



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

1-800-221-2141 (English)*

1-800-986-9505 (español)

*Interpreters available in 150 languages

www.y-me.org




The Ride of a Lifetime

Y-ME National Breast Cancer Organization has been chosen as a third-party beneficiary of Amazon Heart's Changing Gears, a weeklong motorcycle adventure to be held October 2-9, 2004, up the coast of California from San Diego to San Francisco.

During the seven-day ride, 20 young breast cancer survivors will journey more than 800

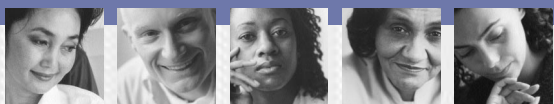
miles to raise awareness for the unique needs of young women facing the disease. These incredible women will share stories of their personal experiences with breast cancer, challenge media stereotypes and raise funds to ensure that no one faces breast cancer alone. Teresa Rosainz, rider, explains her motivation for participating, "I will ride for my 12-year-old daughter who I wish will never have to face cancer, and my 8-year-old son who will never forget that his mom, who just finished chemo for the second time, got to ride a Harley across California."

For more information, and to support Teresa and the other 19 riders, visit www.y-me.org or www.changinggears.org. Due to the generous support of Harley Davidson, motorcycles and riding gear will be provided for each rider. 

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.

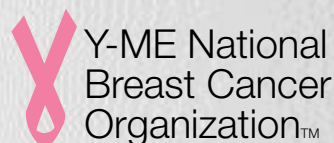
mission





Lifeline

A Quarterly Publication of Y-ME National Breast Cancer Organization



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Enhanced Hotline and Peer Counselor Training Embrace Diversity

Cheryl Locke, 51, an African-American schoolteacher, resides in Chattanooga, Tenn., and has taught special education students for 28 years. Cheryl is an avid reader of suspense novels, mysteries and cookbooks; not surprisingly, she likes to spend time in the kitchen, experimenting with new recipes. Cheryl also enjoys spending time with her husband, two college-age children and a very large extended family.

Helen, 41, of Chicago, Ill., is also married and has two young children. Helen is Asian-American and works full time as an accountant; in her spare time she spends time with her family and attends her children's various sporting activities. She expresses her artistic side through a new interest—scrapbooking.

Janice Workcuff, 48, of Missouri City, Texas, aptly describes herself as a "people person." In addition to her roles as wife, mother and new author, Janice works as a cardiac sonographer and is a part-time research assistant/peer counselor at M.D. Anderson Cancer Center. She is very involved in the Sisters Network, Houston Chapter, a breast health organization serving the needs of African-American women. Janice also serves in the prayer and marriage ministries of her church. To help balance the demands of her hectic, yet rewarding schedule, Janice enjoys reading and listening to jazz.

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How Important Is Ethnicity in Breast Cancer?

According to the American Cancer Society, one in seven American women is expected to be diagnosed with breast cancer in her lifetime. That number has increased dramatically from only one in 20 in 1940. Although that sounds disheartening, mortality rates have remained relatively stable since the 1950s. Thanks to great leaps in research, we are learning which treatments are most effective and coming closer to discovering factors that may contribute to breast cancer.

There is growing evidence that ethnicity and genetic variations predispose some people to breast cancer. Potential differences are hereditary risk factors, lifestyle, exposure to cancer-causing agents and socioeconomic status. Cultural differences are also under scrutiny.

*we must not tailor treatment to different cultures,
"Unequal treatment equals unequal outcomes."*

In reporting such information, it is essential to understand that the available statistics are not to be taken as absolutes. Long-term survival rates are difficult to gauge. Record keeping across the nation and at health facilities is not consistent and interpretation of data is subjective. Sheryl Kelber, biostatistician at the University of Wisconsin-Milwaukee Center for Nursing Research and Evaluation, points out that there is no common denominator for comparison of breast cancer in ethnic groups and she urges caution in close evaluation. Lovell Jones, Ph.D., director of the Center for Research for Minority Health at M.D. Anderson, Houston, Texas, points out that more data is needed to evaluate all ethnic groups.

"We must do clinical research differently in the 21st century," Dr. Jones states. But for now he warns that we must not tailor treatment to different cultures, "Unequal treatment equals unequal outcomes."

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message from margaret



Dear Readers,

Probably the nicest thing we can say about breast cancer is that it is a democratic disease. It affects women and men across cultures and economic backgrounds, and is influenced in part by family history and lifestyles. It is for that reason that we're focusing on multiculturalism in this issue of *Lifeline*. For an overview of the subject, take a look at our cover story, *How Important Is Ethnicity in Breast Cancer?* While we may not see eye to eye on other issues and while we may have cultural differences, we're drawn together by the common bond of experiencing the disease.

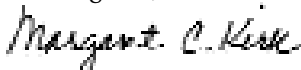
Y-ME has long recognized the extraordinary power peer support has had in the fight against breast cancer. In 1994, before it was fashionable to acknowledge and accept differences, Y-ME created its Spanish-language Hotline (1-800-986-9505) that is still the only 24-hour breast cancer support hotline like it in the United States. We didn't stop there, however. On the English Hotline (1-800-221-2141), interpreters are now available in 150 languages. To reinforce our efforts, Chinese, Korean and Vietnamese Web pages recently have been added to our Web site to complement the existing Spanish-language site, and early detection brochures are available in the Asian languages as well. To learn more about Y-ME's efforts to expand and enhance the Hotline, see page 1.

Since peer support is the cornerstone of Y-ME, we've always been careful to make sure anyone who needs to talk has a resource. For example, our Match Program pairs people with others who have had similar diagnoses or life experiences. Likewise, the Men's Match Program and Partner's Match Program are resources for people who would like to speak with others who are supporting a loved one through treatment.

Going through treatment, finishing it and/or continuing to be treated long-term are all aspects of survivorship. In the summer issue of *Lifeline*, our lead article focused on the subject and you responded with phone calls and e-mails. Many of you enjoyed considering the meaning of "survivor" in a new way, while others felt that too much emphasis was placed on those who beat the disease. We'd love to hear how the rest of you feel about the subject, so feel free to write or e-mail us your opinions at the address on page 22. We'll print a selection of them in the winter issue.

October is National Breast Cancer Awareness Month and we rally across the country in support of everyone touched by breast cancer. Although many of us wear pink ribbons and support breast cancer organizations with pride, let's take our personal commitment to the cause even further this year. Why don't we schedule our age-appropriate clinical exams and mammograms (see www.y-me.org for guidelines), and let's encourage all the women in our lives to do the same. Together we can support and empower our friends and family, ensuring that no one faces breast cancer alone.

Best regards,



Margaret C. Kirk

Y-ME Chief Executive Officer

How Important Is Ethnicity in Breast Cancer?

In the U.S., the occurrence of breast cancer is highest for white women, followed by African-Americans, Asians, Hispanics and American Indians. Information provided by Cornell University Studies, April 2003.

NEW CASES OF BREAST CANCER DIAGNOSED EACH YEAR PER 100,000 WOMEN:

139 White
121 African-American
98 Asian and Pacific Islanders
82 Hispanic
42 Native Americans

DEATHS FROM BREAST CANCER FOR EACH 100,000 WOMEN:

37 African-American
28 White
17 Hispanic
15 Native American
13 Asian and Pacific Islanders

The following groups in the United States will be examined in this article: Whites, African-Americans, Hispanics, Asians and Pacific Islanders, Native Americans and Ashkenazi Jews.

WHITES

White women (in this article non-Hispanic white women will be referred to as “white women”) in the United States have the highest incidence of breast cancer and there is an annual increase of 1.3 percent each year, according to the National Cancer Institute. White women are more likely to delay childbirth and are older when they have their first child—and are more likely not to have children—all factors for increased breast cancer risk. Other risk factors that are higher for white women are early start of menstrual periods and later menopause. Alcohol consumption is associated with increased breast cancer risk in all groups and white women consume alcohol more frequently than any of the others cited. However, regular screening and earlier detection are credited for higher survival rates in whites than in Hispanics and African-Americans. Deaths due to breast cancer dropped 2.6 percent among U.S. white women in 2003.

HISPANICS

Although Hispanics have lower rates of breast cancer incidence than white or African-American women, it is the leading cause of cancer deaths for this group. Latino diets high in grains and beans seem to inhibit estrogenic activity, and are believed to be part of the reason that breast cancer incidence is lower in Latina women. Possible reasons for the less favorable survival statistics are that Hispanic women have lower breast cancer screening rates than whites and tend not to seek and attain healthcare as much as other groups. Poverty, lack of insurance, low education levels, limited access to healthcare, lack of awareness of screening methods, language barriers, culture and negative family attitudes play important roles in lower rates of screening services used by Hispanic women, reports *En Acción*, a newsletter published for The National Hispanic Leadership Initiative on Cancer. The report further shows that the higher the income, the more likely women are to receive screening. Screening rates vary among sub-groups and locations of Hispanics. Lack of screening often translates to advanced-stage diagnoses when fewer treatment options are available, resulting in poorer outcomes and higher mortality.

