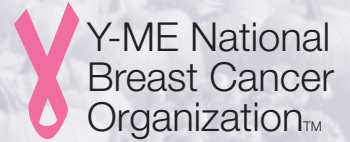


# Lifeline

A Quarterly Publication of Y-ME National Breast Cancer Organization



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## The Many Voices of Y-ME

*Encouraging Support within a Diverse Community*

When Mamta Kalidas, M.D., assistant professor at Baylor College of Medicine in Houston, Texas, recently met with a Vietnamese breast cancer patient at a local breast oncology clinic, a county interpreter was unavailable. A board member of the Texas Gulf Coast Affiliate of Y-ME, Dr. Kalidas knew that the Y-ME Hotline provided interpreters. She immediately contacted the Y-ME Hotline and a peer counselor was able to set up a three-way call with an interpreter. "It was a tremendous help because the patient spoke no English and the Y-ME Hotline was able to interpret for the patient in Vietnamese," Dr. Kalidas recalls. The patient was in treatment and Dr. Kalidas was able to give her valuable information about her treatment plan and side effects. "Y-ME peer counselors have always gone out of their way whenever we ask for help...They have always been there to help out the patients," Dr. Kalidas adds.

This story serves as one example of how the free 24-hour Y-ME National Breast Cancer Hotline embraces diversity within the breast cancer community. In fact, whatever language you speak, Y-ME speaks your language. In addition to a designated Spanish Hotline number, the Y-ME Hotline offers interpreters in 150 languages, and accessing an interpreter in your language of choice is easy. Simply call the Hotline at 800-221-2141 and state the desired language in English

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## Breast Cancer Doesn't Discriminate

*An overview of the disease in diverse communities*

Marilyn Douglas, 42, a Seminole Indian from Okmulgee, Okla., may well owe her life to the proactive and compassionate outreach of her nurse at the Creek Indian Clinic. Douglas had her first mammogram only because this clinician scheduled the appointment when Douglas visited her for birth control.

"I went for the mammogram and they found a lump," says Douglas, surprised because she was so young.

In small towns and big cities across America, people are working to educate diverse communities, encourage routine breast exams and provide access to treatment—even when women have no insurance. One excellent model, where cultural communities, the state and support organizations like Y-ME are working together to make a difference is in Oklahoma, the site of the largest Native American population in the country.

Cherrah Quiett, a social worker who holds an elected position on the Muscogee (Creek) Nation National Council as Tulsa District Representative, says there is a push in Indian Country to try to educate women about breast cancer.

"Our people are very proud and very private," says Quiett. "Many of them still use traditional healers or medicine men. Often they do not ask for information from anyone. We have to go to them and not expect them to come to us. We have to let our people know that it is okay to ask for help."

For reasons that are still unclear, breast cancer strikes more white women than any other race or ethnic group, followed by African Americans.

Among other things, Quiett educates tribal women about the new Medicaid program for breast cancer under the Oklahoma Breast and Cervical Cancer Treatment Program and assists them in getting approved for the program. She helps arrange child care and transportation as needed. Quiett and Beth Cordingley, executive director of Y-ME Northeastern Oklahoma, are talking about starting a tribal support group for women with breast cancer.

Douglas says she received medical care from both the Creek and Cherokee tribes, and then signed up for the Oklahoma Breast and Cervical Cancer

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# message from margaret



Dear Readers,

We take the mission of Y-ME—to ensure that no one faces breast cancer alone—very seriously. It's important to us that we truly reach out so that “no one” has to cope with the disease without support. Our mission extends to people of all ages and cultures because we recognize that breast cancer doesn't discriminate. In fact, the two greatest risk factors are being a woman and getting older, both of which clearly are not based on ethnicity, culture or language. No matter who you are, Y-ME is here to provide information and support.

Even in our early years, Y-ME served diverse communities. From the launch in 1994 of our Spanish-language Hotline, to our bilingual Spanish/English newsletter called *Latina News*, Y-ME has directed its efforts to anyone in the Latina/Hispanic population touched by breast cancer. Since 2003, we also have been offering real-time interpreters in 150 languages on our Hotline (see “Y-ME Launches Web Sites in Five More Languages” on Page 18). While we do not claim cultural competency in 150 traditions, we can speak the language of most any caller and refer her/him with sensitivity to the resources she/he needs. Additionally, we offer Web content in seven languages and some print materials in eight languages.

One of the things that first drew me to Y-ME was its commitment to valuing differences. Increasing diversity on our staff and board of directors, and providing outreach programs such as *A Day for You* (see “Y-ME's *A Day for You* Brings Breast Health to Underserved” on Page 14), demonstrates Y-ME's dedication to including everyone. That's why this issue of *Lifeline* focuses on breast cancer in diverse communities.

October is National Breast Cancer Awareness Month, and people everywhere have breast cancer on their minds. While Y-ME focuses on the disease year 'round, we realize that the heightened awareness affords us a special opportunity to encourage women and their loved ones to take action. Some people ignore earlier detection guidelines because they prefer not to face the possibility of a diagnosis, but we believe that not knowing is even worse. Last year, results of a study conducted by researchers from the University of Michigan Health System showed that the average woman guessed her breast cancer risk to be three times higher than it actually was. The findings illustrate that people who don't know their risk are likely to exaggerate it.

We recommend that you do all you can to be informed about breast cancer—know your risk, make appointments for age-appropriate screenings and urge the women in your life to do the same. It is empowering to know you are doing everything you can. If you have any questions about breast cancer or earlier detection, please know that Y-ME is here whenever you need to talk—feel free to call us at 800-221-4121.

Sincerely,

A handwritten signature in cursive script that reads "Margaret C. Kirk".

Margaret C. Kirk  
Y-ME Chief Executive Officer

# letters to the editor

## Readers weigh in on breast cancer and relationships



In each issue of our monthly eNewsletter, *Peer to Peer*, readers send us their comments on the featured topics. Several months ago, we asked how breast cancer has affected relationships, and our readers shared with us a variety of ways.

Many readers expressed that they are more appreciative of their families and friends. One woman said, “Having cancer has been tough, but my life has taken on new meaning, and I have never been happier or more grateful for the love of family and friends.”

Others let us know that they wished loved ones would continue to talk about breast cancer, even after treatment is completed. A reader told us, “Since I have been through my treatments, no one really asks how I am doing anymore. For me, sometimes talking about it helps a little.”

To read more—and to sign up to receive *Peer to Peer*—visit [www.y-me.org](http://www.y-me.org) and click on “Join Mailing List.”

I’d like to thank Y-ME for being there pre-surgery and since then as well. I always learn something from *Lifeline*. Keep up the good work.

~ Patricia O’Hanlon  
Jersey City, NJ

## Thank You For All You Do

After reading your summer issue it inspired me to write a poem and I just thought I would share it with you. I still would like to see more information and articles on mastectomy with reconstruction—I have implants and no one seems to address the issues pertaining to that process. I thank you for all you do.

Here is my poem:

### Cancer Came to Visit Me

*Cancer came to visit me,  
Doctors said remove your breasts  
that would be the best.*

*I have three sons and nursed them all,  
Grown and strong men who now stand tall.  
One said to me "Remove them, Mom  
No questions asked,  
Remember Mom they've finished their task."*

*So surgeons took my breasts  
And set me free.  
The visit ended and Cancer left me.*

*While Cancer may have come to visit me,  
I had Cancer it didn't have me.  
It could not take me heart and soul.  
With a bit of a fight I set it free,  
and now a survivor I would be.*

*Now I'm Mom  
and free to be me!  
~ Christine L. Davis  
Detroit, Michigan*

## We Want to Hear from You!

This issue of *Lifeline* focuses on breast cancer in diverse communities and we would love to know what you think about the subject. What are your experiences and ideas?

Please e-mail us at [contact@y-me.org](mailto:contact@y-me.org), write via the Web site—[www.y-me.org](http://www.y-me.org)—or mail to  
Y-ME,

Attn: *Lifeline* Editor,  
212 W. Van Buren Street, Suite 1000,  
Chicago, IL 60607

Please include the city and state where you live.

Letters may be edited for length and clarity. All names and locations will be included unless otherwise requested.

# Breast Cancer in Young Women



There is a widespread misperception that young women do not get breast cancer. The reality, however, is that they can—and *do*. Just ask GERALYN LUCAS or GINA LAPAPA. They are among the more than 250,000 women in the U.S. younger than age 40 who are living with breast cancer today. While only 5 percent of all breast cancer cases occur in women under 40, it means another 11,100 women in this age group will be diagnosed with breast cancer this year. And 1,100 will die—making breast cancer the leading cause of cancer death among women aged 15 to 54.

“I never thought I could get breast cancer in my 20s,” says GERALYN, who was diagnosed 11 years ago at age 27 when she found a lump through breast self-examination, which her doctor-husband urged her to perform after he saw a 28-year-old patient die of breast cancer. “I had no family history of breast cancer. I was doing medical stories for ‘20/20’ [at the time she was a producer at the ABC TV news magazine], and thought I was informed. But there’s so much misinformation out there.”

There also was little research or educational material devoted to the issues relevant to younger women, such as fertility, pregnancy, breast-feeding, treatment choices and psychological and social considerations. This lack of resources prompted GERALYN to write about her experience in a gutsy, funny and poignant memoir entitled, “Why I Wore Lipstick to My Mastectomy.”

