforts in local communities.

Honor or Remember a Loved One with a Y-ME Tribute Gift

Use a tribute gift to commemorate a holiday, birthday, wedding or other occasion. Y-ME will notify the person(s) you identify of your generous gift. Visit www.y-me.org and click on Donate Now to make a tribute gift online or call 312-986-8338.

Remember Y-ME

Support Y-ME in the 2005 Combined Federal Campaign, United Way and Workplace Giving Campaigns. Help support our efforts to ensure that no one faces breast cancer alone by designating your contributions to Y-ME (CFC & United Way #2808).

Last Chance For Vehicle Donations?

New legislation will likely be approved in 2005 that will significantly affect the amount donors may claim on their taxes as a charitable deduction for a vehicle donation. If you are thinking about donating a vehicle to Y-ME, the time is now! Just a note that Y-ME only accepts vehicles that are in at least fair condition. Call the Car Program at 1-800-513-6560 to make a vehicle donation benefiting Y-ME.

Y-ME Rated Exceptional by Charity Navigator

Charity Navigator rated Y-ME as Exceptional (☆☆☆☆) — its highest possible rating - in its recent profile of the organization. Charity Navigator is a non-profit that helps donors make intelligent giving decisions by providing information and evaluating the financial health of charities. It strives to help people give with confidence while highlighting truly effective charities. To see the full Y-ME profile or learn more about Charity Navigator, visit our Web site at www.y-me.org.

Receiving duplicate newsletters?

Please let us know! While we make every effort to send only one newsletter to each family, sometimes we send duplicates. If you're receiving more than one copy, call us at 312-986-8338 or e-mail your changes to dtewes@y-me.org.

Y-ME Partners Match Program Lends Peer Support

The Y-ME Partners Match Program on the Hotline reaches beyond breast cancer patients and provides support for their husbands, partners and caretakers. To find just the right people to provide peer support, the Match Program refers them to peer counselors with similar experiences or concerns.

This unique program began in 1994 when the husbands of several breast cancer patients got together to discuss their own experiences and problems as caregivers. A decade ago, there was more reticence about discussing breast cancer and less information on the disease. These men realized that they could help each other during this difficult time and decided to reach out to help other spouses and partners of breast cancer patients.

They realized that there are topics that partners are reluctant to discuss with doctors or significant others. For example, there are questions that come up about care, treatment, day-to-day living and end-of-life issues. They believed that only a man in similar circumstances could understand their feelings, confusion and reluctance to bring up personal and intimate questions about emotions, sex, anxiety about the future, changing relationships and family problems that occur during breast cancer treatment.

Tom Stern, one of the founders of the Men's Match Program, saw firsthand how this service helped others. "Men are often too macho to say 'I don't know what to do,'" says Tom, whose wife Sandee has been a Hotline peer counselor since 1992. "Doctors typically did not address family issues. We tell partners that there is no question too silly or too stupid to ask."

Tom and his group went to Y-ME with the idea to put men in touch with male peer counselors whose situations were similar to their own experiences. As a result, the Match Program was unveiled at the Y-ME Fashion Show in

October of 1994 and immediately began providing much-needed support for partners.

Volunteer Bob Marovich, whose wife died of breast cancer at an early age in 2000, takes calls from men who need to know what to expect as their loved ones approach death. He answers questions about discussing the situation with family, hospice care and how to handle end-of-life issues. Bob started volunteering while his wife was still living. "A guy wants to talk to another guy in these times," he observes. "I enjoy helping and bringing a little hope. I hope my experience can help someone else go through this."

Both Tom and Bob believe that an important part of counseling their peers is making certain that they understand how vital—and often overlooked—it is for the loved ones and caretakers to address their own concerns and make time to take care of themselves, too.

Match peer counselors agree that speaking with other partners and caregivers is uplifting and rewarding because of the support they share. It's also a way of "giving back" for the assistance and information they received when their loved ones were going through treatment.

The Partner's Match Program grew out of the Y-ME Men's Match program. With this initiative, mates of breast cancer patients are matched with a peer counselor who shares factors such as age, ethnicity, type or stage of cancer, and/or family situation. The program serves mates of male or female breast cancer patients, parents or children of patients and others who are supporting a loved one through the disease.✕

Y-ME also facilitates a Match Program for breast cancer patients who wish to speak with someone who has had a similar diagnosis or life experience. For more information about being paired with a match peer counselor or becoming one, please call 312-294-8514 or e-mail kbonen@y-me.org.