Divyesh G. Mehta, M.D., associate professor of medicine and medical director of clinical oncology at the University of Illinois at Chicago, found that a large number of women younger than 30 years of age had been diagnosed with advanced breast cancer at a county hospital in Phoenix, Ariz. For these women, regular clinical breast examinations were not obtained for several reasons: their husbands did not want them to have the examination; they lacked funds and insurance; many were undocumented aliens who were afraid to go to clinics; and language difficulties imposed limitations.

Overcoming these problems required effort by the entire community to bring standard medical care to Hispanics in the Phoenix area. Health education was key, reports Dr. Mehta, starting with the men. The hospital advertised in Spanish language newspapers to promote its messages. Teaching that the breast is simply another part of the body was a large part of that message. The professionals also learned that they must assure Hispanics that female nurses and residents rather than male doctors would do the breast exams. Free mammograms were made available and mechanisms were put in place to take care of patients at all stages of the disease. Medical personnel were educated, as well. They learned that they must address cultural beliefs and values before progress could be made. All the community services cooperated and provided screening and follow-up treatment in a most successful endeavor, according to Mehta.

How Important Is Ethnicity in Breast Cancer?

The death rate from breast cancer among Hispanic women overall has been dropping 1.8 percent a year for the last decade. And further good news about this segment of the population is that the prevalence of mammography testing among women older than 40 was 65.4 percent in 2000 (according to the American Cancer Society), up from 50.6 percent in 1989 in parts of the U.S. (according to the National Cancer Institute).

AFRICAN-AMERICANS

While whites have a higher breast cancer incidence than African-Americans, the latter group is more likely to die from the disease. The spring 2004 issue of *Lifeline* carried the findings of Dr. Harold P. Freeman, director of North General Hospital and director of the Ralph Lauren Center of Cancer Treatment and Prevention in Harlem, N.Y. His study found that the main causes of death from breast cancer among African-Americans are cultural bias, late diagnosis and treatment at a late stage.

Dr. Freeman has developed an outreach program to help minority breast cancer patients. With lower than average economic means and education, these individuals have late diagnoses and, therefore, poorer survival rates. His program includes education, breast examination, mammography and treatment—and one more thing: navigators. Navigators are individuals who are attuned to cultural sensitivities, beliefs, values and lifestyles of the minority patients and can lead them through confusing, complex healthcare and insurance information. With individuals receiving the information and guidance needed for early detection, the five-year survival rate of the breast cancer patients in this study went from 39 percent in the last available study to 70 percent.

ASIANS AND PACIFIC ISLANDERS

Breast cancer occurrence in Asian and Pacific Island women in the U.S. peaks at about the age of menopause.

Lifestyle changes are commonly believed to be the cause for increased breast cancer incidence among Asian women who migrate to the United States. These women have a lower statistical risk of breast cancer than other ethnic groups. One possible explanation is that their diet of green tea, fish, plant oils, soy products and certain fruits and vegetables may reduce estrogen activity or retard the growth of tumors through chemical interaction. Asian women exercise more and are less likely to be obese. While much lower rates prevail in their native countries and shortly after their arrival in the U.S., incidence rates increase to nearly that of American white women within several generations.

Cancer incidence rates vary within ethnic subsets. The highest rates are in Hawaiian women, followed by Japanese, Filipino, Chinese, Vietnamese and Korean, according to the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Cancer Registry.

NATIVE AMERICANS

Life expectancy rates among Native Americans and whites are similar and yet whites have a breast cancer incidence three to four times that of Native Americans. The exception seems to be Native Americans in New Mexico where the incidence rate for the group rises. Researchers are questioning whether this is due to a shift away from traditional Native American behaviors or diet. While the incidence of breast cancer in Native Americans is lower than in other groups, the five-year survival rates are also lower. Members of the American-Indian Health Council believe that lack of access to early detection services is the major contributor to this poor survival rate.

The Tribal Observer, published semi-monthly by the Saginaw Chippewa Indian Tribe of Michigan and distributed across the United States, quotes a Native-American 15-year breast cancer survivor who says she believes cultural barriers are largely to blame for the high incidences of death. Because the Navajo language literal translation for "cancer" is "the sore that never heals," the group tends to believe that a breast cancer diagnosis is a death sentence rather than an illness that can be treated. Breast cancer is considered a forbidden subject because some believe that speaking about it will cause the disease. Many Native American women are embarrassed to talk about the subject or feel shame in conducting breast self-exams.

Another reason for poor survival rates is the difficulty to make and keep appointments for those without telephones or transportation and who live on remote reservations. Language barriers can lead to difficulties in communicating with medical professionals, therefore limiting healthcare knowledge. A *Tribal Observer* story dated November 1, 2003, in Farmington, N.M., tells of a Navajo woman who did not get treatment after her breast cancer diagnosis because she misunderstood the process and believed that her throat would be slit when a catheter was inserted. There was no one there to explain it to her in her native language.

In order to tear down some of these barriers, the Northeastern Oklahoma Affiliate of Y-ME sponsors an active Native American support group that addresses some of these issues. Jo Stand, a Native American board member of the Affiliate and survivor of more than 10 years, works with her community to dispel myths and raise breast cancer awareness.

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Q *In the spring 2004 issue of Lifeline, “On the Side” explained some of the side effects experienced by those who take aromatase inhibitors. What can we do to alleviate the discomfort?*

~ Question submitted by Debbie Laxague, Lifeline reader

Managing the Side Effects of Aromatase Inhibitors

For women who have had breast cancer, the fear of recurrence is always present, and the drug tamoxifen has been used for more than 20 years to reduce the risk of recurrence. In the past few years, a new class of drugs called aromatase inhibitors, AIs, has been added to the arsenal.

AIs are recommended for post-menopausal women whose ovaries no longer produce estrogen, but whose bodies still yield estrogen. Aromatase is an enzyme that is necessary for the production of estrogen. With AIs, less estrogen reaches the estrogen receptors on cancer cells that can trigger trouble.

In the past, AIs were most commonly prescribed for women with metastatic disease who had already taken tamoxifen for five years and had a recurrence. Today, studies suggest that AIs should be given to post-menopausal women as adjuvant therapy instead of tamoxifen. As more and more women take these drugs, the side effects that go along with them become more apparent.

Bone Pain & Stiff Joints

Clearly there are more musculoskeletal problems in women taking AIs than in those not taking AIs, said Eric P. Winer, M.D., director of the Breast Oncology Program at the Dana-Farber Cancer Institute in Boston. He prefers to begin treating bone pain and achy joints with milder drugs rather than starting patients on stronger agents. Analgesics like aspirin and acetaminophen would be step one, followed by anti-inflammatory drugs like ibuprofen and naproxen. For more severe symptoms, non-steroidal anti-inflammatory agents called Cox-2 inhibitors (drugs like celecoxib or rofecoxib) would be recommended.

Bone Loss

There is no question that, as a class of drugs, AIs cause some degree of bone loss. Hence, Dr. Winer recommends that any woman taking an AI should have a bone density test. Almost all women should take calcium and vitamin D supplements and increase their weight bearing exercises such as walking. For women with substantial bone loss, drugs called bisphosphonates may be prescribed to slow the mechanism by which bone loss occurs and to reduce the risk of skeletal fractures.

Hot Flashes and Sexual Function

Two other common side effects of AIs are hot flashes and problems with sexual function. Although one thinks of hot flashes as a symptom of menopause, they are definitely common in women taking AIs, said Dr. Winer. Studies have shown that anti-depressant drugs called selective serotonin reuptake inhibitors (SSRIs) are as effective in decreasing hot flashes as estrogen replacement therapy (which women on AIs cannot take). Before starting an anti-depressant, it may be worthwhile to try Vitamin E (800 IU daily) because it has also shown modest success in reducing hot flashes.

Quality of life studies show that more women taking AIs had problems with sexual function than did women not taking AIs. Given that vaginal dryness constitutes part of the problem, good lubrication is important. Some doctors are perfectly comfortable talking about this issue with their patients and will warn them of the problem, while others are not so forthcoming. Anyone who is concerned about sexual function is encouraged to discuss it with a doctor.

AIs Are Good Drugs

Despite their side effects, Dr. Winer emphasizes that AIs are good drugs because they unequivocally reduce the risk of recurrence. He concedes that some women stop taking AIs because of the side effects, but he estimates that fewer than five percent actually do so. “When we have a new class of drugs we shouldn’t think that they have to go with other medications unless it’s absolutely critical,” he cautions.

Dr. Winer offers the following “take home” messages:

- Don’t attribute everything you’re feeling to the drug that you’re on. It’s best to consult your doctor and ask what else may be causing difficulties.
- Don’t feel trapped by your medication. Consult your doctor about how to alleviate side effects so that you can still garner the benefits of the AI you’re taking.
- Don’t hesitate to tell your doctor if you’re experiencing any side effects. In some cases, the benefit of the medication may be too small to justify their severity.

Have a question? Call the 24-hour Y-ME National Breast Cancer Hotline, 1-800-221-2141, and speak with a survivor who is a trained peer counselor.

Continued from cover

Enhanced Hotline and Peer Counselor Training Embrace Diversity

Though separated by miles, these three individuals are linked by mutual experience and a shared aspiration. They are breast cancer survivors and graduates of the new peer counselor certification program for the Y-ME National Breast Cancer Hotline, and they are deeply committed to helping others manage the physical and emotional concerns that often accompany a breast cancer diagnosis.