“When I was diagnosed, I didn’t know any other young woman with breast cancer,” she says. “I so wanted to hear someone else’s voice, someone who was going through what I was going through. Even doctors were so reactive to my age, saying ‘You’re only 27!’—which made a hard situation worse, and I felt even more alone.”


Young women often are diagnosed at a later stage than older women, because they—and their doctors—assume they are too young to get breast cancer and ignore warning signs.

Gina LaPapa felt alone in her struggle, too. In 2003, the stay-at-home mom who runs a nutritional supplement business from her Lemont, Ill., residence was 25, eight months pregnant with her second child and breast-feeding her first, when her nipples started to crack and bleed. For more than a year, Gina tried to find out why.

“One set of doctors dropped me because I wouldn’t stop nursing,” she recalls. “But I was sure this wasn’t a nursing issue.” Fearing cancer, she went to see two different breast specialists and asked them to perform a biopsy. One simply refused; the other said she was “awfully young” to have cancer and suggested she see a dermatologist. By chance, she mentioned it to her family doctor when she took her daughter

## Thank You for the Prostheses

Y-ME thanks Elegant Essentials in Medina, Ohio, for its generous donation of bras and prostheses. The post-mastectomy boutique collected donations from its customers and in turn passed them on to Y-ME.

The Y-ME Wig & Prosthesis Bank provides free-of-charge products to women with limited resources. For more information, call 800-221-2141. 



## Have a Breast Cancer or Breast Health Question?

Feel free to call the Y-ME National Breast Cancer Hotline at 1-800-221-2141 or visit [www.y-me.org](http://www.y-me.org) to submit your questions. All online requests are answered promptly.

for a routine check-up; he had been a breast surgeon before going into family practice. He took one look and diagnosed Gina's condition as Paget's disease, a rare form of intraductal breast cancer that involves the nipple and areola.

A biopsy confirmed the diagnosis. Gina underwent a mastectomy and reconstructive surgery. She continued to nurse on the other side until her daughter was two-and-a-half years old. What's more, she got pregnant again, giving birth to a healthy son in 2005 whom she also breastfeeds.

"But I had such a hard time getting information about my situation," she says, referring to the Paget's disease as well as her desire to continue breastfeeding. "It was frustrating; I'm a proactive person, and I couldn't find information.

"It led me to say, 'I need to do something about this,'" Gina says. And that led her to Y-ME, where she is undergoing training to be a peer counselor. "I need to step forward and be there for someone else. It's part of educating younger women."

"There is something universal about the experience of having breast cancer no matter what your age," Geralyn notes. But being a young woman with cancer in a beauty-obsessed culture, along with facing the possibility that your life as well as your dream of having children might be over, makes it especially cruel, she adds. Even though she underwent chemotherapy, which in many younger women can trigger early menopause, Geralyn today has two children. She and her family reside in New York City.

Both women admit they were lucky. "Others may not be," says Gina. In fact, young women often are diagnosed at a later stage than older women, because they—and their doctors—assume they are too young to get breast cancer and ignore warning signs. In addition, young women's cancers may be aggressive and result in lower survival rates. And women who are diagnosed at a younger age are more likely to have a mutated BRCA1 or BRCA2 gene.

The best way to screen for breast cancer in younger women? While regular mammograms are not recommended for women younger than age 40 (in part because younger women tend to have dense breast tissue, making mammography less effective), they may be appropriate for younger women with a family history of breast cancer and

Being a young woman with cancer in a beauty-obsessed culture, along with facing the possibility that your life as well as your dream of having children might be over, makes it especially cruel.

other risk factors. Breast MRI, which can "see through" dense breast tissue, also is being evaluated as a screening tool. And the American Cancer Society recommends that all women 20 years of age or older perform monthly breast self-examinations, and have a clinical breast exam performed by a doctor every three years.

Most importantly, younger women need to understand their risk factors and be able to talk to their health care providers about breast health. "Don't take a back seat when it comes to your health care," Gina urges. "Be in the driver's seat."



*Geralyn Lucas' memoir, "Why I Wore Lipstick to My Mastectomy," has been made into a Lifetime Original Movie that will air on the Lifetime television network during National Breast Cancer Awareness Month on Monday, October 23, at 9:00 p.m. Eastern/Pacific time. Geralyn is Lifetime's director of corporate communications and works on the network's*

*breast cancer awareness campaign. ✂*

**Lifetime**

theme for the winter issue of *Lifeline*

Opening the door to communication

## Breast Cancer Doesn't Discriminate

Treatment Program at the Indian Clinic. "I didn't know how easy it was to get on that program," she adds. Further, the Seminole and the Creek Nations, which help provide funding for anything needed to keep a family together, help Douglas with general household expenses. "And Beth goes to doctor appointments with me to take notes whenever I ask," says Douglas.

This comprehensive package of personal attention, both comforting and healing, reflects the flurry of activity across the country as energized individuals everywhere fight breast cancer.

### By the numbers

According to the latest statistics from the American Cancer Society, an estimated 212,920 women will be diagnosed with breast cancer this year, and 40,970 will die. Breast cancer is the most commonly diagnosed cancer among women by far, affecting even the young. For reasons that are still unclear, it strikes more white women than any other race or ethnic group, followed by African Americans.

"The most robust determinant of disparities, however, is who dies from the disease," says Harold Freeman, M.D., president and medical director of the Ralph Lauren Center for Cancer Care and Prevention in Harlem. "Blacks have the highest mortality, followed by whites. Hispanics are considerably lower, followed by American Indians and then Asians."

More than 76 million Americans have no insurance or inadequate insurance, yet women from diverse cultural communities struggle with barriers beyond poverty.

What this suggests, Freeman says, is that being a minority does not necessarily mean that you do worse. It is more complicated than that. It may be something about the environment and may also include lifestyle, diet and other factors. We do not yet understand.

"We do know blacks do worse than anybody," says Freeman. "For example, the five-year survival rate for white women with breast cancer is 90 percent, while the rate for black women is 76 percent."

"Most likely, it is their high poverty rates, less education, and importantly, coming into the health care system at a later stage of the disease. Blacks are less likely to receive standard treatment too. Further, some studies suggest that young black women have a higher frequency of aggressive forms of breast cancer, making early diagnosis more critical than ever."

More than 76 million Americans have no insurance or inadequate insurance, yet women from diverse cultural communities struggle with barriers beyond poverty. These

include language, lack of awareness and a myriad of psychosocial issues. For instance, gender issues arise within some cultures when husbands try to determine the course of treatment their wives should receive for breast cancer. Breaking down these barriers requires counselors to talk with patients to address their full range of needs. Communities nationwide are finding creative ways to address these needs.

### Reaching out to others

In Harlem, N.Y., and in more than 200 other communities nationwide, the Patient Navigation Program, designed by Freeman, provides personal navigators to assist patients, answer their questions and help them move through the health care system.

In Rochester, Minn., the Mayo Clinic has large Latino and Somali populations for whom English is a second language. To address the language barrier, the Mayo Clinic has partnered with a local education center that focuses on teaching English. Together, they provide health screenings—including mammograms—and help with finding financial assistance if follow-up treatment is necessary.

In Royal Oak, Mich., a program of the Beaumont Cancer Institute reaches out to African Americans, Arabs, Chaldeans, American Indians, Latinos and Asians. Beaumont's yearly forums for African-American women and, more recently, Arab women, are among their most popular culturally-sensitive programs to raise awareness about cancer screenings and early treatment for cancer.

In Queens, Flushing, N.Y.—the most diverse county in the country—Karen Karsif, M.D., breast surgeon and director of the Breast Center at New York Hospital, is thriving on the fertile opportunities she has for outreach.

"There are 160 languages spoken here and large populations of African Americans, Chinese, Hispanics, Greeks, Russians and Croatians," says Karsif.

During the daytime, she is a surgeon and counselor. During off-duty hours, she talks to women in the community. Her outreach to the Chinese community, for example, began when she first came to New York Hospital seven years ago.

"There was no outreach at all and we are in the middle of Chinatown!" she says. "I met with leaders in the Chinese community and I asked, 'What can I do for you?' They said, you could give us two free screening days a year—which I do in October. And I go to speak with them a couple of times a year, too. So I have a strong connection with the Chinese community now. It's the kind of thing that requires a lot of mental energy and a lot of work, but I get a lot out of it."

Karsif says that one of the biggest barriers she faces is correcting the myths of cancer. One myth common across many cultures in Queens is that if you do not have anyone in your family with breast cancer, you cannot get it.

Continued on Page 18



## Y-ME Helps Sister Study Recruit Women from Diverse Backgrounds

The Sister Study is the only long-term study of women aged 35 to 74 whose sister had breast cancer. It is a national study to learn how environment and genes affect the chances of getting breast cancer. The goal is to enroll in the study 50,000 women whose sister had breast cancer, and who do not have breast cancer themselves.

More than 27,000 women have already joined the Sister Study. While hundreds of African-American, Latina, Native Americans and Asians have joined the effort, the Sister Study is making a special call to diverse women to ensure that the results benefit all women. In the next year, the Sister Study would like to double the number of minority women enrolled. The study also needs women aged 65-74, women with a high school education or less, and more women in industrial trades and unions.

For more information and to participate, please visit [www.sisterstudy.org](http://www.sisterstudy.org).