Interested in Becoming a Match Peer Counselor?

Y-ME is interested in you! Call us today at 312-294-8514 for more information. Match Program peer counselors should meet the following criteria:

- Have a home telephone and a willingness to counsel those who have had similar experiences.
- Complete a two-day Y-ME peer counselor and certification training.

- Pass an online exam
- "Shadow" a peer counselor to gain Hotline experience.

If you have supported, or are currently supporting, a loved one through breast cancer, we would like to hear from you. By expanding our Match Program we will ensure that no one faces breast cancer alone.

New ED for Y-ME Northeastern Oklahoma



Beth Cordingley recently joined Y-ME as the new executive director for Y-ME Northeastern Oklahoma. Beth first learned about Y-ME in February of 1998, when she was diagnosed with breast cancer. A colleague of her husband's told her about the organization and invited her to attend Camp Hope, a free "day away" for survivors

and their supporters to refresh and recharge themselves (visit www.y-me.org/northeasternoklahoma for more information). Beth participated and soon afterwards became a board member for the affiliate. In 1999, she developed a program called FACE IT! and made presentations around town, discussing her personal

journey with breast cancer and how others could benefit from Y-ME's programs and services.

As many of our volunteers hold full-time jobs, Beth became the manager of Chamber Music Tulsa, a non-profit arts presenting organization, where she raised funds, negotiated contracts and ran a "one-woman office." Beth, however, became so passionate about the work of Y-ME that she decided to put her fundraising skills to great use and work full time for Y-ME. In August of 2004, Beth was hired as the Y-ME Northeastern Oklahoma executive director. "We can't wait for a cure. Over 1,600 women will be diagnosed in Tulsa County this next year alone. We must be available to them to ensure through information, empowerment and peer support that no one faces breast cancer alone." Her motto is Carpe Diem and on some occasions it's simply Carpe Dessert. "You don't know what turns your life is going to take so enjoy each day and eat dessert first!" ❧

Walk to Empower Unveiled for the First Time

As we've discussed in previous newsletters, Y-ME is launching fundraising walks in affiliate markets. Currently, Y-ME Affiliates are working to incorporate the Y-ME Walk into their development strategies. Two Y-ME affiliates, Y-ME Texas Gulf Coast and Y-ME San Diego, are primed for participation in 2005, and additional affiliates are preparing to join the program in the coming years.

On Mother's Day 2005, thousands in San Diego and Houston will have a meaningful morning, and a truly empowering experience in Y-ME's inaugural Walk to Empower. On the same day, participants in Chicago's Y-ME RACE Against Breast Cancer will come together for their own event.

The 2005 Y-ME RACE and inaugural Walks in San Diego and Houston offer tremendous opportunities for sponsorship and product presentation, as well as for families touched by breast cancer to raise funds for Y-ME and honor a loved one. These events are effective vehicles to reaching thousands of breast cancer patients and survivors across the country.

For more information about participating in, or sponsoring, the RACE or Y-ME's latest fundraiser, Walk to Empower, visit www.y-me.org. If you don't live near a site, we do have opportunities to be a "long-distance runner"—visit the Web site for the details. ❧




VONS Teamed up with Y-ME San Diego to *Paint the Town Pink*



VONS employees make and sell tasty root beer floats to benefit Y-ME San Diego.

During October, San Diego County VONS shoppers were invited to *Paint the Town Pink* by purchasing special \$1 pink paper ribbons at the checkout counter. Proceeds from the sales at 58 stores benefited the San Diego Affiliate of Y-ME National Breast Cancer Organization. In addition, VONS employees organized a variety of fundraisers to benefit Y-ME San Diego. Their activities included golf tournaments, a 5K run, root-beer float sales, book sale and parking lot BBQs.


Dr. Gerrit Los, board president of Y-ME San Diego says, "We're delighted to again work with VONS to raise awareness about breast cancer and Y-ME's local services. Our partnership with VONS has grown over the years and it is rewarding to work with a company that really cares about the its customers and the community."