The 24-hour Y-ME Hotline is building on its reputation as the most accessible and culturally responsive breast cancer support resource in the country by incorporating major new technology into its operating system. Y-ME still administers a separate Spanish Hotline that serves the Latino community and interpreters are now available in more than 150 languages on the English Hotline.

What can callers expect to receive from the enhanced Hotline? All will receive prompt response from a trained and certified peer counselor, using a state-of-the-art telephony system that eliminates an answering service and line connection delays. All Hotline peer counselors are breast cancer survivors who genuinely understand the myriad challenges a cancer diagnosis presents, ranging from acute anxiety at diagnosis to concerns about treatment, symptoms, communication and risk of recurrence. Hotline volunteers offer valuable support, encouragement, information and personal insight. All callers can receive follow-up support via the Hotline's personalized match program. The program matches a caller with a peer counselor who has had a similar experience. It is available to women and men with breast cancer and also for those who are helping a loved one cope with the disease.

Helen's personal connection with a Hotline peer counselor was a pivotal factor in her decision to become one herself. "I called the Y-ME Hotline the evening that I was diagnosed and I spoke to a lady who was very supportive and encouraging," Helen recalls. "She was a 20-year survivor and it was such a relief to talk with her." Serving as a Hotline peer counselor from her home affords Helen the convenience of integrating Y-ME volunteer activities with the demands of a busy schedule.


This past May, Helen participated in the newly standardized peer-counselor training and certification program and

derived tremendous benefits from the entire learning process. The comprehensive training format is designed to provide a core curriculum, augment quality assurance and increase sensitivity to callers from diverse backgrounds. As of this writing, more than 100 individuals have participated in the two-day training in cities throughout the country and many have signed up for future sessions.

Cheryl, a nine-year breast cancer survivor, has been serving as a Y-ME Hotline peer counselor for five years and recently renewed her certification in April. "It [the training] was an enriching and rewarding experiencing," said Cheryl. "It also reinforced the fact that we must always be good listeners when providing the support that we are called upon to provide." Through her involvement with Y-ME Chattanooga, Cheryl also presents "Woman to Woman"—early detection workshops in African-American, Hispanic and rural communities.

Janice attended the Y-ME training seminar in June with the goal of expanding her support capabilities to encompass the needs of all women, regardless of age or race. "The training was very good and enhanced the instruction I had received at M.D. Anderson. I received more facts, more information and more direction on how to handle some of the questions that I will come across on the Hotline," said Janice. "Most of all, I learned to be a better listener, and to not simply try and fix a situation." Janice is dedicated to providing the type of support that was difficult to come by 16 years ago at the time of her diagnosis. To foster this effort, she recently authored an inspirational resource book entitled *Road to Restoration Through the Diagnosis of Breast Cancer and Walking on by Faith*. The book details her breast cancer experience and those of 15 other long-term survivors.

This year, more than 217,000 people—of both genders, all ages and all ethnicities—will be diagnosed with breast cancer. With the implementation of progressive Hotline technology and a nationwide peer counselor training program, Y-ME remains ardently committed to broadening its reach to all cultures and communities.

For immediate access to the Y-ME National Breast Cancer Hotline, call 1-800-221-2141. To inquire about upcoming peer counselor training sessions, call 312-294-8514. 

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

If you're a breast cancer survivor and are interested in becoming a peer counselor for the Hotline, contact us about participating in the peer counselor training and certification program. The two-day training is held in cities around the country and consists of lectures, discussions and role-plays led by Y-ME staff and volunteers. Medical instruction covers basic breast anatomy, staging, diagnosis, treatment, side effects and reconstruction options.

The training also addresses using effective communication strategies, supporting emotional callers and achieving technological proficiency. After passing a test and shadowing an experienced peer counselor, the 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 1-312-294-8514 or visit www.y-me.org.



ShareRing Network

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

September 22, 2004

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

Speaker: Lynn Danford, MS, CDE, LD,
Lynn Sage Breast Center,
Chicago

Topic: Eating Healthfully and
Joyfully

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

TO REGISTER:

Visit www.y-me.org for dial-in instructions or call 1-800-221-2141. Pre-registration is required.


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



Judy Houston, Y-ME Hotline peer counselor, answers the first call using the enhanced Hotline system in June. Since then, more than 4,000 callers have turned to Y-ME.

DOD Funding

The House Appropriations Committee allocated level funding for the Department of Defense Cancer Research Programs: Breast, Ovarian, Prostate, etc. The Senate Appropriations Committee allocated a combined amount of \$200 million for all of the programs (\$45 million short of level funding) with no designation of how the money would be divided.

Unrelenting grassroots advocacy efforts left the committee with little choice. The House numbers prevailed and the women's health research programs will be funded under the Department of Defense bill passed at the end of the July: \$150 million for the Peer-Reviewed Breast Cancer Research Program and \$10 million for the Ovarian Cancer Research Program. At this time we know that Y-ME was represented at this year's DoD peer-review by Jane Perlmutter (National Board Member), Nan Finken (Y-ME National Capital Area) and Chris Tannous (Y-ME Southland California). 

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: Washington, D.C.

DATE: November 10-14, 2004

APPLICATION DEADLINE: September 10, 2004

Visit www.y-me.org, or call Y-ME at 1-800-221-2141 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.

NBCAM Commemorates 20 Years

NBCAM (National Breast Cancer Awareness Month) celebrated progress in breast cancer awareness with a national summit entitled, "20 Years of National Breast Cancer Awareness: the People, the Progress, the Future." It was held on May 14, 2004, in New York, N.Y. Leading breast cancer experts, physicians and patient advocates from around the country gathered to discuss breast cancer treatment and diagnosis during the past 20 years.

Margaret C. Kirk, Y-ME CEO, and Lillouise Rogers, Y-ME education project manager, attended the summit.

The NBCAM summit featured a number of breast cancer experts: Keynote Speaker, Larry Norton, M.D., deputy physician-in-chief for Breast Cancer Programs, Memorial Sloan-Kettering Cancer Center; Daniel Kopans, M.D., professor of radiology, Harvard Medical School and director of Breast Imaging, Massachusetts General Hospital; Robert Bazell, chief science

How Important Is Ethnicity in Breast Cancer?

ASHKENAZI JEWS

Ashkenazi Jews from central or Eastern Europe often carry a genetic mutation—others carry it, too—linked to higher breast cancer risk than other Americans. The affected genes are BRCA1 and BRCA2. According to the National Cancer Institute's Web site, one in 800 individuals in the U.S. carries one of these genes. Among Ashkenazis, the genes are found in one in 44. More frequent and earlier screening, therefore, is recommended for the group. Research in Great Britain indicates that BRCA1 and BRCA2 may serve as genetic caretakers—part of the cell's machinery that detects and mends damaged genetic material. Failure to repair this damage can lead to cancer. Research on how these genes function is opening up new possibilities in prevention, diagnosis and treatment.


Testing for the genetic mutation is an option. *USA Today* featured a story on January 10, 2002, of two Ashkenazis, Shelly and Monica, who both tested positive for one the genes. Shelly had resisted her doctors' recommended removal of her breasts and ovaries and opted for more frequent exams and sonograms. Monica had watched one sister die of breast cancer and another develop breast cancer at the age of 40 so she opted to have her breasts removed. These are hard decisions to make. One point to remember is that not all women who carry the mutated BRCA1 or BRCA2 gene will develop breast cancer and those who do have no worse survival chances than others.

SUMMARY

While differences exist across ethnic groups, many risk factors are the same for all groups. The number one risk factor is being female; nearly 1,500 men and 216,000


women will be diagnosed this year. The second greatest risk factor is advancing age, which puts all women at greater risk. Close relatives diagnosed with breast cancer increases risk as well. Breast cancer incidence is higher in women of all races and ethnicities who have more education or family income, according to Cornell University Program on Breast Cancer and Environmental Risk Factors. The degree to which consumption of fruit, vegetables, fiber and foods containing phytoestrogens affects breast cancer has not been established and their impact on racial/ethnic differences in breast cancer occurrence is unknown, according to the Cornell study. Fatty diets, however, are believed to play a part in breast cancer occurrence, as does obesity and lack of exercise. Studies are underway to determine the link between tobacco and breast cancer.

Reasons for the difference in survival rates among ethnic groups are not yet fully understood and are thought to be the result of complicated interactions between socioeconomic and medical factors such as stage of the cancer at the time of diagnosis, types of treatment received, tumor aggressiveness, differences within and access to medical service systems, care during and after treatment and general health.

In order to reduce barriers to quality healthcare and promote breast health, with a generous gift from the Avon Foundation, Y-ME has implemented "A Day for You" in underserved communities in San Diego, Chicago and the National Capital Area. Participants in the program learn about earlier detection methods, including breast self-examination (BSE), and receive a clinical breast examination. If appropriate, on-site mammograms are performed, and the program assists women who have abnormal screening results to obtain proper follow-up care. For more information about "A Day for You," call 312-294-8522. 

correspondent, NBC; Diane Blum, M.S.W., executive director, CancerCare, Inc.; Susan J. Blumenthal, M.D., M.P., U.S. assistant surgeon general and rear admiral in the U.S. Department of Health and Human Services; Susan Shinagawa, co-founder/co-coordinator, Asian Pacific Islander National Cancer Survivors Network.