Donna (left) with Gail

*My sister Gail and I were best friends and pretty much did everything together. Sadly, Gail passed away as a result of breast cancer when she was only 46 years old. As soon as I heard about the Sister Study, I knew I had to sign up. I am doing this study in her honor. Unfortunately, breast cancer seems to be more aggressive in African-American women and we need to find out why.*

*Continued from cover*

### The Many Voices of Y-ME

desired language in English (e.g. “Cantonese”). A trained peer counselor, who is also a breast cancer survivor, will contact Language Line Services to request an interpreter who then joins the call to address your questions and needs—from concerns about your mammogram or a recent breast cancer diagnosis, to questions about

## African-Americans More Likely to Have Aggressive Form of Breast Cancer

An analysis of the Carolina Breast Cancer Study, published in the June 7, 2006, issue of the *Journal of the American Medical Association*, found that young African-American women with breast cancer are more likely to have an aggressive form of the disease compared with older African-American women and also pre- and post-menopausal non-African-American women. The authors suggest that this higher frequency of basal-like tumors (basal cells are at the bottom of the outer skin layer), as well as lack of access to proper care and treatment, are the main reasons for the poor survival rate observed among young African-American women with breast cancer.

This study suggests a biological explanation to the discrepancy in mortality rates between African-American and non-African-American breast cancer patients. The basal-like subtype has been associated with poor clinical outcomes in previous studies, and likely reflects the lack of targeted treatments available for this type of breast cancer.

Recognizing that younger African-American women are more likely to develop a more aggressive form of breast cancer is an important first step toward developing appropriate targeted treatments. However, more clinical research is needed in order to identify the biomarkers which define the basal-like subtype and to subsequently develop treatments that will target these biomarkers.

By showing that young African-American women with breast cancer are more likely to die from the disease than non-African-American women even after the basal-like subtype is omitted from analysis, the study suggests that subtype might not be the only factor affecting prognosis and survival. Poorer survival rates may also be a result of a variety of interacting factors—including access to care and treatment, unidentified biological factors or other factors.

*This information was excerpted from the National Breast Cancer Coalition's Web site.*

### What you can do about it

Learn about Y-ME's earlier detection guidelines at [www.y-me.org](http://www.y-me.org). Remember we're here 24/7 if you or a loved one need to talk. Call us at 800-221-2141.

treatment side effects, to simply speaking with a caring individual who has been there. Moreover, peer counselors may be able to match you with a survivor who understands your culture, speaks your language, and has had a similar diagnosis or life experiences. All calls are completely confidential.

## Y-ME Reviewers at DoD BCRP

In July and August, 15 survivors represented Y-ME as Department of Defense Breast Cancer Research Program (DoD BCRP) reviewers, helping decide which research proposals would be funded. While Y-ME's mission does not include funding breast cancer research, we take an active role in helping to increase government funding and we serve as consumer reviewers on research panels.

For 2007, the Senate appropriations committee has recommended \$150 million for the DoD BCRP. At press time, however, the full Senate had yet to vote on this issue. After the Senate votes, the conference committee, comprised of both House and Senate members, will determine the final research funding amount.

The DoD BCRP was established in 1992 and provided \$25 million that year for research on breast cancer screening and diagnosis for military women and family members. The following year, grassroots advocates, including Y-ME and the National Breast Cancer Coalition, influenced public policy to increase funding—\$210 million—for peer-reviewed breast cancer research.

Since its inception, the BCRP has funded research at universities, hospitals, nonprofit and for-profit institutions, private industry, and state and federal agencies. This research targets the eradication of breast cancer. From 1992 to 2006, nearly \$2 billion has funded research. ♪



Save the Date!



Save the date for the National Breast Cancer Coalition's annual advocacy training conference. The 2007 program will take place April 28 to May 1, 2007, at the Hyatt Regency Crystal City in Arlington, Va.

In 2006, more than 600 people attended, with more than 70 representatives from Y-ME. Early bird registration is now offered for a discount until December 15, 2006. For more information and to sign up, visit [www.stopbreastcancer.org](http://www.stopbreastcancer.org). ♪

## Stay Current on Breast Cancer Issues

Looking for a way to support breast cancer legislation? Y-ME has you covered. We'll inform you of the issues and help you contact your members of Congress when they're voting on crucial legislation.

Sign up for Y-ME Advocacy updates at [www.y-me.org](http://www.y-me.org) when you click on Advocacy. Now, our monthly advocacy updates appear in Y-ME's e-mail newsletter, *Peer to Peer*, which contains the latest in information and support. Don't be the left in the dark! Sign up today at [www.y-me.org](http://www.y-me.org). ♪

## Visit [www.y-me.org](http://www.y-me.org) for Breast Cancer Info




Visit Y-ME's Web site and learn something new today. From monthly themes to regular updates, [www.y-me.org](http://www.y-me.org) has information you can use. The easy-to-find content on breast cancer and breast health provides answers to your questions. If you'd like more information about anything you read, you're welcome to "Ask Y-ME" online, and a peer counselor will get back to you.

Each Y-ME Affiliate has its own Web site within the National site so you can access support group and event listings, in addition to other local information. ♪



## Election Day is November 7

Election Day is right around the corner and with it comes a chance for those interested in breast cancer issues to make their voices heard. One way is to back members of Congress who support breast cancer issues. You can contact your legislators to let them know your feelings on the topic and that you appreciate their continued work on behalf of breast cancer patients and survivors. You also can vote for candidates who support funding for breast cancer issues.

Not registered to vote? Have you moved since you last voted? Please visit [www.y-me.org/advocacy](http://www.y-me.org/advocacy) for links to resources that will help you register in time for the November 7 elections. 

## 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.

Visit [www.stopbreastcancer.org](http://www.stopbreastcancer.org) to request applications and scholarship forms, and to view the next Program dates.


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 Y-ME National headquarters at 312-986-8338 between 9:00 and 5:00 CT on weekdays.



## Matching Gifts Double – or Triple – Your Gift

You may be able to double or even triple the impact of your gift to Y-ME National Breast Cancer Organization if your employer offers a matching gift program. Retired employees, spouses of employees and even widows/widowers of employees may be eligible for matching gift programs.

Contact your company's human resources department to find out if it offers a matching gift program or to request a matching gift application. Just fill out your company's matching gift form and send it to us with your contribution and we'll take care of the rest. Please visit [www.y-me.org](http://www.y-me.org) and select Ways To Give for more information. 

## An Unexpected Breast Cancer Patient

Jim Clauson and his wife, Linda, were lying on a beach in the Bahamas when he mentioned to her that he had a lump close to his nipple. It was April 2004, less than one year since Linda had discovered she had breast cancer, and neither Jim nor Linda suspected he might have the same disease. But he did.

The Clausons' initial reaction to the news that he had breast cancer, says Jim, was shock. "At that point, I didn't know that men could get breast cancer and neither did my wife. But we all know that men have breasts, and it makes sense a man could develop cancer. It's the same disease that women can get."

Breast cancer among men receives little attention, in part because of the low incidence of the disease. According to estimates of the American Cancer Society, breast cancer among women is 100 times more common than among men. However, there is an underlying assumption that men do not get the disease, and Jim fears this may prevent men from detecting the disease at an early stage. Today, he is a match peer counselor for Y-ME and is trying to spread the word that breast cancer can happen to anyone.

"My big thing is that I see all kinds of commercials that relate to women, and they never mention men. I can sit on the sidelines a little bit because there are 213,000 women diagnosed annually and only around 1,700 men, but at the same time, it wouldn't hurt if people were told that men get breast cancer too," he says.

The rates between the genders may differ, but the risk factors for men are very similar to those of women. The chance that a man will develop breast cancer increases with age. The development of breast cancer in relatives or the presence of mutations to the BRCA1 or BRCA2 genes also places men at higher risk.

In addition to the challenges of physically overcoming breast cancer, some male patients struggle emotionally with having a disease that occurs predominantly in women.

Likewise, breast cancer in men and women has virtually the same treatment considerations, and stage for stage, the same prognosis. The sooner breast cancer is discovered and treated in men, the more likely they are to survive.

Because men have much less breast tissue than women, cancer does not have to grow far to reach the skin surface and usually presents itself as a small lump, dimpling of the skin or changes in the nipple. Once brought to the attention of a doctor, a biopsy or mammogram may be used to determine if breast cancer is present. Treatment depends on

the individual case, with options that include mastectomy, chemotherapy, radiation therapy and hormone therapy.

In addition to the challenges of physically overcoming breast cancer, some male patients struggle emotionally with having a disease that occurs predominantly in women. Jim says that he focused on survival when he was a patient, but he has certainly found as a match peer counselor that men can view the disease as an attack on their masculinity.

"As far as cancer goes, I personally feel like whatever the doctors say they have to take off, it's got to go," he says. "But I did a match call with a guy who was as different as night and day from my feelings on the subject. I don't think it affects any two people the same way. But you know, everyone sheds a few tears."

The Clausons are a lesson in resilience, having both survived breast cancer that occurred within months of each other. "In a strange way, Linda and I feel blessed that through our experiences we can help others cope with breast cancer," Jim says. "We want to spread the word that men do get breast cancer. It sounds weird, but things happen for a reason, and I just have a feeling that that's why this happened." ❧

RESOURCES:  
The American Cancer Society  
[www.cancer.org](http://www.cancer.org)

John W. Nick Foundation  
[www.johnwnickfoundation.org](http://www.johnwnickfoundation.org)

### Speak with Someone Who's Been There

Jim Clauson is a match peer counselor on Y-ME's Hotline, both as a survivor and as a partner of a survivor. If you would like to speak with someone who has had a similar diagnosis or life experience as you, please call us at 800-221-2141 and we'll pair you with a person who really understands your concerns—a woman or man who has been there.