In 2003, VONS donated nearly \$70,000 to Y-ME San Diego. Nationally, Safeway (VONS' parent company) has contributed over \$6.4 million to breast cancer organizations since 2000. 

Y-ME San Diego Helps Navigate the Healthcare System


Recently, Y-ME San Diego's Y-MAP (Y-ME Medical Access Program) staff helped a 28-year-old woman in need of diagnostic services for a lump in her breast that she discovered during Y-ME's *A Day for You*, a one-day breast health seminar for women in underserved communities. Unfortunately, the lump turned out to be malignant—the good news is that she is currently receiving treatment with the help of Y-MAP's navigation services.

To highlight *A Day for You* and the assistance she received from Y-ME, the woman joined Bertha Tiznado, *A Day for You* coordinator, on Univision, a Spanish television station, where they discussed how grateful she was to have Y-ME and its programs and services.

The San Diego Affiliate's Y-MAP helps uninsured women locate screening, diagnostic and treatment services. 


SK Institute Hosts Breast Cancer Program

Once a month, SK Institute, a spa in La Jolla, Calif., hosts its Breast Cancer Spa Night to pamper patients with relaxing spa services and camaraderie. Recently, Y-ME CEO Margaret C. Kirk was a guest speaker at the event and had the opportunity to explain Y-ME's programs and services to the guests. Margaret says, "SK Institute's Breast Cancer Nights provide an excellent service to the guests, who can relax and chat with other attendees as they indulge in top-quality spa treatments."

Founded by Stephen Krant, M.D., F.A.C.S., the evening is free-of-charge and includes two spa services. Dr. Krant is a member of the Y-ME San Diego Medical Advisory Board and held a fundraiser that benefited Y-ME San Diego in 2001. In November, Susan Leonard, Y-ME San Diego health services manager, was a featured speaker at the Breast Cancer Spa Night. For more information, contact the institute at 858-459-3334. 

Comcast Airs Y-ME PSA

In October, Comcast teamed up with Y-ME National Capital Area to air Y-ME's public service announcement 200 times per week — that's a donation of \$256,800 in airtime. Comcast subscribers in the region also received Y-ME information along with their monthly statements.

Thanks to the company, residents in the Washington, D.C., area were empowered with Y-ME's Hotline number, and the support and information that is provided 24/7 by our peer counselors. 

The Sister Study




The Sister Study is a national effort to learn about environmental and genetic causes of breast cancer. It is a long-term study of 50,000 women from all walks of life who have had a sister with

breast cancer. This research is sponsored by the National Institute of Environmental Health Services, one of the National Institutes of Health (NIH).

Eligible women:

- Have a sister who was diagnosed with breast cancer
- Are 35-74 years old
- Have never had breast cancer

Y-ME National Breast Cancer Organization supports the Sister Study to help discover the causes of breast cancer. Y-ME encourages all eligible women to participate, either by enrolling in, or creating awareness about the study.


For more information, and to enroll, call 1-877-4SISTER or visit www.SisterStudy.org. 

Allos Enrich Trial

This study will evaluate whether Efaproxiral given before whole brain radiation therapy will work better on brain metastases from breast cancer than whole brain radiation therapy alone.

This 360-patient study is actively recruiting women in the US and Canada. The screening process will require a brain scan and may include a liver scan. Other screening measurements will include a day-to-day functioning


assessment called a KPS, measurement of the amount of blood oxygen using a non-invasive device, lung function tests and an electrocardiogram. About 2 teaspoons (10 mL) of blood will be taken, and a pregnancy test will be done on the blood of women of childbearing potential.

For more information, speak with your doctor and visit www.allos.com. 


Get Back As Much as You Give: Become a Hotline Peer Counselor!

If you're a breast cancer survivor and are interested in becoming a peer counselor for the Y-ME Hotline, contact us about participating in the peer counselor training and certification program. We are in need of people who are bilingual in English and another language, especially Spanish, but all survivors are welcome to apply.


After attending a two-day training, passing a test and shadowing an experienced peer counselor, your certification process will be complete, and you'll be ready to begin answering calls from your area and around the country.

For more information about becoming a volunteer peer counselor, call us at 312-294-8514 or visit www.y-me.org. 