The speakers discussed the progress that has been made during the last two decades and the impact it will have on the future of breast cancer diagnosis and treatment. Topics included new developments in mammography, breast cancer in the media, the evolving role of the patient, breast cancer as a critical health priority and breast cancer detection and treatment disparities in minorities.

As part of the summit, NBCAM honored worthy individuals from the medical community, patient advocate organizations, government bodies and the media for their significant contributions to the fight against breast cancer. Ann Marcou, co-founder of Y-ME National Breast Cancer Organization, was honored for outstanding advocacy and education on behalf of breast cancer patients and women concerned about breast cancer. Martha Haley, patient advocacy consultant, Y-ME National Breast Cancer Organization, was honored for outstanding advocacy on behalf of minorities. To view other award winners and learn more about the summit, visit www.nbcam.org. 

on the side: lymphedema

A Lesser-Known Side Effect of Breast Cancer Surgery

Lymphedema can occur in persons whose lymphatic system has been compromised due to the radiation or surgical removal of lymph nodes. Generally, the more lymph nodes removed, the greater the person's risk is for the chronic condition. Because the lymphatic system has been impaired, the remaining lymph nodes have a harder time circulating lymphatic fluid, causing a build up of excessive fluid that cannot be drained.


Symptoms include debilitating pain and swelling of the limb and can manifest immediately after the injury, or months, even years, later. If left untreated, the condition may worsen and become a more dangerous condition, called cellulitis, requiring hospitalization. To minimize the risk of lymphedema all cancer patients who have had radiation and/or removal of lymph nodes should not allow anyone to give an injection, withdraw blood or take blood pressure from the affected arm. These guidelines should be followed for the rest of the patient's life because lymph nodes do not grow back.

The following precautions may also be taken to prevent or minimize lymphedema:

- Never overuse or over-exercise the affected limb.
- Never perform any heavy lifting with the arm.


- Immediately treat all cuts to the hand or arm. If uncertain about the severity, seek advice from a doctor who knows your medical history. Infections accompanied by a fever are generally treated promptly with antibiotics.
- Protect hands with garden or rubber gloves when doing yard work or chores.

When the patient takes precautions, she has a good chance of avoiding the condition. If lymphedema does occur, it can be managed throughout life, and in some cases, reversed.

One treatment for lymphedema includes a combination of therapies that work together to alleviate symptoms of the condition. Known as complex physical therapy, or CPT, the four-pronged approach to treatment includes the following: 1) skincare to prevent infections; 2) appropriate massage developed for the condition; 3) specially-fitted compression bandages and garments; and 4) special exercises performed at home. Over-massaging can be detrimental to the condition; therefore it is imperative to have a qualified therapist administer the massage to aid fluid drainage. 

Still Time to Purchase the Breast Cancer Stamp



At post offices across the country, the breast cancer stamp will be available through 2006. So far, proceeds from the sale of the stamp have resulted in \$38.7 million for breast cancer research. The goal is to raise \$50 million—let's help make it happen! 



Sherrill, a breast cancer survivor, and Connie are just two of the sisters participating in the Sister Study.


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

It is especially important that women from minority populations participate so that the results of the study will apply to all women in the United States.

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

GAP Flap Procedures in Breast Reconstruction

Implants and tissue expanders remain the most common choices for postmastectomy breast reconstruction, but women are increasingly opting for procedures that use their own tissue. Although the abdomen is commonly chosen as the donor site, the buttock has become a viable alternative, especially for patients who have a thin abdomen, have had previous abdominal surgery, or are nulliparous (have never given birth).

When buttock tissue was initially used in breast reconstruction—first in Japan in 1975 and later in the United States—muscle was transferred along with the fat and skin in a procedure called the *gluteal myocutaneous flap*.

“We could get some excellent results because tissue from the buttock is thick and fat and makes a natural breast, but it was a very, very difficult operation,” says Robert J. Allen, M.D., chief, plastic surgery, Louisiana State University Medical Center, New Orleans, La. “The main shortcoming was that the blood vessels beneath the muscle were too short to easily connect to those in the breast area. If one was able to connect them without vein grafts, the leash was so short that freedom of shaping and positioning the new breast was limited.”

Because of these limitations, Dr. Allen set out to develop a “more doable, much easier, and more reliable operation,” and in the early 1990s, pioneered the gluteal artery perforator (GAP) flap for breast reconstruction.

Perforators, small blood vessels that branch off a main artery and course through muscle, can be dissected through the muscle and transferred to the breast area from the buttock and other potential donor sites, including the abdomen, back and thigh (see page 13). This technique provides surgeons with longer blood vessels with which to work, thus making vein grafts unnecessary, and allows preservation of the muscle at the donor site.

Muscle preservation has many advantages, including maintaining muscle function, decreased postoperative pain and hernia risk and shorter hospital stays, according to Dr. Allen. “In addition, by not taking the muscle, which is typically two inches thick, one avoids the creation of a depression at the donor site, an important consideration in body aesthetics,” he says.

Since 1993, Dr. Allen and associates have performed more than 250 GAP flap breast reconstructions, primarily using the superior GAP (S-GAP) flap procedure (using tissue from the upper buttock). After creating various skin pattern designs—both S-GAP and inferior (lower buttock) GAP (I-GAP) flaps—they recently began hiding the scar in the crease between the lower buttock and thigh, a procedure that maintains the natural buttock shape while giving a “lift.”

Now, after having completed 14 such surgeries, Dr. Allen says, “I was shocked and euphoric to see how nicely it turned out, and so for me, the I-GAP in the crease is the latest breakthrough. I may use it exclusively some day.”

Dr. Allen explains that the inferior gluteal myocutaneous flap (first described in the 1980s) was abandoned primarily because of sciatic nerve complications. “Problems can arise if muscle over the nerve is removed,” he says. “The I-GAP in the crease does not remove muscle, thus the sciatic nerve is protected and free of risk.”

Not far away, at another practice in New Orleans, Drs. Scott Sullivan and Frank DellaCroce, co-directors of the Center for Restorative Breast Surgery, team up to perform bilateral simultaneous S-GAP flaps—32 of them in the past year alone.

Each surgeon works on one side of the patient—preparing the chest, elevating the flaps, closing the buttock, and placing the flaps in the breast pockets. Together, they connect the perforators and close the chest.

“It takes between six and seven hours to do the entire reconstruction, and the benefit to the patient is that it’s one operation and one hospitalization,” says Dr. Sullivan. “We think that we get a better result with bilateral flaps than with staged unilateral operations because we can compare flaps and breast pockets for shape and symmetry.”

The surgical duo prefers performing the S-GAP over the I-GAP flap and tries to locate the flap as high on the buttock as possible, sometimes even incorporating unwanted lower back fat into the flap.

muscle preservation has many advantages, including maintaining muscle function, decreased postoperative pain and hernia risk, and shorter hospital stays

Dr. Sullivan cites several disadvantages of the I-GAP flap procedure, including a higher incidence of sciatica than with the S-GAP flap, the loss of padding from the area on which one sits, the possibility that the scar (initially placed in the crease) will migrate out of the fold and become visible, and less attractive buttock projection.

All three surgeons say that the success rate for GAP flap procedures is nearly 100%. Complications, although rare, include postoperative vascular problems that require readjustment, fluid accumulation in the breast or at the donor site, infection and pain.

“If anything, the results with GAP flap procedures get better over time,” Dr. Allen says. “The scars fade and the nerves slowly grow into the breast. Over time, most women accept the new breast as a body part because it is their own tissue.” 🍷

What Patients Are Saying About the GAP Flap. . .

Lori Green, 43, Farmington, Mich.: unilateral I-GAP flap on May 17, 2004.

"I arrived for my surgery thinking that tissue from my abdomen would be used for the reconstruction, but upon examination and further discussion, it seemed that the I-GAP would be the better choice because recovery would be easier, the scar would be less obtrusive and tissue from the buttock would make a firmer breast. All of this turned out to be true. My mobility two days after surgery was amazing, and when I left the hospital on May 21, I went directly out to lunch to enjoy the local cuisine."

Julie Milner, 41, Tacoma, Wash.: bilateral simultaneous S-GAP flap and second mastectomy on December 29, 2003.

"I wasn't impressed with the high rate of readjustment after implant surgery and didn't want the TRAM flap because it sacrificed stomach muscles. Also, I didn't have enough tissue in my stomach for the DIEP, so the day before the surgery, I decided that I'd better go with the GAP flap. Surgery went as well as it could possibly have gone and the pain wasn't as bad as I thought it would be. Leaning back and getting comfortable in bed were the hardest things to do, but I was off of the pain killers in a couple of weeks."

Linda Craig, 50, Baton Rouge, La.: bilateral staged S-GAP flap on February 13 and February 18, 2003.