Likewise, our Partners Match Program provides support and education for people who are supporting a wife or partner through breast cancer. Simply call the Hotline at 800-221-2141 and ask to leave a message for the Partner's Match Program volunteer who will return your call as soon as possible.

## Overcoming Barriers to Care: Breast Cancer and the Lesbian Community

Regardless of age, race, gender or sexual orientation, breast cancer can be a daunting experience; however, for lesbian, bisexual and transgendered individuals, special circumstances and concerns may impede access to breast cancer diagnosis and treatment.

Due to the efforts of organizations such as the Mautner Project in Washington, D.C., Chicago-based Lesbian Community Cancer Project (LCCP) and Y-ME, things are beginning to change. Yet, unfortunately, one of the primary barriers to health care within the lesbian community is actual or feared discrimination.

“One of the things that we’ve found in our research is that discrimination, or fear of being discriminated against or ‘outed,’ keeps lesbians from getting medical care,” says Kathleen DeBold, executive director of the Mautner Project. Moreover, the reaction or behavior of a doctor’s office staff has a lot to do with how comfortable people feel in a medical setting. “We have documented cases of negative comments during intake or treatments,” DeBold adds.

Unfortunately, one of the primary barriers to health care within the lesbian community is actual or feared discrimination.

The belief that certain screening measures may not be necessary, and thus are not sought, is often a complicating factor. “As lesbians, we might not think that we have the same risks that other women have, so there is the early detection piece,” explains Catherine Jefcoat, director of development and communications for the LCCP. “At the same time, you’re facing medical systems that do not understand you; you don’t see yourself or your life reflected in that system, so you think of not even accessing [it] to begin with,” she adds.

Another key aspect, Jefcoat points out, is that lesbian women who feel marginalized receive mixed messages: negative messages that serve to foster feelings of low self-esteem and, on the flip side, encouraging missives that they should be taking care of themselves. “Unfortunately, those negative messages seep through and women don’t always seek the health care assessments that they should,” says Jefcoat.

DeBold also states that the reasons why heterosexual women visit their gynecologists—sexually transmitted disease concerns, birth control, infertility issues, among

others—are not perceived to be as pertinent for lesbian women, so lesbians may not receive checkups or clinical breast examinations as regularly. Moreover, lesbians who are estranged from family members may not have access to family or genetic history.

Both DeBold and Jefcoat agree that economic barriers and lack of medical insurance are obstacles to breast cancer care and health care in general. “Women generally have two main ways of getting health insurance: through jobs and marriage—and lesbians can’t get married,” DeBold says. “Even though we’ve made advances, a lot of workplaces don’t allow domestic partnership coverage.” And even if they do, she adds, lesbians may be afraid to take advantage of coverage because it may expose their sexual orientation to colleagues. According to DeBold, existing research shows that lesbians earn lower salaries and have less earning potential than heterosexual women.

Thankfully, strides are being made to overcome these barriers. In addition to the Mautner Project’s research, outreach, advocacy and direct service support programs, DeBold also credits the “openness” of partners like Y-ME and “the greater visibility of lesbians in the mainstream.” For example, Singer Melissa Etheridge made it easier to use the words ‘lesbian’ and ‘cancer’ in the same sentence. Within the health care system, DeBold notes that there is growing acceptance from health care providers in terms of alternative support systems. She says, “Whoever is part of your support system is welcome. Straight and lesbian women are able to bring friends. The caregiver group is not just made up of a spouse; it is sisters and friends and co-workers.”

Within the health care system, Hallem notes that there is growing acceptance from health care providers in terms of alternative support systems.

Both the Mautner Project and LCCP have implemented training programs to foster cultural and gender sensitivity and, in Jefcoat’s words, “to get the lesbian experience of cancer integrated into the larger cancer world.” Says DeBold, “Health care providers want to help people. If we break through ignorance, we can provide better health care for everyone.” ♧



# Another Outstanding Mother's Day for Y-ME!

Mother's Day, May 14, 2006, marked the 15th anniversary of the Y-ME RACE in Chicago, as well as the return of Y-ME's Walk to Empower to Houston and San Diego, and the birth of Y-ME's Mother's Day tradition in Seattle, Sacramento, Denver, Tulsa, Miami and Washington, DC.

These nine events raised \$6 million to support Y-ME's mission to ensure that no one faces breast cancer alone, with nearly 40,000 participants joining in to make the day their own.

Thousands of teams came together to honor and remember their loved ones. Hundreds of corporate sponsors made their commitments to invest in Y-ME on Mother's Day. More than 1,000 volunteers arrived at the event sites before dawn to welcome and host participants. And Y-ME delivered on its promise to provide a moving and empowering morning for all those in attendance.

Thank you for your involvement! ❧

Coming in 2007

The Y-ME RACE is undergoing a name change for 2007, and will now be known as Y-ME's Race to Empower, bringing the event further in line with Y-ME's message of empowerment.

Y-ME National  
Breast Cancer  
Organization™

race  
to empower  
chicago ❧ mother's day

## CHICAGO



Y-ME welcomed 30,000 participants to the 15th annual Y-ME RACE, raising more than \$4.2 million on an absolutely beautiful day in Chicago's Grant Park.

Corporate Chairman Peter McDonald of local presenting sponsor, United Airlines, and Family Teams Chair Kay Witkowski of Team WIT "Whatever It Takes," cut the ribbon at the RACE start, with other honored guests from sponsoring companies McDonald's, Walgreens, Grant Thornton, Dominick's and National City.

## HOUSTON



This year's Walk to Empower in Houston welcomed 1,400 walkers, and has raised more than \$185,000!

Corporate Chairman Alan Slusher, of local presenting sponsor, AstraZeneca, and Family Teams Chair Lynette Jupp of Jupp's Jewels (*team pictured at left*), kicked off the Walk on a lovely morning in Houston's MacGregor Park.

## SAN DIEGO



More than 1,300 walkers crossed the finish line in San Diego's beautiful Mission Bay Park, including the pink cowgirl pictured at left. The San Diego Walk to Empower Corporate Chairman George DeVries of local presenting sponsor, American Specialty Health, and Family Teams Chair Cynthia Fleming of the Pretty in Pink team led this year's Walk to success, raising nearly \$200,000.

## DENVER



More than 500 walkers joined Y-ME for the first-ever Walk to Empower in Denver's City Park, raising \$100,000. Teams from Fox 31, Elway Chevrolet, Grant Thornton, Washington Mutual, Curves and a host of families marked this new Mother's Day tradition. Kicking off the morning's activities was Steve Kelly, Walk emcee and Fox 31 anchor.

## SEATTLE



Debbie Turner, daughter of Y-ME Co-Founder Mimi Kaplan, (pictured left with her loved ones donning signs in Mimi's memory) helped to launch the first-time Walk in Seattle. She joined her brother, Joe, and dad, Dan, who were also walking, in Sacramento and Chicago, respectively.

Also leading by example was Ann Killian, family teams chair, who helped to recruit more than 35 family teams to participate in this inaugural Walk. Y-ME welcomed 550 walkers to the Seattle Center Mural Amphitheater and raised \$125,000.

## SACRAMENTO



The first Sacramento Walk to Empower, which took place at Crocker Park, has raised nearly \$150,000, with 1,000 walkers participating. Corporate Chairman Patrick Terry of local presenting sponsor, Genomic Health, set the pace for this inaugural event, with a team of 42 members, raising just over \$16,000.

Patrick helped to cut the ribbon with several other special guests, including Y-ME Co-Founder Mimi Kaplan's son, Joe.

## TULSA



Congratulations to Y-ME Northeastern Oklahoma on a very successful Walk! The Tulsa Walk to Empower, held at LaFortune Stadium at Memorial High School, welcomed 750 walkers, raising more than \$165,000.

Corporate Chairman Paula Marshall-Chapman of local presenting sponsor, Bama Foods, along with Family Teams Chair Sherri Swanson of the Sherri's Soldiers "Fighting for a Cure" team, led this year's Walk, and helped to recruit the more than 75 teams.

## WASHINGTON, DC



The rain didn't keep away the 750 walkers who joined Y-ME for the first Washington, D.C., Walk to Empower, which took place at Bull Run Regional Park.

Corporate Chairman Ed Mensch of local presenting sponsor, Safeway, and Carolyn Finegar of the Carolyn Cares team, took their volunteer roles very seriously, leading this first-time Walk to true success.

Congratulations to Y-ME National Capital Area, with more than \$140,000 raised!

## MIAMI



Through the support of local sponsors, Grey Goose, American Academy of Professional Coders and National School of Technology, and team support from national sponsor, McDonald's, and many family teams, the Miami Walk raised \$100,000 on a beautiful Mother's Day in Coconut Grove's David Kennedy Park.

Cutting the ribbon with Ronald McDonald is Y-ME Board Member Gloria Suardiaz Alvarez.

### VERY SPECIAL THANKS TO NATIONAL SPONSORS OF Y-ME'S MOTHER'S DAY EVENTS

National Presenting Sponsors



National Official Sponsors



Interested in participating in 2007? Visit [www.y-me.org](http://www.y-me.org) for details.