Donate Your Wig to Y-ME

If you have a new or used wig you no longer need that is in good condition, donate it to the Y-ME Wig & Prosthesis Bank. We're always in need of all styles, but we particularly need brown and black wigs. Thank you for helping us provide free-of-charge wigs to women with limited resources. For more information, call 312-986-8338. 

Y-ME Promotes Earlier Detection in Russian

In addition to our other foreign-language brochures, Y-ME now has a pamphlet, *Every Woman's Guide to Breast Care*, that details the three methods of earlier detection in Russian. Spanish, Chinese, Korean and Vietnamese brochures are also available, in addition to our English materials. To get your copy, visit www.y-me.org or call 1-800-221-2141. 

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Dr. Norton Speaks on Survivorship

A webcast of Y-ME's fourth annual breast cancer forum, "Leading the Way in a New Age of Breast Cancer Survivorship," is now available at www.y-me.org. Whether you missed the summer event or would like to review the information again, visit Y-ME's Web site to access the webcast, produced in partnership with HealthTalk.

The following excerpt from the forum is sure to pique your interest:

You have a choice when you've been touched by a serious illness... You can succumb to it and see yourself as damaged and not as great as you were before, not having the robust health you might have enjoyed before. But you're psychologically changed. You've got to make that psychological change in a positive sense, and I think that survivorship should be a state of improvement.

— Larry Norton, M.D., deputy physician-in-chief for breast cancer programs at Memorial Sloan-Kettering Cancer Center

Intrigued? Visit www.y-me.org and learn more about what Dr. Norton has to say about survivorship. 


Feedback on the Concept of Survivorship

In the Fall 2004 issue of *Lifeline*, we asked for your thoughts on the idea of "survivorship." We received the following response:

I personally feel that we should NOT be called breast cancer survivors. To me, a person survives a fire or a shipwreck or some other one time catastrophic event. The battle with cancer is ongoing. Until we die from other causes, we will probably die from cancer.

So I would like to see it changed to breast cancer WARRIORS (think ZENA). And the ribbons should not be baby pink....they should be a deep, bold fuschia.

Karen Kropidlowski

Breast cancer in 1997, and again this July....and still fighting, not just surviving... 

Y-ME Supporters Look Fabulous in Pink

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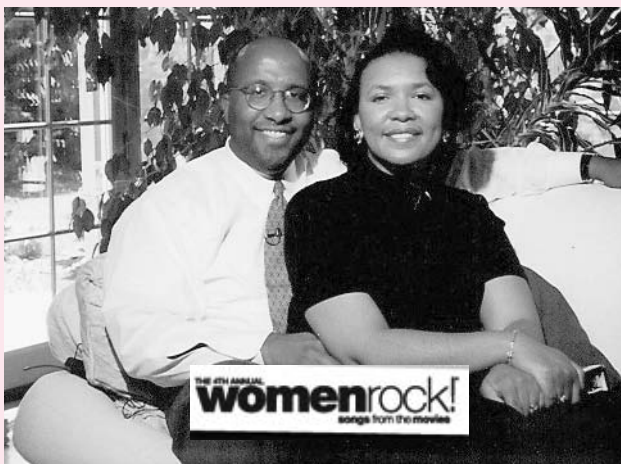


In October, Y-ME supporters did a good deed while looking fabulous with the Reflect limited edition Think Pink Benefit Kit. This pink-powered lip kit was created in honor of those facing the difficult realities of breast cancer,

and to benefit Y-ME National Breast Cancer Organization. Reflect donated 10% of all Think Pink purchases directly to Y-ME in support of our mission to ensure that no one faces breast cancer alone.

For more information, visit www.y-me.org and click on Donate Now, then Corporate Partners. ♪

Leonard and Toya Are Breast Cancer Heroes



Adding to Y-ME's nominated winners, Margaret Harte and Ann Marcou, Leonard and Toya Thompson-Thomas were recently named *Lifetime* television Breast Cancer Heroes for their involvement with Y-ME. Congratulations to both of them for their commitment to providing support to others touched by breast cancer.

Leonard and Toya Thompson-Thomas have been a part of Y-ME ever since Toya's sister was diagnosed with the disease in 1978, the year Y-ME was founded. Toya's sister lost her battle when she was 40 years old—the same age as Toya when she was diagnosed. Last summer, 10 years after her first bout with breast cancer, Toya was diagnosed again.