"Scar tissue returned three times in two years with my breast implants, so the only alternative was to have them removed. While trying to decide what to do, I saw a TV special on the GAP flap and eventually had the procedure done—in two different stages because the scar tissue was so severe. After coming out of recovery from the first stage, I experienced immediate relief from the pressure, and by the next day, actually looked forward to having the other side done. I was sore for a couple of weeks, but the outcome was worth it."

Jeannine LeBrun, 45, Lakewood, Colo: bilateral staged S-GAP flap on January 29 and February 5, 2004.

"I chose microsurgery using the GAP flap over muscle sacrifice because it offered the quickest recovery, least amount of sacrifices to my body, and the most natural appearance to the 'real thing,' with no implants. My only complication was fluid accumulation at one of the donor sites, but it was drained and healed in a few weeks, with the use of a surgical girdle to keep the area firm. I couldn't be more pleased with my new breasts—they have the same feel and appearance of normal breasts, but firmer and more youthful."

Vicki Stall, 44, Las Vegas, Nev.: S-GAP flap on January 28 and I-GAP flap on February 4, 2004.

"After exploring my options, I opted for the GAP flap because there wasn't enough tissue on my abdomen for remodeling and I didn't want to lose the latissimus muscle from my back or have a foreign implant. I was well enough after my first surgery to get out and do a little shopping before the second one, which was a week later. I healed well, with no complications, and used very little pain medication. My nipple reconstruction was done in May, and I am back in a bathing suit, sun tops and sundresses!"

Betty Doucet, 48, Lafayette, La.: unilateral I-GAP on June 2, 2004.

"I did not want an implant because it seemed unnatural. I was reluctant to have my abdomen cut because physical activity would be limited for the rest of my life and there was a chance of getting a hernia and losing my waistline. I liked the idea of using my own tissue because the reconstructed breast would become part of my body. I chose the lower buttock because recovery would be faster and the incision would be less visible. My surgery went well—there was no pain in the breast area and the discomfort in the buttock was tolerable."

GAP Flap is not for everyone. If you have questions about this or any other reconstruction options, call Y-ME at 1-800-221-2141 and/or consult your physician.

Breast Reconstruction Options

Artificial Surgical Implants

- Implants (filled with saline or silicone gel)
- Permanent tissue expanders

Flap Procedures Using One's Own (Autogenous) Tissue

- Perforator procedures use skin and fat only
 - Deep inferior epigastric perforator (DIEP) flap: abdomen
 - Superficial inferior epigastric artery (SIEA) flap: abdomen
 - Lateral thigh perforator flap: "saddle bag" area of the lateral thigh
 - Thoracodorsal artery perforator (T-DAP) flap: upper back
 - Superior gluteal artery perforator (S-GAP) flap: upper buttock
 - Inferior gluteal artery perforator (I-GAP) flap: lower buttock
- Nonperforator procedures use skin, fat and muscle
 - Transverse rectus abdominis myocutaneous (TRAM) flap: abdomen
 - Latissimus dorsi flap: upper back
 - Lateral thigh flap: "saddle bag" area of the lateral thigh
 - Superior gluteal myocutaneous flap: upper
 - Inferior gluteal myocutaneous flap: lower buttock

Questions? Call the Y-ME Hotline at 1-800-221-2141 for more information.

ASCO 2004 UPDATE: *Clinical Trials and Treatment Breakthroughs*

True to the mission and primary goal of the American Society of Clinical Oncology (ASCO) to improve cancer care and prevention, this year's annual meeting in New Orleans, June 5-8, announced several new trials reporting significant breakthroughs for the treatment of breast cancer.

Participation in Clinical Trials: A Must for Treatment Breakthroughs

Clinical trials are the necessary link between cancer research and improved treatment options for patients, and participation is critical. However, despite the availability and high degree of follow-up, enhanced communication between you and your medical team, and the enhanced quality of care delivered in clinical trials, currently only 6 percent of people in the U.S. participate in cancer clinical trials. Patient participation is essential to ensure that the process of improving cancer care continues to move forward. When you participate in a clinical trial, not only do you receive quality treatment, but you also are playing an important role in helping advance medical knowledge for the prevention, detection, treatment, and one day, the cure of cancer.

Exciting Clinical Trial News in Breast Cancer

Major treatment findings were presented at ASCO, including a study of aromatase inhibitors (e.g., letrozole) as hormonal therapy in early stage breast cancer patients previously treated with tamoxifen, as well as extremely positive results in a trial of Herceptin® plus chemotherapy as targeted therapy prior to surgery, and the use of new chemotherapy regimens and combinations for the treatment of women with breast cancer.

Aromatase Inhibitors

This year at ASCO, exciting new information about the use of aromatase inhibitors, a newer class of agents, to treat early stage breast cancer was reported. These agents aid in the prevention of estrogen produced by inhibiting the enzyme (protein) aromatase, which is linked to the production of estrogen in the body. Although they cannot block estrogen produced by the ovaries, they can block other tissues from producing the hormone. For this reason, aromatase inhibitors are used mostly in postmenopausal women when the ovaries are no longer producing estrogen.

Data from a large international study of over 5,000 postmenopausal women with early-stage breast cancer reported that women taking the aromatase inhibitor letrozole (Femara®) after completing five years of tamoxifen therapy had an overall 18 percent reduction in the risk of death versus placebo and a 39% reduction in the risk of death in women with cancer that spread to the lymph nodes. Additionally, the study demonstrated an approximate 40 percent reduction in the risk of recurrence compared to placebo. These new findings provide a promising new treatment alternative for postmenopausal with hormone positive breast cancer who have either completed five years of tamoxifen or are currently being treated with tamoxifen.

Use of Herceptin in Pre-operative Early Stage Breast Cancer

Herceptin®, a targeted monoclonal antibody therapy, showed significant improvement of anti-cancer responses in HER-2 positive breast cancer

Continued on page 22

Support Y-ME This October



Since 2000, Clarke American Checks, Inc., has offered the Loving Reflections™ line of products, which helps make a difference in the fight against breast cancer. Y-ME receives five percent of every purchase. For more information, visit www.y-me.org and click on Donate Now at the top of the page.



Enesco, producer of fine gifts, collectibles and home décor accessories, will donate a minimum of \$50,000 to Y-ME from the proceeds of its "A Journey of Hope" Precious Moments® figurine. If you haven't had a chance to pick up this piece of Y-ME history for yourself or a friend, go to any store where Precious Moments figurines are sold. Visit www.enesco.com or call 1-800-NEAR-YOU for more information and to locate a retailer in your area.



Essie Cosmetics, LTD, and Y-ME have joined forces to raise awareness for breast cancer through the sale of Essie Pink Ribbon, a limited edition nail polish (a soft pink with a touch of shimmer), that will be available in October. Y-ME will distribute Pink Ribbon polish through fashion show fundraisers and educational programs at local Y-ME Affiliates. One percent of the proceeds of Essie Pink Ribbon will be donated to Y-ME, with a minimum of \$5,000, to benefit the organization.

womenrock!

LIFETIME Television will bring together some of the brightest talent of today to champion the fight against breast cancer with the fifth annual "Women Rock!" The signature concert is part of LIFETIME's award-winning public awareness campaign, "Our Lifetime Commitment: Stop Breast Cancer for Life," now in its tenth year. "Women Rock!" will air Thursday, October 28, 10-11:30 p.m. (ET/PT), on the LIFETIME Television Network.

**SHOE
CARNIVAL**

Stop by Shoe Carnival during October and enter to win tickets for a weeklong vacation aboard "Cruise for the Cure" sponsored by Eastland. Proceeds from raffle ticket sales will benefit Y-ME. For the past two years, Shoe Carnival has donated nearly \$150,000 to Y-ME as a result of this yearly promotion. For more information, visit www.shoecarnival.com.



Wein-Bauer, Inc. and Schlink Haus German Wines have partnered with Y-ME National Breast Cancer Organization in a yearlong promotion: \$3.00 per case of Schlink Haus wine sold will be donated to Y-ME with a minimum contribution of \$75,000. Schlink Haus wines, from Germany's Nahe region, are offered in four different styles (Riesling, Kabinett, Spatlese and Auslese). The wines retail from \$6.99 to \$10.99 per 750-ml bottle and are sold nationwide in stores and restaurants. For more information, visit www.y-me.org or www.weinbauer.com.

October Delivers Breast Cancer Awareness

October is upon us, the month of special significance within the breast cancer community. Now in its twentieth year, National Breast Cancer Awareness Month continues to raise awareness and promote breast cancer education across the country.

Founded in 1985, National Breast Cancer Awareness Month (NBCAM) was conceived by 17 national public service organizations, including Y-ME, the AstraZeneca HealthCare Foundation, the American Cancer Society, the Centers for Disease Control and Prevention, Cancer Care, Inc., the National Cancer Institute, the National Medical Association and others. The beneficiaries of this campaign are inestimable in number, as the level of awareness increases every year.

With emphasis on earlier detection, the third Friday of October is designated as "National Mammography Day." A day marked by the provision of free or discounted mammograms in medical centers across the country, this year's date falls on October 15, 2004. Y-ME, along with several other national organizations, will have a list of participating mammography centers in your area. For more information, call 1-800-221-2141.