# profiles in encouragement

In each issue of Lifeline, we spotlight a different Y-ME Hotline peer counselor, sharing with you inspiring descriptions of those who staff our 24-hour Hotline.

lori mcdaniel

“I think being a peer counselor on the Y-ME Hotline has helped me emotionally to come to terms with and accept my new normal,” said Lori McDaniel. “It also has given me the satisfaction to know that in some way I have made a difference to someone else. If I can make a difference, I have achieved something.”



In fact, Lori makes a difference in many ways. She is a nurse, working primarily in the newborn and neonatal intensive care units, and occasionally in the surgical unit with women who have breast cancer surgery. She worked with mastectomy patients before she was diagnosed, but being a nurse and a patient gave her a new perspective. She says she has a better understanding of what her patients are going through.

Lori found a lump in March 1999. She called her gynecologist, who examined her, then sent her for a mammogram, which came back negative. “He felt the lump and he listened to me,” she says. “I truly believe he saved my life by being persistent. He insisted I see a surgeon for a biopsy and the final result was that I had cancer. I truly believe you have to listen to that inner voice you have. I know my body. I felt

something was wrong and my doctor listened to me. That made all the difference.”

She became involved in treatment decisions and attacked the whole journey with a “can-do” attitude. She had a mastectomy and reconstruction in April, followed by chemotherapy and radiation. “I worked eight to 12 hours a day throughout radiation,” she said. “I did well. I found a Bible verse that helped me through: ‘Fear not, because I am with you.’ It helped me then and it helps me now.”

Lori also believes support makes a difference in how you recover from breast cancer. “My family and fellow nurses were supportive throughout. One nurse shared her breast cancer experience and told me when I was ready, she knew exactly where I could help others—with Y-ME.”

In January 2002 Lori became a match peer counselor through Y-ME Indiana. “When the Hotline went national, I was thrilled to be able to answer calls from my home. I really enjoy being a Hotline peer counselor and a match counselor. I intend to do it for a long time.” ❧

## Y-ME’s *A Day for You* Brings Breast Health to Underserved

Breast cancer is a cancer common among Latina and Asian women, and is a leading cause of cancer death. However, these populations are less likely to screen for the disease and are more frequently diagnosed at a later stage than their white counterparts. To fight this problem, Y-ME launched *A Day for You*, a free and confidential program devised to promote breast health and awareness in underserved communities.

*A Day for You* participants attend an all-day activity and learn about earlier detection methods, are taught breast self-examination (BSE) and receive clinical breast exams. Onsite mammograms also are available, if appropriate. Women who live in underserved communities in Illinois, Houston, the National Capital Area, Northern California and San Diego are invited to attend *A Day for You*. Y-ME program coordinators target information to the communities they serve—Asian and Latina—through foreign-language materials and culturally sensitive details.

Working in conjunction with *A Day for You*, *Friends of Ann & Mimi* assist *A Day for You* participants in need of follow-up services. Women are accompanied to appointments, when necessary, so they may arrive informed and confident. For example, if a mammogram indicates the presence of a suspicious area, the program coordinator ensures the participant gets the needed follow-up services.

*A Day for You* and *Friends of Ann & Mimi* are available in Houston, Texas, areas in Illinois, Washington, D.C., and in Davis, and San Diego, Calif. Since 2003, Y-ME has provided services to more than 11,000 women.

If your health care center is located in one of our service areas and is interested in hosting *A Day for You*, or if you would like more information, e-mail [contact@y-me.org](mailto:contact@y-me.org) or call (312) 986-8338. ❧

# cause for applause

## Walgreens and Olivia Newton-John Team Up with Y-ME



Walgreens is once again teaming up with Y-ME to help alert customers that support, hope and comfort are just a phone call away. For some of us, letting our loved ones touched by breast cancer know we care about them can be difficult, especially when we can't find the right words at the right time. Luckily, Y-ME and Walgreens continue to help give hope and support to those who need it in more than 5,000 Walgreens in the U.S. this fall.

Breast cancer awareness products that include a special gift tag along with Y-ME's 24-hour Hotline number are available while supplies last. Twenty-five percent of the purchase price of select Walgreens merchandise—mugs, pins, socks, T-shirts and hats—will benefit Y-ME.

Another exclusive item to be sold only at Walgreens is Olivia Newton-John's new CD, *Grace and Gratitude*. Ten percent of every CD sold will benefit Y-ME.

In 2005, Walgreens made a donation to Y-ME of more than \$750,000, Y-ME's largest cause-related gift to date.

For a Walgreens location near you, visit [www.walgreens.com](http://www.walgreens.com).



## Organize with Style... and with Y-ME

Home Products International (HPI), the storage and organization experts, is selling its pink laundry and organization products during National Breast Cancer Awareness Month in October. With each purchase, 5 percent of net sales will be donated to Y-ME.

"We are very honored to demonstrate our commitment to community involvement through our association with Y-ME," says Lisa Skrdlant, HPI senior marketing manager for storage. "Because breast cancer has touched the lives of everyone, we are proud to show our support for the many worthwhile programs funded by Y-ME."

The specially chosen products include a pink and white compact laundry bag, clear storage containers with pink lids designed to fit on closet shelving, stacking bins in light and dark pink, and the EasyBoard® ironing board with a pink cover and pad highlighting the Y-ME pink ribbon. All products are Homz-branded and in special pink packaging.

Home Products International, Inc. is an international consumer products company specializing in the design and manufacture of quality, innovative house wares. The company sells its products under the HOMZ brand through global and national retailers. For more information about these products, visit [www.homz.biz](http://www.homz.biz) or call 800-327-3534.



## Soft & Dri Draws Attention to Breast Cancer

When picking up your personal care "essentials" this fall, you may notice Y-ME in the aisles. That's because Soft & Dri is making a donation to Y-ME for each purchase of antiperspirant, with a maximum contribution of \$100,000. Sold in more than 10,000 retailers nationwide, Soft & Dri will help draw attention to the more than 2 million people living with breast cancer. At the same time, the donation helps ensure that no one faces breast cancer alone.

The Dial Corporation, based in Scottsdale, Ariz., manufactures and sells consumer products and employs

more than 2,300 people worldwide. The company has been providing products to American consumers for over 130 years.



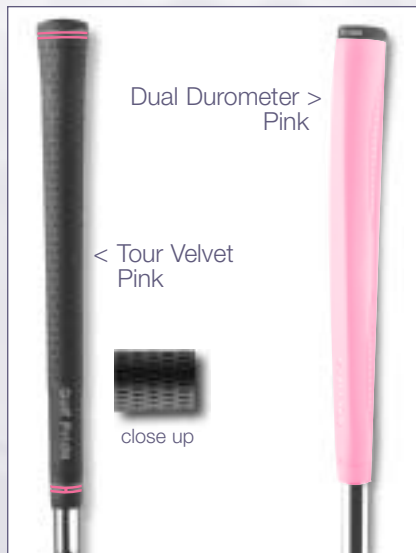
*There is no proof that the use of antiperspirants or deodorants causes breast cancer, according to a study reported in the Journal of the National Cancer Institute (Vol. 94, No. 20: 1578-1580).*

~From the American Cancer Society

## Golf Pride Supports Y-ME

As part of a strong commitment to breast cancer awareness, Eaton Corporation's Golf Grip Division will donate 25 cents to Y-ME from each Golf Pride Tour Velvet® Pink and Dual Durometer™ Pink putter grip sold in the United States, Japan and the United Kingdom through January 2007.

For information about purchasing the grips, please visit [www.golfpride.com](http://www.golfpride.com). ♪



## Shoe Carnival Revs Up Y-ME Support

During the past several years, Shoe Carnival has raised more than \$400,000 for Y-ME and we are pleased to announce that the retailer is continuing its support this October.

“Because of its commitment to helping those who cannot wait for tomorrow’s cure, Y-ME resonates with Shoe Carnival customers. We are proud to continue our partnership with Y-ME to ensure that no one faces breast cancer alone,” says Stacy Fleming, Shoe Carnival promotions manager.

Special thanks to Shoe Carnival and its customers for its annual support of Y-ME. For locations, visit [www.shoecarnival.com](http://www.shoecarnival.com). ♪

**SHOE  
CARNIVAL**



## Shopbop.com and Primp Encourage Consumers to Shop for a Cause

Fashion-forward women’s online retailer, [www.shopbop.com](http://www.shopbop.com), and Primp have teamed up to encourage customers to shop for Y-ME. Last year, Shopbop made an outstanding contribution of nearly \$60,000 to Y-ME. This year, the donation is predicted to double.

Darling Tees and Thermals that have been created with breast cancer ribbon graphics and special rhinestone detailing will be on sale exclusively at Shopbop.com for October, National Breast Cancer Awareness month. Fifty percent of the purchase price will be donated to Y-ME.

“As a women’s online retailer, we like to support causes that directly affect women,” said Shopbop President Bob Lamey. “We are very pleased to be teaming up with Primp and Y-ME to do our part in contributing to this important cause.”

The Shopbop and Primp exclusive Breast Cancer Tees and Thermals will be available at Shopbop.com beginning in September. The Thermals will retail for \$79 and the tees will retail for \$70. Visit [www.shopbop.com](http://www.shopbop.com) to purchase yours today! ♪



**Be Fashionable.  
Get into Your Genes.**


Fashion designer Daniella Clarke of Frankie B., Genentech and Y-ME National Breast Cancer Organization have launched a national public awareness campaign to educate women about HER2-positive breast cancer and the importance of HER2 testing. For each pair of HER2 Genes by Frankie B. sold through November, Frankie B. will donate \$107 to Y-ME.