Following surgeries and months of aggressive chemotherapy, she remains full of hope for the future. Leonard considers himself a survivor too, since he has been with Toya every step of the way.

In 1994, when Toya was volunteering with the Y-ME Hotline, Leonard helped found Y-ME's Men's

"As a couple surviving breast cancer, we will continue our journey promoting breast cancer awareness and providing peer support. And the journey continues."

Hotline, which has evolved over the years to Y-ME's Match Program (see *Y-ME Partners Match Program Lends Peer Support* on page 15). It provides support and education for anyone who has a wife, partner, mother, daughter or friend with breast cancer.

Together, Toya and Leonard have volunteered in many different capacities, performing community outreach and education, fundraising, chairing special events, volunteering on the Hotline and serving on the boards of both the national organization as well as the Illinois Affiliate of Y-ME. Leonard and Toya are both leaders in the corporate community who work tirelessly to ensure that through information, empowerment and peer support, no one faces breast cancer alone. ♪

Changing Gears: The Adventure of a Lifetime

From October 2 - 9, 2004, 22 young breast cancer survivors experienced the adventure of a lifetime, riding motorcycles up the coast of California.

At the end of the week, the tired but triumphant riders drove across the Golden Gate Bridge into San Francisco after an epic 1,000-mile journey. Along the way they

raised nearly \$30,000 for Y-ME and the Young Survival Coalition while raising awareness of young survivor's issues and impacting the lives of women. ♪



Women in P-O-P Host Gala to Support Y-ME



Women in P-O-P present Y-ME with a donation at the benefit. Pictured from left to right are: Michele Malo of Kellogg Co., Margaret C. Kirk of Y-ME, Stacy Sullivan of Southern Wine & Spirits and Jill Perrin of Under Armour Performance Apparel.

Y-ME National Breast Cancer Organization and Women in P-O-P hosted a Hoyt Publishing event in Chicago’s Navy Pier Grand Ballroom on Thursday, September 23. Each year, the Women in P-O-P Benefit to Fight Breast Cancer is the industry’s premiere charity event and the see-and-be seen gala for attendees and exhibitors of *The P-O-P Show/Chicago*.

“The corporate community is made up of families, families that need assistance 24/7 when the unthinkable arises. The more knowledge that we can bring about the Y-ME Hotline to educate those communities, the more help corporate America can bring to their families in time of need,” explains event co-chair Michele Malo, Kellogg Co.

Y-ME was chosen as the 2004 beneficiary and received \$104,000 in support of our programs and services. Thank you Women in P-O-P!

The P-O-P industry is comprised of brand marketers who are leaders of in-store advertising and promotions. They are always looking to increase our pool of support—please call 847-675-7400, ext. 123, or e-mail stacie_mathews@instoremarketer.org to find out how you can get involved. ♣

Thank you, Coloplast-Amoena

Y-ME gratefully accepted a large supply of breast prostheses from Coloplast-Amoena, based in Marietta, Ga. The donation will enable Y-ME to continue providing free-of-charge breast prostheses to women with limited resources. Amoena is committed to helping women recover from the experience of breast cancer. ♣



Jodi Fyfe (front), along with supporters from Blue Plate and Y-ME, gathered at NBC Studio 5 Plaza to garner support for the Y-ME RACE.

Y-ME Names RACE Corporate Chairman

Y-ME named Jodi Fyfe, president, Blue Plate, Corporate Chairman for the 2005 Y-ME RACE Against Breast Cancer. The 2005 Y-ME RACE will take place on Mother’s Day, in Grant Park, May 8, 2005.

As Corporate Chairman of the 2005 Y-ME RACE, Fyfe is charged with growing corporate support and leading fundraising efforts for the Y-ME RACE in Chicago. Fyfe will secure top-level corporate sponsors, form and lead a corporate team, and conduct promotions leading to new and renewed support.