National Breast Cancer Awareness Month emphasizes the earlier detection of breast cancer because in the battle

against breast cancer, most of us know that size does matter—smaller is better when it comes to tumor size or cancer occurrence in general. In an attempt to remain vigilant, women of every age and ethnicity are encouraged to follow some basic tips.

Recommended by breast cancer organizations are simple, yet easy to neglect, methods of earlier detection. They include monthly breast self-exam (BSE) for women 20 and older, clinical examination of the breast by a health care professional and mammograms for women 40 and older (sometimes younger if there is a family history). Implement these practices, and encourage others to do the same, so that if breast cancer is present it may be caught early.

For those who wish to become more involved, opportunities abound in all communities. Anyone who desires to spread the word about early detection and breast cancer awareness may become a National Breast Cancer Awareness Month (NBCAM) Program Leader. From diverse backgrounds, these leaders facilitate breast cancer programming in community centers, schools, churches, shopping malls and even in private homes. If you are interested in leading the way in making a difference in your community, visit NBCAM at www.nbcam.org.

Olivia Newton-John Promotes Early Detection



Margaret C. Kirk, Y-ME CEO (right), joins Olivia Newton-John at a press lunch announcing Y-ME as the call center for all Liv Aid breast-health-related questions.

Six-time Grammy winner and 12-year breast cancer survivor Olivia Newton-John has been working with Y-ME and other breast cancer organizations to promote earlier detection. Earlier this year, Olivia introduced the Liv Aid, a simple device she hopes will easily enable a woman to feel what is "normal" for her breasts, increasing her chances of discovering lumps, bumps or abnormalities at an early stage.

If a woman finds something suspicious, she is instructed to see her medical professional. "But if she has more questions or is looking for support, she is invited to call the 24-hour Y-ME National Breast Cancer Hotline at 1-800-221-2141," explained Margaret.

Olivia said, "I'm absolutely thrilled to partner with Y-ME and the women who will be able to share a range of experiences, impart information to women and appease their fears."

The Liv Aid is available nationwide at Albertsons stores (www.albertsons.com), including Savon Drugs, Jewel Osco, Osco Drugs, Shaws, Acme and savon.com.

Y-ME continues to uphold its policy of not endorsing any products or services. While we are not endorsing the product itself, we are pleased that through this partnership more people who need our services will know about Y-ME.

Y-ME Welcomes Its Newest Affiliate: Y-ME Texas Gulf Coast



Created by Y-ME to fill a much-needed gap in resources, Y-ME Texas Gulf Coast will bring programs and services to the greater Houston area. Leading the new Affiliate is Debra Johnson, executive director.

Debra Johnson comes to Y-ME from Hope Cottage Pregnancy and Adoption Center in Dallas, where she was director of development. Prior to that she was executive director of Prevent Blindness in Fort Worth. She also has worked for the American Red Cross in New Jersey and for Easter Seals in Texas. A graduate of Connecticut College and Yale Divinity School, Debra was the first woman ordained by the Hungarian Reformed Church.

This year about 6 percent of all Americans diagnosed with breast cancer will be Texans. To address the needs of those survivors, Debra plans to instate Y-ME Open Door support groups in Houston. Through "A Day for You" programs in Asian and Hispanic communities, the new Affiliate will provide breast health information and mammograms to women with limited resources. Texan survivors already are being trained to be peer counselors who will answer the Hotline.

For more information and to get involved with the Affiliate, contact Debra at djohnson@y-me.org or (713) 624-7155. Y

One Call + Two Inspiring Days = An Opportunity to Help Others

To broaden the reach of the enhanced Y-ME Hotline and to further advance staff and volunteer expertise, Y-ME Affiliates have successfully mobilized efforts to institute the National Peer Counselor Training and Certification program. Breast cancer survivors who wish to donate their time and support to others—and seek a flexible volunteer schedule—can easily arrange to participate in one of the two-day workshops offered throughout the country. The standardized curriculum encompasses educational modules designed to foster effective communication strategies and clarify medical information relevant to breast cancer. A separate course is available to train instructors interested in facilitating peer counselor trainings.

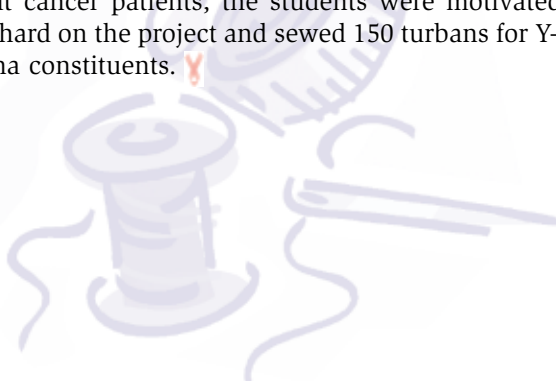
More than 100 active peer counselors have attended training since the national program was instituted earlier this year; one-third have received new certification status through the National Capital Area Affiliate, and the rest became involved through other Y-ME Affiliates and the national office. Although she has effectively administered a separate HOPEline and counselor-training program since 1989, Kathy Alleman, Y-ME NCA executive director, fully supports the uniform training initiative. In fact, members of the National Capital Area Affiliate have been instrumental in the development of the new curriculum.

A winning combination of direct referrals and marketing efforts continue to assist the Virginia-based Affiliate to attract and retain peer counselor candidates. "The majority of our Hotline volunteers are clients who have been helped and they want to give back to others," explains Kathy. "Our current volunteers also speak with those they know who may qualify." Other avenues of recruitment include advertising training dates in their *Images* newsletter, on their Web site and through local community volunteer bureaus.

According to Dina Clevenson, board president of the National Capital Area Affiliate, the training program also strives to address issues of diversity with units that cultivate sensitivity to cultural mores and perspectives on cancer. Efforts to disseminate information to diverse populations advanced even further with the hiring of a Latina coordinator for the "A Day for You" program, as well as the hiring of a part-time volunteer coordinator. Y

If you are a breast cancer survivor seeking a unique opportunity to help others manage their cancer experience, consider serving the Y-ME community as a Hotline peer counselor. For more information, call 1-312-294-8514.

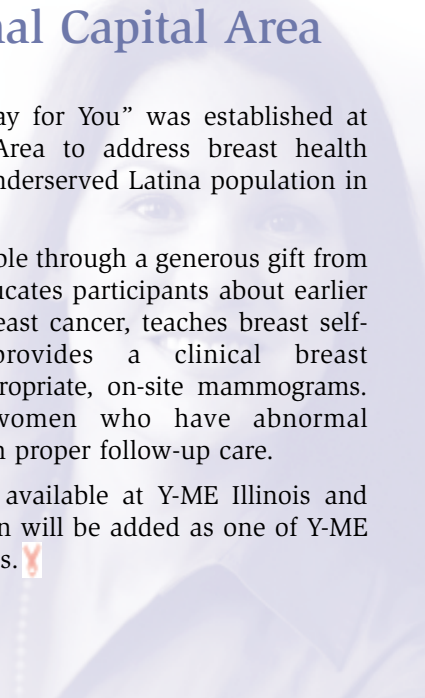
Indiana Students Sew Turbans for Cancer Patients

Y-ME Indiana was the beneficiary of a unique school project—turbans for breast cancer patients. Kay Brown's sewing class at Franklin Central High School gathered scraps of fabric left from other projects and decided not to let them go to waste. Knowing that the turbans would benefit cancer patients, the students were motivated to work hard on the project and sewed 150 turbans for Y-ME Indiana constituents. 

“A Day for You” Now at Y-ME National Capital Area

This past summer, “A Day for You” was established at Y-ME National Capital Area to address breast health issues in the medically underserved Latina population in the region.

The program, made possible through a generous gift from the Avon Foundation, educates participants about earlier detection methods for breast cancer, teaches breast self-examination (BSE), provides a clinical breast examination, and, if appropriate, on-site mammograms. The program assists women who have abnormal screening results to obtain proper follow-up care.

“A Day for You” is also available at Y-ME Illinois and Y-ME San Diego, and soon will be added as one of Y-ME Texas Gulf Coast's services. 