To learn more and order your own pair of limited edition HER2 “Genes” visit [www.HER2Genes.com](http://www.HER2Genes.com). ♪



## Empower yourself with a Precious Moments Gift

The Precious Moments cloisonné pin, “Walk.Run.Empower.,” named after Y-ME’s Mother’s Day events, along with a companion figurine, are available for purchase this October. Each pin includes a Y-ME Hotline wallet card with the number that friends, family and loved ones can access 24/7 should breast cancer ever touch their lives.

Empower yourself and those you care about—consider these great gifts. Visit [www.preciousmoments.com](http://www.preciousmoments.com) or call 888-878-8148. 



Walk. Run. Empower.  
cloisonné pin

70% of the purchase  
price benefits Y-ME.



Walk. Run. Empower.  
figurine


\$2 of every figurine  
sold benefits Y-ME.

## Presents for Purpose

This October, Presents for Purpose will launch *Spotlight*, a program designed to call attention to charities throughout the year. Y-ME National Breast Cancer Organization will be the first organization to take the *Spotlight*. As part of the program, custom-designed products and information about each charity will be featured at [www.presentsforpurpose.com](http://www.presentsforpurpose.com).

“Giving the *Spotlight* to Y-ME highlights National Breast Cancer Awareness month and helps raise needed funding for support. This program is very exciting for us and important to our mission,” says Presents For Purpose Founder Alayna Kassan. “In keeping with our tradition of inspirational and stylish products, the Y-ME Tee collection tells the story of support and empowerment which is essential to the Y-ME mission that no one faces breast cancer alone,” she added.

The Y-ME Link Tee features a rhinestone studded metallic chain inscribed with the words empower, support and love. The Y-ME Heart Tee features a red rhinestone heart surrounding Y-ME’s signature pink ribbon. These stylish and meaningful Y-ME Tees are designed exclusively for Presents For Purpose by Chrissy Azzaro for My-Tee. Five dollars from each Heart T (\$36) and \$10 from each Link Tee (\$56) will benefit Y-ME. They are available exclusively at [www.presentsforpurpose.com](http://www.presentsforpurpose.com).

Presents For Purpose, founded in 2001, is dedicated to raising national awareness and needed funding for charitable organizations. The company’s mission is to offer stylish items that afford everyone the opportunity to make a difference. For more information, call (212) 580-0515 or visit [www.presentsforpurpose.com](http://www.presentsforpurpose.com). *Shop in style. Make a difference.* 





## Y-ME Launches Web Sites in Five More Languages

Y-ME National Breast Cancer Organization has launched five new foreign languages on its Web site to provide breast cancer information and support in Chinese, Korean, Vietnamese, Russian and Tagalog, in addition to the Spanish and English content already available.

The new content complements Y-ME's main service, its 24/7 Hotline staffed by breast cancer survivors with interpreters in 150 languages.

Chinese, Korean, Vietnamese, Russian and Tagalog are available, in addition to Spanish and English

Studies show that Asian women in the U.S. have lower cancer screening rates and are usually diagnosed at later stages. With cancer being the leading cause of death for female Asian Americans, it is important not only to have access to information but also have it available in other languages.

Y-ME's Web site provides information and support for people who have been diagnosed with or are concerned about breast cancer. Topics include types of breast cancer, treatment options and side effects. Different language choices can be found along the top navigation bar on the home page at [www.y-me.org](http://www.y-me.org).

There is also content on coping and quality of life, including day-to-day living issues such as diet, nutrition and exercise. Visitors to the Web site will find helpful tips on which questions to ask their doctors and how to talk with family and friends about a diagnosis.

"We are very excited to provide this vital information to Asian women," said Y-ME CEO Margaret C. Kirk. "We want to ensure that no one faces breast cancer alone—no matter what language is spoken. For the first time, people who speak Chinese, Korean, Vietnamese, Russian and Tagalog are able to access Y-ME's online breast cancer information in their own languages. These sections of Y-ME's Web site have a global appeal to women, wherever they are, who are diagnosed with breast cancer and need information and support." ❧

*Continued from Page 6*

## Breast Cancer Doesn't Discriminate

"This is not true. But it is very hard to convince women to get a mammogram if they don't believe they can get breast cancer. In fact, most breast cancer occurs in women who have no family history.

"That's always a big shocker," she says.

Like many individuals spearheading outreach programs in diverse communities, Karsif is selfless in her dedication to raising awareness and helping women access care.

Karsif's outreach program has been recognized for its effectiveness by the Health Association of New York State (HANYS), she says. "All the hospitals belonging to HANYS were given a little booklet and told that this is the way you do Best Care Outreach in Diverse Communities. I tell people that I am happy to speak anywhere, as long as there is an interpreter and people to listen.

"My work is in empowering women," says Karsif. "I love it." ❧

### Sources:

CA: *A Cancer Journal for Clinicians*, Figure 1. Ten Leading Cancer Types for the Estimated New Cancer Cases and Deaths, by Sex, US, 2006. From <http://amcancersoc.org>; American Cancer Society, Inc.

National Center for Health Statistics, Centers for Disease Control and Prevention African American to White Cancer Mortality Rates - Ratios, U.S., 1997-2001. *Cancer Facts & Figures for African Americans 2005-2006*, Page 3, Table 4.

## Support Y-ME with a Bequest or Planned Gift

Support Y-ME through a bequest in your will or a beneficiary designation on a life insurance or retirement account policy. A bequest is a wonderful way to leave a legacy for the next generation.

Benefits of making a bequest include deferring your gift until after your lifetime and exemption from federal estate taxes. Y-ME strongly encourages you to consult with your legal or financial advisor when considering a bequest. Please visit [www.y-me.org](http://www.y-me.org) and select Ways To Give for more information. ❧



## *How do you care for patients who have specific cultural needs?*

Harold Freeman, M.D., president and medical director of the Ralph Lauren Center for Cancer Care and Prevention in New York City has been a surgeon in Harlem for 39 years. He believes that the only way to effectively care for patients with various cultural needs is to design community-based programs to answer questions and to help ensure that these individuals do not get lost in the complexities of the health care system.



“The entire community needs to care,” he says. “Patients should ask their doctors to talk to them, but the reality of it is that doctors don’t have time to answer all their questions. Insurance companies sometimes penalize doctors for spending too much time with patients.”

The greatest cultural barriers to health care in America are poverty and lack of education, says Freeman, who also is senior advisor to the director of the National Cancer Institute for reducing disparities.

“Forty-six million Americans are uninsured and another 30 million have inadequate insurance. If you don’t have insurance, you just don’t go to the doctor,” Freeman explains.

“The most important thing we should be doing for people with different cultural needs is to educate these communities and advise them on health care issues, but then to marry that advice to real access.”

Freeman explains that after medical school, he went to Harlem as a young doctor hoping to heal the sick. Instead, he was faced with patients coming into the hospital with very late cancer—breast cancer in particular. His studies showed that in a 22-year period ending in 1986, one half of more than 600 breast cancer patients treated at Harlem Hospital had late stage breast cancer when they first went to the hospital.

Following on the heels of this study, Freeman became president of the American Cancer Society in 1988-1989. In this role, he held national hearings on cancer in poor people. Poor American people testified that they met barriers when they attempted to seek cancer care.

All kinds of cultural barriers affect access to care, Freeman says. These barriers stem from miscommunication, lack of trust for doctors and different belief systems in different parts of the country. A study two years ago, for

example, indicated that poor people of both white and African-American communities believe that if air touches cancer, it will spread. People who believe this myth tend to avoid surgery.

Further, some Hispanic women believe that no one except their husbands should touch certain parts of their bodies. Women who believe this refuse breast and pelvic exams.

And some Native Americans will not talk about cancer, even if they have cancer, fearing they will bring cancer into their families.

In 1979, Freeman set up free screening clinics for breast cancer. This helped, but was not enough, because many people had no way to pay for treatment. To solve this part of the problem, Freeman initiated the nation’s first Patient Navigator Program at Harlem Hospital Center in New York City in 1990.

“Essentially, we select smart, compassionate patient navigators from the community to serve as a personal contact with our patients. The navigator’s task is to speak personally with any patient the doctor has seen who has a finding that indicates a need for further procedure, diagnosis or treatment. The navigator helps the patient to access that care. And if a breast cancer patient, for example, has an issue with fear or distrust that might work against her recovery, it is the navigator’s job to talk her through that problem.”

Programs based on Freeman’s model began to multiply around the country through the 1990s. Finally this program caught the attention of Congress. On June 30, 2005, President Bush signed the Patient Navigation Act, which established funding for a competitive grant program designed to help patients access health care services.

“It is now the law of the land,” Freeman says. “There are more than 200 Patient Navigation Programs across America today, 88 percent of them in urban or semi-urban areas.”

Freeman suggests that women without access to formal Patient Navigation Programs contact groups such as Y-ME, the American Cancer Society and CancerCare to learn how they can find support.

“It’s been a long time, but I’ve begun to see results.” ❧

Peer counselors on the Y-ME Hotline are available 24 hours a day to discuss with you any concerns you have. Call anytime at 800-221-2141 and speak with a breast cancer survivor.