Continued on page 23



Y-ME & YSC Present Film

In October, Y-ME joined forces with the Young Survival Coalition to commemorate National Breast Cancer Awareness Month with a screening of *Breast Cancer Legacy*. The film addressed the role family history plays in a young woman’s risk for breast cancer, and the decisions she may have to make as a result. Attendees at the Chicago event enjoyed an evening of insight and camaraderie. The document also aired on the Discovery Channel in October. ♣

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Y-ME Names RACE Corporate Chairman

Fyfe's set the goal for Blue Plate to raise as much as \$125,000 to benefit Y-ME through corporate sponsorship and team participation. Y-ME selected Fyfe based on her involvement in the 2004 Y-ME RACE. She spearheaded the most successful Y-ME RACE Family Team in the event's 13-year history. Fyfe's team was named "Carrie's Crusade," in the memory of Fyfe's cousin and best friend, Carrie Kenney, who lost her battle to breast cancer last year. With approximately 170 members, the team raised a record breaking \$50,000.

"It's an honor to be selected as this year's Corporate Chairman," said Fyfe. "This cause has personal meaning for my company and me and as our company is 90 percent women, we are determined to shatter the previous year's record. When Carrie needed to speak with someone for breast cancer guidance or support, she reached out to Y-ME."

To find out more about how to involve your business or family in the Y-ME RACE or about joining Blue Plate/Carrie's Crusade team, visit <http://race.y-me.org>.



save the date

The National Breast Cancer Coalition (NBCC) 2005 Advocacy Training Conference will take place May 21-24, 2005, in Washington, D.C. For more information and to register, visit www.stopbreastcancer.org.

Lifeline

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In addition to our publications and Web site, www.y-me.org, Y-ME would like to recommend the following resources for breast cancer information.

Organizations

Fertile Hope

www.fertilehope.org

1-888-994-HOPE

Founded in October 2001, Fertile Hope is a national nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility. The organization will strive to advance fertility research, help advance the understanding of fertility risks and preservation options, allow and encourage personal educated decisions, make preservation treatments available regardless of economic status and help patients cope with important family planning issues.

Pregnant with Cancer

www.pregnantwithcancer.org

1-800-743-4471

The mission of the Pregnant With Cancer Network is to let you know that you are not alone. Being diagnosed with cancer when you're pregnant can be a terrifying and lonely experience. The Pregnant With Cancer Network connects you via phone or e-mail with a woman who has gone through a similar experience.

Publications

Couples Confronting Cancer: Keeping Your Relationship Strong

By Joy L. Fincannon R.N., M.S., Katherine V. Bruss, Psy.D., American Cancer Society, 2003.

www.cancer.org

In this book, you'll find information about how others experience cancer, the problems it often causes, and how to resolve-even prevent-those problems. Hands-on tools are offered throughout the book that can help partners become closer as well as communicate more easily and truthfully.

Sexuality and Fertility After Cancer

By Leslie R. Schover, Ph.D., John Wiley & Sons. New York, 1997.

As the title suggests, this book tackles all aspects of sexuality and fertility after a cancer diagnosis. Topics such as sexual problems, infertility treatments, pregnancy risk and body image are all knowledgeably addressed. Sex after breast cancer is covered as well.

When the Woman You Love Has Breast Cancer

Y-ME National Breast Cancer Organization, 2004.

This Y-ME publication is for partners of women who have been diagnosed with breast cancer. Written from the perspective of the supporter, the booklet addresses common concerns that span the length of treatment and beyond. Subjects include ways to support your loved one, how you both might be feeling and intimacy.

Janet & Me, An Illustrated Story of Love and Loss

Simon & Schuster, October 2004, Paperback Original

In words and drawings both candid and human, Stan Mack follows his eighteen-year relationship with Janet Bode, a lighthearted fling that beat the odds to become an enduring love affair. The only thing they couldn't beat was cancer. As Janet and Stan confront the jagged terrain of cancer, then navigate the twilight of terminal illness, two portraits emerge: of a woman who faced her cancer the same way she lived her

life, with guts and charm; and of the man who held her close and shared her struggle. For anyone who can't resist a beautifully told love story; for anyone who is touched by someone suffering from serious illness and looking for emotional and practical guidance and for anyone who appreciates a life lived to the fullest, *Janet & Me* will resonate long after the last page is turned.

Excerpt from the Book: The surgeon met us in a busy and narrow corridor just off the main lobby. There, opposite the cashier's office, he gave us the bad news . . . and rushed off. His abruptness was so unnerving we could hardly absorb the diagnosis. We left the hospital looking for a lighthearted way to talk about information that was too new, too scary, too shocking to face directly.