Affiliates of Y-ME National Breast Cancer Organization

CALIFORNIA

Northern California Affiliate

Velma Lagerstrom, CEO
900 Kent Drive
Davis, CA 95616
Tel: (530) 753-3940
Fax: (530) 753-5013
M-F 9a.m.-5p.m.
www.y-me.org/northerncalifornia
vlagerstrom@y-me.org

Southland California Affiliate

Linda DuPon, President
17300 17th Street, Suite J-203
Tustin, CA 92780
Tel: (714) 836-5886
Toll free: (877) 377-4963
Fax: (775) 659-2605
M-F 8a.m.-5p.m.
www.y-me.org/southlandcalifornia
ldupon@y-me.org

San Diego Affiliate

Kathryn Hudson, Executive Director
254 East Grand Ave., #205
Escondido, CA 92025-2803
Tel: (760) 839-1491
Fax: (760) 839-1703
Hotline: 877-929-9283
M-F 9a.m.-5p.m.
www.y-me.org/sandiego
khudson@y-me.org

COLORADO

Rocky Mountain Affiliate

3773 Cherry Creek Drive North
Suite 575
Denver, CO 80209
Tel: (303) 331-6420
Fax: (303) 331-6421
Office Hours: M-F 8a.m.-5p.m.
Hotline Hours: M-Su 7a.m.-10 p.m.
www.y-me.org/rockymountain

CONNECTICUT

Connecticut Affiliate

Barbara C. Oliver
Executive Director
1169 Main Street, #B3
Branford, CT 06405-3779
Tel: (203) 483-8200
Fax: (203) 488-5670
Hotline: 800-933-4963 *CT only
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boliver@y-me.org

ILLINOIS

Illinois Affiliate

Ruth Brody, Executive Director
203 N. Wabash Avenue
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Chicago, IL 60601
Tel: (312) 364-9071
Fax: (312) 364-9066
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INDIANA

Indiana Affiliate

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Executive Director
1050 East 86th Street
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Fax: (317) 844-6024
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dmelton@y-me.org

OKLAHOMA

Northeastern Oklahoma Affiliate

Beth Cordingley, Executive Director
6465 South Yale
Suite 611
Tulsa, OK 74136
Tel: (918) 481-4838
Fax: (918) 481-4837
Tu, W, Th 9:30 a.m.-2:20 p.m.
www.y-me.org/northeasternoklahoma
bcordingley@y-me.org

TENNESSEE

Chattanooga Affiliate

Lynda Levan, Executive Director
Memorial Hospital
Breast Resource Center
2525 deSales Avenue
Chattanooga, TN 37404
Tel: (423) 495-7724
Fax: (423) 495-4451
M-F 8:30 a.m.-4:30 p.m.
www.y-me.org/chattanooga
llevan@y-me.org

TEXAS

Texas Gulf Coast Affiliate

Debra Johnson, Executive Director
1535 West Loop South, Suite 200
Houston, TX 77027
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VIRGINIA

National Capital Area Affiliate

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Hotline: (703) 461-9616
M-F 8:45 a.m.-4:45 p.m.
www.y-me.org/nationalcapitalarea
kalleman@y-me.org

Enrolling Minorities and the Elderly

Breast cancer clinical trials serve the function of investigating risk reduction strategies and cutting-edge therapeutic options, yet enrollment, low in all patient groups, is especially so among minorities and the elderly.

"Without sufficient numbers of minority and elderly patients participating in trials, it is difficult to develop diagnostic and therapeutic strategies that are applicable *specifically* to these populations," says Vivek H. Murthy, M.D., M.B.A., Harvard Medical School, Department of Medicine, Brigham and Women's Hospital, Boston, Mass. "Additionally, individual trial participants likely benefit from the meticulous care that is provided as part of trial protocols—regardless of whether they are in the experimental or placebo group—as well as from the knowledge that their participation is helping scientists to learn more about treating and curing breast cancer."

Clinical trials are conducted by federal agencies, such as the National Institutes of Health and the National Cancer Institute (NCI); nonprofit organizations—most commonly, academic medical centers and community hospitals; and private industry.

Overall, about 6 percent of patients with breast cancer participate in clinical trials.

In a recent study, the results of which were published in the *Journal of the American Medical Association*, Dr. Murthy and colleagues examined race-, sex-, and age-based participation disparities in breast, colorectal, lung and prostate cancer clinical trials conducted by NCI-funded cooperative groups between 2000 and 2002.

The authors found that of the 19,893 women enrolled in therapeutic nonsurgical breast cancer clinical trials, 87 percent were white; 7 percent were black; 3 percent, Hispanic; 2 percent, Asian/Pacific Islander; and less than 1 percent, American Indian/Alaskan native.

Study results showed that women aged 65 years and older were significantly underrepresented in breast cancer trials, compared with women aged 30 to 64 years, and that women aged 75 years and older were *more* underrepresented than those between ages 65 and 74 years. In addition, the "strikingly low" participation of elderly patients, which also has been observed in earlier studies, has changed little during the past decade, Dr. Murthy says.

"Many barriers—lack of medical insurance, time, invitation, access to the institution or doctors


conducting the trial and knowledge about the trial, as well as misbeliefs about trials and the bias of providers toward including certain groups in trials—discourage underserved groups from participation," says Electra D. Paskett, Ph.D., associate director for Population Sciences in the Ohio State University Comprehensive Cancer Center, Columbus, Ohio.

Dr. Paskett, herself a breast cancer clinical trial enrollee who credits participation with saving her life, says that recruitment strategies (e.g., mass publicity campaigns, mailings and physician referral) should define and address the *specific* target population. She advocates taking the message directly to ethnic neighborhoods, using a "familiar face" to introduce the trial to the community, and providing benefits, such as free medical testing and medications, for participation.

In an article recently published in *Clinical Advances in Hematology and Oncology*, Dr. Paskett and colleagues proposed the Accrual to Clinical Trials (ACT) framework, a paradigm for enhancing the recruitment of underserved populations in clinical trials at multiple levels—patient/provider, system, and community/society. Using strategies like ACT, the representation of minorities in clinical trials will increase, thus making possible improvements in the incidence, survival and mortality rates in minority populations, the authors write.

According to Dr. Murthy, ensuring access to cancer research studies for ethnic/racial minorities, women and the elderly has been "an important aim of national research policy." He points to the 1993 NIH Revitalization Act, in which Congress mandated that minorities and women be included in trials in sufficient numbers to conduct analyses applicable to the subgroup in question, as the most notable action to encourage minority participation.

Dr. Murthy states that to address concerns about enhancing the heterogeneity of trial populations, the NCI created the minority-based Community Clinical Oncology Program (CCOP), developed focused initiatives with the Centers for Disease Control and academic medical centers, and increased emphasis on clinical trials that focus specifically on the elderly.

Minority and elderly participation is "a dynamic, complex challenge that will likely demand further research to elucidate the causes of low participation and to develop and test interventions from the policy level to the population level," says Dr. Murthy. 

Enrollment Underway for Ovarian Cancer Prevention and Early Detection Study

The enrollment phase of the Ovarian Cancer Prevention and Early Detection Study, a clinical trial sponsored by the National Cancer Institute (NCI) to identify ways of decreasing the risk of ovarian cancer and improving strategies for early detection, is underway at 80 Gynecologic Oncology Group (GOG) centers across the country.

“About 30 percent of women with ovarian cancer survive longer than five years, but if diagnosed and treated before the cancer spreads beyond the ovaries, 90 percent to 95 percent of patients live longer than five years,” said Mark H. Greene, M.D., Division of Cancer Epidemiology and Genetics, National Cancer Institute, Rockville, Md. “Developing effective prevention and early detection methods is crucial in fighting this disease, particularly for women who are at much greater risk.”


Women aged 30 years and older who are at increased genetic risk of developing ovarian cancer because they have a strong family history of breast and/or ovarian cancer, a BRCA1 or BRCA2 gene mutation or a close relative with such a mutation may be eligible for participation. Participants will be divided into two groups to evaluate intervention strategies for the prevention and early detection of ovarian cancer. Group assignments will be based on participant preference.

Women in the prevention group will undergo removal of the ovaries and fallopian tubes to determine the extent to which prophylactic surgery decreases the risk of developing ovarian cancer. Women in the early detection

group will be screened frequently with a CA-125 blood test to determine whether ovarian cancer can be detected in its early stages. At study entry, all participants will complete personal, medical and family history questionnaires and undergo screening mammogram, transvaginal ultrasound and CA-125 blood testing.

“Women with a strong family history of breast cancer are eligible for this study because breast cancer is an integral component of the most common genetic forms of ovarian cancer—that is, the syndromes caused by mutations in the BRCA1 and BRCA2 cancer susceptibility genes,” Dr. Greene said. “For this reason, women from multiple-case breast cancer families in which a disease-causing mutation in one of these two genes has been identified as the genetic basis for their family’s breast cancer predisposition are routinely counseled regarding how to manage their risk of ovarian cancer, *even when no ovarian cancer has yet been identified in their family.*”

Trial investigators expect to enroll about 3,400 women during the next three years. Once enrolled, women will be followed for five years.

Additional information about the Ovarian Cancer Prevention and Early Detection Study can be obtained by visiting the study Web site (<http://ovariancancer.gog199.cancer.gov>) or by calling GOG (1-800-255-3053) or the NCI information service (1-800-4-CANCER). 

Y-ME does not endorse any trial or study. Always discuss participation with your medical team prior to enrollment. For more information, call the Y-ME Hotline at 1-800-221-2141.

Y-ME Forum Webcast Now Available

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 event or would like to listen again, visit Y-ME’s Web site to access the webcast, produced through a partnership with HealthTalk.

The program features Y-ME National Board Member Larry Norton, M.D., who spoke on the latest developments that prolong survivorship and increase quality of life. Sarah Rosenbloom, Ph.D., followed with a presentation that addressed psycho oncology, quality of life and how cancer diagnosis and treatment affects people’s life goals.

About the Speakers

Larry Norton, M.D., deputy physician-in-chief for breast cancer programs at Memorial Sloan-Kettering Cancer Center, has broadly influenced breast cancer treatment and

research for more than 25 years. Dr. Norton is a former president of the American Society of Clinical Oncology (ASCO), a current Y-ME National Board member and has won numerous awards in the field.