# affiliate news & happenings

Y-ME Affiliates know that breast cancer does not discriminate, and that the biggest risk factors for breast cancer—being a woman and getting older—cut across many of our differences. That’s why our Affiliates are in cities across the country, serving diverse communities so that no one faces breast cancer alone.

## Cultural and Ethnic Diversity

**Y-ME Illinois, Y-ME National Capital Area and Y-ME Texas Gulf Coast** are among the Affiliates that conduct the *A Day for You* program in Latina, Asian and African-American communities. Through the program, women from underserved communities are invited to attend all-day seminars and learn about earlier detection methods, are taught breast self-examination (BSE) and receive clinical breast exams. In some cases, onsite mammograms also are available.

**Y-ME Southland California** is taking another culturally sensitive approach: it has formed a Latina taskforce of bilingual and bicultural members to reach out to one of the fastest growing Latino populations in the United States.

Oklahoma has the largest Native American population in the United States, so **Y-ME Northeastern Oklahoma** has been building relationships with Native-American community leaders and coalitions during the past several years. They are working together to determine how Y-ME might help fill the programming gap between existing clinics, outreach programs and health fairs. For more information on Y-ME Northeastern Oklahoma’s outreach, please see “Breast Cancer Doesn’t Discriminate” on Page 1.

## Geographic Diversity

Many of our Affiliates cover large geographical territories and rural areas where treatment centers and support groups may be hundreds of miles away from those who need them. **Y-ME Northern California** and **Y-ME Chattanooga** are paying closer attention to the barriers that keep breast cancer patients in rural communities from getting the treatment they need.

## Age Diversity

**Y-ME Connecticut** works with aging populations, conducting breast health awareness workshops in senior activity centers and retirement communities. Executive Director Barbara Oliver believes that older women in particular need this outreach because talking about breast cancer and being familiar with their breasts was considered taboo when they were younger. The Affiliate teaches older women about breast health and performing breast self-exams.

On the other end of the age spectrum, **Y-ME Indiana** co-hosted a live all-day radiothon about breast cancer awareness on the market’s major FM radio station targeting women 18-32 years of age. The Affiliate works collaboratively with organizations such as the Young Survival Coalition.

To learn more about the services and programs provided by an Affiliate nearest you, explore our Web site at [www.y-me.org/affiliates](http://www.y-me.org/affiliates). ♧

## Fly a Pink Ribbon Flag and “Paint Your Town Pink™”

Y-ME National Capital Area and Pink-Ribbon-Store.com have teamed up in the fight against breast cancer. Join them in this year’s first-annual “Paint Your Town Pink™” campaign. By ordering one of the many flags designed by Fran Romeo, founder and owner of Pink-Ribbon-Store.com, that benefit Y-ME, you can display your support of Y-ME and its mission to ensure no one faces breast cancer alone.

Paint Your Town Pink with car, house, garden and/or mailbox flags. Fran Romeo states, “I launched the site for all those who have been touched, in some way, shape or

form, by breast cancer.” Pink-Ribbon-Store.com will donate a portion of all proceeds to Y-ME NCA in support of its advocacy program and mammogram services in Y-ME’s *A Day for You* program.

“Pink-Ribbon-Store’s mission is to raise awareness, fund mammograms and help spread the message of the ‘Pink Ribbon,’” states Fran. As Pink-Ribbon-Store.com and Y-ME NCA join together, make sure your flag is in hand so you can Paint Your Town Pink. To purchase a Pink Ribbon Flag, visit [www.pink-ribbon-store.com](http://www.pink-ribbon-store.com). ♧






## Y-ME Illinois Fashion Show & Luncheon

### Survivors Honor Supporters at the Y-ME Illinois Fashion Show & Luncheon

Every year, nearly 2,000 men, women and children gather at the Y-ME Illinois Fashion Show & Luncheon to honor those who have been touched by breast cancer. This year, the event will provide breast cancer survivors the opportunity to pay tribute to the individuals who helped them in their battle against the disease. Survivors have been asked to submit entries for the friends, family members, physicians or counselors who have made the greatest difference in the lives of Illinois breast cancer survivors as they weathered the road to recovery. A select number of these key supporters will accompany breast cancer survivors and members of the media on the runway during the 2006 Y-ME Illinois Fashion Show & Luncheon,

“Circle of Help and Healing,” scheduled for Saturday, October 28, 2006, at the Chicago Hilton and Towers.

“The Fashion Show & Luncheon has always been a powerful and exciting way to honor those who have been touched by breast cancer,” said Ruth Brody, executive director of Y-ME Illinois. “This year we are thrilled to pay tribute to those who have helped breast cancer patients in their struggle, as the dedicated support of a friend, family member or trusted doctor can make all the difference in coping with diagnosis and recovery.”

To purchase a ticket or make a donation, visit [www.y-me.org/illinois](http://www.y-me.org/illinois) or call (312) 364-9071. 



*Cookie & Earl Medansky shine at the 2005 Y-ME Illinois Fashion Show & Luncheon.*

*Breast cancer survivors and dedicated supporters of Y-ME Illinois model the latest fashions at the 2005 Fashion Show & Luncheon.*



## Affiliates and Satellite Locations of Y-ME National Breast Cancer Organization

### CALIFORNIA

#### Northern California Affiliate

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### WASHINGTON


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[jfischer@y-me.org](mailto:jfischer@y-me.org)

## Request a Free Brochure on Breast Health — in Eight Languages



*A Woman's Guide to Breast Care* explains the three steps to earlier detection: breast self-exams (BSE), mammography and clinical exams. Order this handy brochure—with an illustrated guide on how to perform BSE—for yourself or for the women in your life. These brochures are available in English, Spanish, Chinese, Korean, Vietnamese, Hindi, Russian and Tagalog!

To reserve your free copy, or to place a bulk order, visit [www.y-me.org](http://www.y-me.org) and click on Publications, or call 800-221-2141. 




## Buy Your Holiday Cards at the Y-ME Card Shop


It's not too early to start thinking about holiday cards! Buy yours from the Y-ME Greeting Card Shop and know you're supporting a great cause—Y-ME's programs and services.

You can purchase personalized, quality, ink-on-paper greeting cards right on the Y-ME Web site at [www.y-me.org](http://www.y-me.org).

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 each, with bulk rates available. The customized card is then packaged in a quality envelope and elegantly addressed, stamped and sent via First-Class Mail.

\$1 of each card purchased benefits Y-ME. 

## Designate Your 2006 CFC Contributions to Y-ME (#2808)

If you are a federal employee and plan to participate in the upcoming 2006 Combined Federal Campaign (CFC), please consider designating your contributions to Y-ME by selecting #2808. Your CFC donations help support Y-ME programs and services, including the 24-hour Y-ME National Breast Cancer Hotline. 




## Sisters Network Inc. Conference Addresses Survivorship



Sisters Network Inc. held its 8th Annual National African-American Breast Cancer Conference, April 7-9, 2006, at the Intercontinental Hotel in Houston, Texas. More than 500 breast cancer survivors and health care professionals attended the conference called "Celebrating Survivorship." The purpose of the

conference was to address African-American breast cancer survivorship, and included six general sessions on breast cancer topics and a signature awards luncheon honoring outstanding Sisters Network Chapters.

Keynote speaker for the Signature Awards Luncheon was Dr. C. Kent Osborne, director, Breast Center Baylor College of Medicine, who spoke on the "Tumor Fingerprint: What It Means and How It Can be Used to Improve the Care of the Breast Cancer Patient." His talk focused on research on the biology of breast cancer and developing new treatment approaches. He has studied the mechanisms by which hormonal therapies inhibit breast cancer growth and how breast cancers become resistant to these therapies. African-American women have tumors with a poor prognosis. The tumors are often estrogen receptor negative, larger and diagnosed at a more advanced stage. These unfavorable characteristics have prompted researchers to try to identify a tumor fingerprint (marker) that can be linked to a biological difference in African-American women.

Y-ME representatives attended the conference and reached out to conference attendees with information on Y-ME's programs and services. 

### African-American Breast Cancer Statistics

- An estimated 19,240 newly diagnosed cases in 2006,
- An estimated 5,640 expected to die in 2006,
- Breast cancer is the most common cancer and the second leading cause of cancer death in this ethnic group,
- Five-year survival rate of breast cancer is 75 percent, compared with 89 percent in white women,
- The incidence of breast cancer in women younger than 45 years of age is higher compared to that of white women,
- More likely to be diagnosed with larger tumors and more advanced stages of disease.

Sources: American Cancer Society: Cancer Facts & Figures for African Americans, 2005-2006, and Fred Hutchinson Cancer Research Center, 2003.




## ShareRing Network

ShareRing Network transcriptions are available online! Visit [www.y-me.org](http://www.y-me.org) today.

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.


Visit [www.y-me.org](http://www.y-me.org) or call 1-800-221-2141 to view upcoming teleconference topics and speakers, and to register. 

## You Can Make a Difference This October and All Year

### *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. Y-ME needs survivors who are willing to share their experiences by volunteering as peer counselors—all are welcome to apply.

If selected after an initial screening, you will attend a two-day training, be required to pass a test and shadow an experienced peer counselor. Then your certification process will be complete. Next, you'll be ready to have the Hotline equipment installed on your computer—training is provided—and to begin answering calls. We request that on-call peer counselors commit to a minimum of 20 hours a month. If you volunteer 24 or more hours a month, Y-ME will reimburse you up to \$30 for high-speed Internet connection fees.

For more information, call us at 312-294-8514 or visit [www.y-me.org](http://www.y-me.org). 

## Join Us for a Program on New Treatment Options and Quality of Life

Thursday, October 12

Research, New Treatments & Communicating with Your Health Care Team

Attend by Phone or Web

7:30 - 8:30 p.m. ET / 5:30 - 6:30 p.m. PT

Join this live program and learn about research advancements that could help to improve quality of life. We'll be discussing treatment innovations that may help provide more targeted and less invasive therapies, reduce side effects of treatment and even prevent recurrence.

Don't miss this opportunity to hear renowned experts discuss the latest breast cancer research and what it means for you. You'll also have a chance to ask the experts your questions.


To register visit: [www.healthtalk.com/YME](http://www.healthtalk.com/YME). 

An Enhanced National Hotline Founding Sponsor



## Y-ME Peer to Peer Keeps You Current

*Peer to Peer*, Y-ME's monthly e-mail newsletter, is packed with articles on breast cancer topics and support. We address subjects such as clinical trials, survivorship and exercise, to name a few.

Not on our list? Visit [www.y-me.org](http://www.y-me.org) and click on "Join Mailing List" to stay connected to the latest online support and information on breast cancer. 



## Sexual Dysfunction

Sexual dysfunction is a common side effect of breast cancer treatment, and its causes are often both physical and psychological. On the physical side, chemotherapy can cause the ovaries of premenopausal women to shut down and stop producing estrogen, triggering early menopause. Menopause may cause vaginal dryness that makes intercourse more painful than pleasurable, reducing a woman's ability to have an orgasm. When the ovaries shut down they also stop producing testosterone—often called the “hormone of desire”—which can lower libido (the desire for sex). In addition, fatigue, pain, nausea, vomiting and hot flashes that can accompany chemotherapy, radiation and hormonal therapies can put a damper on libido at any age.

While there's no magic solution, there are approaches to help reduce the side effects of chemotherapy-induced menopause [that affect sexual health].

The psychological impact of breast cancer treatment can make sexual dysfunction even more complicated. When a woman's breast, so strongly associated with sexuality, is altered by surgery, her body image and self-esteem may cause her to question her attractiveness and desirability. Factor in the stress of a breast cancer diagnosis, fear of recurrence, depression and anxiety about a partner's emotions, and it's no wonder that sexual dysfunction is a common side effect, regardless of age.

There is good news, however. “While there's no magic solution for getting older before your time, there are approaches to help reduce the side effects of chemotherapy-induced menopause [that affect sexual health],” says Tracey F. Weisberg, M.D., medical director of the Maine Medical Center Breast Care Center and a practicing oncologist at the Maine Center for Cancer Medicine & Blood Disorders in Scarborough, Maine. “These are essentially the same approaches used to help older women who experience sexual side effects as they go through natural menopause, and some are holistic and natural. They include vaginal lubricants, antidepressants for hot flashes and vitamin E.” She notes that vaginal estrogen also is an option for

reducing vaginal dryness in breast cancer survivors at any age, but “absolutely” no oral estrogen.

Managing the emotional fallout from breast cancer treatment is more complex. “Support groups are a good resource for women to talk to one another,” Dr. Weisberg acknowledges. “And as a doctor, I try to listen and be available to patients.” Consulting psychotherapists, sex therapists and social workers who specialize in working with breast cancer survivors are other options. Most comprehensive breast care centers or gynecologists can help women connect with these resources.

Is age a factor in a woman's willingness to broach the subject of sexual functioning in the wake of breast cancer treatment? “In my experience, younger women are no more likely to ask about sexual side effects than older women,” Dr. Weisberg says. “Age isn't really the issue when it comes to sexual functioning; it's more about the quality of the relationship.”

The limited research that exists regarding the sexual side effects of breast cancer treatment seems to bear this out. One study of women with breast cancer aged 35 to 68 reported that “women who sought information about the sexual side effects of cancer treatment and who had strong intimate relationships appeared to experience a more successful adjustment.” That underscores the importance of asking for help.

Sexual intimacy can be one of the most life-affirming experiences available, and can contribute greatly to our quality of life.

When a woman is about to undergo breast cancer treatment, sex may not be high on the priority list of things to talk about. Yet sexual intimacy can be one of the most life-affirming experiences available, and can contribute greatly to our quality of life. Seeking support, involving your partner in treatment decision and openly communicating feelings, wants and needs regarding sex during and after treatment can be vital to maintaining that bond. ♪

sexual dysfunction

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## Y-ME Seeks Bilingual Hotline Peer Counselors

Are you a breast cancer survivor? Are you fluent in both Spanish and English? Help ensure that no one faces breast cancer alone by becoming a Hotline peer counselor.

Y-ME National Breast Cancer Organization is seeking bilingual breast cancer survivors to fill two part-time Hotline Peer Counselor positions. Y-ME offers the only multilingual, 24-hour Hotline in the country staffed by trained peer counselors who are all breast cancer survivors.

For more information, visit [www.y-me.org](http://www.y-me.org) and click on Contact Us, then Job Opportunities. ♯



 Y-ME National Breast Cancer Organization™

# mission

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.

## Lifeline

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\*Interpreters available in 150 languages



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In addition to our publications and other areas of our Web site [www.y-me.org](http://www.y-me.org), Y-ME suggests the following resources for breast cancer information.

## Y-ME online resources



### Y-ME Launches Web Site Section for Newly Diagnosed

#### **My First Steps: individualized treatment information** **[www.y-me.org/myfirststeps](http://www.y-me.org/myfirststeps)**

Y-ME has launched a new section of its Web site to empower newly diagnosed patients to make well-informed treatment decisions with their health care teams.

The section, My First Steps, is accessible from Y-ME's home page. In it, users can find information about tumor types, clinical trials, recurrence and questions to ask their doctors. Many of the pages link back to other parts of our Web site; for instance, "Breast Cancer Information," "Questions to Ask Your Doctor" and "Understanding Your Pathology Report."

The information is based on the latest scientific and medical information. It will allow newly diagnosed patients and their families to understand and discuss with their physicians the many diagnostic characteristics of their breast cancer and the appropriate treatment options.



LOTSAs HELPING HANDS

#### **Lotsa Helping Hands** **[www.y-me.org/lotsahelpinghands](http://www.y-me.org/lotsahelpinghands)**

Lotsa Helping Hands, Y-ME's free online service, helps unite friends and family in providing care and support. Needs are posted on a private and personalized Web site. Caregivers can sign up to help and receive notifications and reminder e-mails.

## Organizations

#### **The Mautner Project for Lesbians with Cancer** **1-866-MAUTNER (628-8637)** **[www.mautnerproject.org](http://www.mautnerproject.org)**

Improving the health of lesbians and their families through research, advocacy, education and direct services.

#### **The Sisters Network, Inc.** **(866) 781-1808** **[www.sistersnetworkinc.org](http://www.sistersnetworkinc.org)**

Sisters Network™ Inc. is committed to increasing local and national attention to the impact of breast cancer in the African-American community.

#### **The Young Survival Coalition** **(646) 257-3000** **[www.youngsurvival.org](http://www.youngsurvival.org)**

The Young Survival Coalition (YSC) is the only international, non-profit network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer. Through action, advocacy and awareness, the YSC seeks to educate the medical, research, breast cancer and legislative communities, and to persuade them to address breast cancer in women 40 and under. The YSC also serves as a point of contact for young women living with breast cancer.

#### **John W. Nick Foundation** **[www.johnwnickfoundation.org](http://www.johnwnickfoundation.org)** **(772) 589-1440**

The John W. Nick Foundation is a non-profit organization, focused on educating the public about male breast cancer.

# October is National Breast Cancer Awareness Month

For more than two decades, National Breast Cancer Awareness Month has been educating people about the disease. Each October, women are reminded that the earlier detection of breast cancer is key, including mammograms when applicable, clinical breast exams and breast self-exams. To view Y-ME's guidelines on earlier detection, please visit [www.y-me.org](http://www.y-me.org) and click on Breast Cancer Information.

Looking for a way to give back this October? Here are some ideas:

- Breast cancer survivors are invited to join the 24-hour Y-ME National Breast Cancer Hotline as volunteer peer counselors after completing a training and certification program.
- Join Y-ME's Advocacy program and help influence federal and state legislative action that will make a difference in the lives of those touched by breast cancer.

- Hold a breast health seminar in your workplace, club or religious institution.
- Make a donation to Y-ME or ask your family and friends to make a donation.
- Shop for the cause. Visit [www.y-me.org](http://www.y-me.org) and click on Corporate Partners for ideas.

Make a difference today! Visit [www.y-me.org](http://www.y-me.org) or call 1-800-221-2141 for information on how to volunteer with Y-ME.

October 20, 2006, is National Mammography Day, designated as the day for women to make an appointment for a mammogram.

## 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](http://www.y-me.org)

## Lifeline Is Available Online

If you'd like to read the current or back issues of Y-ME's quarterly publication, *Lifeline*, online, you can do so by visiting [www.y-me.org](http://www.y-me.org) and clicking on Publications. ✂



Receiving duplicate newsletters?

Has your address changed?

Please let us know! We make every effort to send only one newsletter to each family. If you're receiving more than one copy, or if you prefer to stop receiving *Lifeline*, e-mail your request to [list@y-me.org](mailto:list@y-me.org) or call us at 312-986-8338.



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