Sarah Rosenbloom, Ph.D., is an instructor for the Department of Psychiatry and Behavioral Sciences, Feinberg School of Medicine, Northwestern University. As part of the Center on Outcomes, Research and Education (CORE) at Northwestern University, Dr. Rosenbloom applies clinical research to improve patient care and influence policy.


For more information and to access the webcast, visit www.y-me.org.



Special thanks goes to Novartis Oncology and Pfizer Oncology for supporting this year’s forum.

Y-ME Rated Exceptional by Charity Navigator

Charity Navigator rated Y-ME as Exceptional (☆☆☆☆)—its highest possible rating—in its June 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 Y-ME's Web site at www.y-me.org. 


Consider a Year-End Gift to Y-ME

Be on the lookout for our year-end appeal in your mailbox. Highlights from this year include amazing advancements to the Y-ME National Breast Cancer Hotline, the creation of the Y-ME Support Center and a new training and certification program for peer counselors. Also learn about the benefits of becoming a member of our brand new donor club, *Answering the Call*.

Please consider making a year-end gift by responding to our appeal via mail or online at www.y-me.org. All undesignated funds will be used to support the enhanced Y-ME National Breast Cancer Hotline. Because of your commitment, Y-ME is able to continue working to ensure that no one faces breast cancer alone by providing all of our support and educational programs free of charge to those who need them most.


Take Advantage of Matching Gifts

You may be able to increase the impact of your contribution if your company has a matching gift program. Most programs match contributions dollar for dollar, and some will even double or triple the amount of your gift! Contact your company's human resources department to find out if it offers a matching gift program or to obtain a matching gift application.

By making a contribution to Y-ME before January 1, not only are you supporting groundbreaking programs such as the enhanced Y-ME National Breast Cancer Hotline, but you may also be able to take advantage of federal tax incentives for charitable giving. Please consult your tax preparer for details on available deductions or limitations. 

Make a Gift in Memory or Honor of a Loved One during National Breast Cancer Awareness Month


Remember and honor those in your life by making a tribute gift this October. Tribute gifts are a wonderful way to remember someone who has been touched by breast cancer. Tribute gifts can be used to commemorate a holiday, birthday, wedding or other

special occasion. Y-ME will send an acknowledgment of your gift to the person(s) you identify, to notify him or her of your thoughtfulness and generosity. Visit www.y-me.org to make your tribute gift online or call (312) 986-8338. 

Support Y-ME in the 2005 Combined Federal Campaign

Are you a federal employee? Planning to participate in the upcoming Combined Federal Campaign (CFC)? Help support Y-ME's efforts to ensure that no one faces breast cancer alone by designating your contributions to **CFC CODE 2808**.

The CFC is the annual fundraising campaign in federal workplaces each fall. Every year, federal


employees and military personnel raise millions of dollars through the CFC to benefit thousands of charities, including Y-ME National Breast Cancer Organization. Please keep Y-ME (2808) in mind when choosing your CFC designations for this year's campaign. 



Soraya, a Columbian-American singer-songwriter, battled breast cancer for three years. Now, she's a spokesperson for Aventis and livingwithit.org, and raises awareness of the disease by promoting early detection.

Pictured here is Soraya (left), 2004 Y-ME Celebrity RACE Chair, with Y-ME CEO Margaret C. Kirk earlier this year at a University of Illinois at Chicago concert and breast cancer awareness event.


Margaret C. Kirk among Chicago's 100 Most Influential Women

Margaret joins the ranks of women such as Oprah Winfrey and Maggie Daley as one of the most influential women in Chicago. In its June 7 issue, *Crain's Chicago Business* singled out 100 women who have made significant contributions in the city and beyond. In addition to providing exceptional leadership, Margaret has more than doubled Y-ME's budget in less than three years, enabling Y-ME to expand its community outreach efforts and continue providing programs and services to anyone touched by breast cancer. To read the full story, visit our Web site at www.y-me.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. To obtain a hard copy of the trial brochure or have one sent by e-mail, call 1-800-221-2141. 

Y-ME Goes Multilingual

Y-ME is proud to announce that information written in Chinese, Korean and Vietnamese is now available at www.y-me.org. The new pages focus on early detection and encourage readers to call the Y-ME Hotline to speak with a trained peer counselor through an interpreter. On the Hotline, interpreters are available in 150 languages. 

Where Can You Find Information in Farsi?


On the Y-ME Hotline! Including Farsi, Y-ME provides interpreters for 150 languages 24 hours a day. To use the service, callers simply dial 1-800-221-2141 and say their language in English. Then, they are connected to an interpreter and a peer counselor who facilitates the call. 

Register to Vote!

Now's your chance to make your voice heard. If you haven't already registered, visit one of these Web sites to register online and find information on the subject.

www.workingforchange.com/vote

www.vote-smart.org

www.declareyourself.com 

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ASCO 2004 UPDATE: Focus on Survivorship

patients when combined with chemotherapy prior to surgery. Following neoadjuvant therapy (chemotherapy administered prior to surgery), 67 percent of patients treated with Herceptin® had no detectable cancer, in comparison to the 25 percent treated only with chemotherapy. Although the researchers concluded that the addition of Herceptin® to neoadjuvant chemotherapy in HER-2 positive breast cancer is superior to chemotherapy alone and is well tolerated, continued research is needed to determine the long-term survival benefits. However, researchers at M.D. Anderson have adopted this treatment regimen as the standard treatment for this group of patients.

Recent Developments in Chemotherapy

Weekly paclitaxel. Recent results from a study of metastatic breast cancer concluded that chemotherapy treatment with weekly doses of paclitaxel (Taxol®) provides superior outcomes compared to the standard every-three-week regimen. Anti-cancer responses were achieved in 40 percent of patients treated with weekly paclitaxel compared to only 28 percent of patients treated every three weeks. Overall survival was 24 months for patients treated with weekly paclitaxel, compared to only 16 months for patients treated every three weeks. And, despite a higher incidence of numbness and tingling in the hands and feet, fewer abnormalities of blood cell levels appeared. Researchers concluded that weekly paclitaxel with or without Herceptin® should be adopted as a new standard dosing regimen for patients with metastatic breast cancer.

Gemzar® plus paclitaxel. Recently approved by the FDA for the treatment of advanced breast cancer, Gemzar® (gemcitabine), when combined with paclitaxel, provides significant improvements in patient outcomes compared to treatment with paclitaxel alone. In a study with 529 women with metastatic breast cancer, anti-cancer response rates were reported in 40.8 percent of patients treated with Gemzar® and paclitaxel compared to 22.1 percent for paclitaxel alone. Overall survival rates were significantly improved as well with a 70.7 percent survival rate at one year for Gemzar®/paclitaxel treated patients versus 60.9 percent for paclitaxel alone. Furthermore, the Gemzar®/paclitaxel regimen was very well tolerated with fewer side effects than some single-agent breast cancer therapies. 

Please note, although the data presented here is encouraging, it is important to remember that it is still preliminary. As always, work with your doctor and your entire treatment team to determine which is the best treatment plan for you.

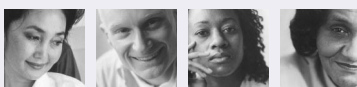
For coverage of additional ASCO announcements, visit www.y-me.org and click on News Room, then Breast Cancer News. To discuss the findings with a trained peer counselor who is also a breast cancer survivor, call the Y-ME Hotline at 1-800-221-2141.

Lifeline

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resources

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

Organizations



The National Lymphedema Network

1-800-541-3259

www.lymphnet.org

Provides education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphedema.

The Lymphology Association of North America

www.clt-lana.org

Promotes standards for management of individuals with lymphedema and or related disorders, establishes and maintains certification for medical professions who provide such services and to promote the awareness and science of lymphology.

Books



Amazon Heart - Coping With Breast Cancer Warrior Princess Style

By Megan Dwyer and Meredith Campbell

Megan and Meredith, two ordinary women in their early thirties, literally faced the challenge of their lives when diagnosed with aggressive breast cancer.

In true Amazon style, they fought their way through months of debilitating treatment to continue working, traveling the globe and competing in elite level sports.

Their story is an inspiration to anyone facing challenges of life changing proportions. More than that, it provides practical coping strategies for dealing with an immediate crisis, and building a life beyond when your worldview has irrevocably changed.

Ten percent of the retail sales price of all books sold will be donated to breast cancer charities that provide peer support, including Y-ME. Visit www.y-me.org today to find out how to order your copy.



save the date

September 14, 2004

Online chat with Y-ME National Board Member Dr. Susan Love and three experts

8:00 p.m. CST at www.susanlovemd.org.

TOPIC: Metastatic Disease: Beyond Hormones

GUESTS: **Debu Tripathy, M.D.**
Director, Komen Center for
Breast Cancer Research
University of Texas
Southwestern Medical Center
at Dallas

Joyce A. O'Shaughnessy, M.D.
Co-Director, Breast Cancer
Research Program
Baylor-Charles A. Sammons Cancer Center
Dallas

Musa Mayer
15 year Survivor, Advocate and
Author of three books on
breast cancer.
New York City

To participate, visit www.susanlovemd.org five minutes before the program begins. If you'd like to submit a question, please do so ahead of time on the same Web site.