YOUR BREAST HEALTH GUIDE

HELPFUL INFORMATION ON PREVENTING, DETECTING AND TREATING BREAST CANCER FROM *SELF* MAGAZINE AND SUSAN G. KOMEN FOR THE CURE®

WHO'S YOUR SUZY?

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YOUR BREAST HEALTH GUIDE

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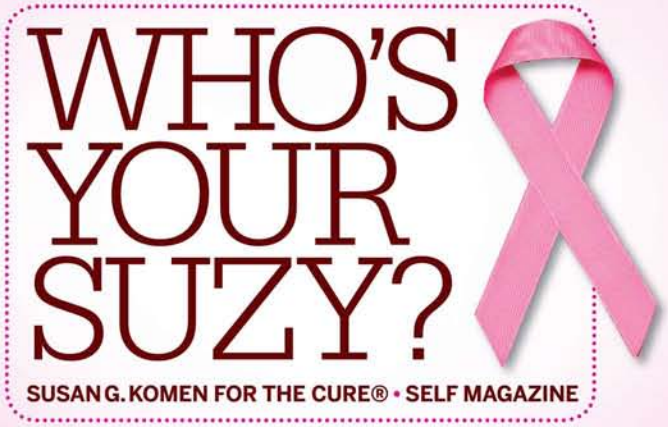


THEN AND NOW Austin in 1970 as an infant with her mother, Judith Austin, and today, holding her newborn daughter, Summer

My mother, my cancer fears

Losing my mom to breast cancer should have made me more diligent about getting screened. Instead, it made me avoid it.

By Sara Austin

I am sitting in a tiny changing room at a mammography center, shirtless, and I am crying. No reason to, logically: I haven't even taken my test yet. Nor have I found a lump. At 35 years old, I know there's little chance this screening will tell me I'm anything but perfectly healthy. "It's a simple baseline mammogram, recommended for women with a family history of breast cancer," my doctor had told me at a checkup, scribbling a referral to a radiology practice near my home in New York City.

When you've nursed someone you love through cancer, though, there's no such thing as a simple screening. And when that person shared your genes, it's doubly fraught. I pull a dusty-pink hospital gown from a pile in the changing room, wipe my tears on the sleeve and wonder, How many times did my mother go through this routine? And what did it feel like when it went wrong? I can't imagine what ran through her mind between the appointment in July 1996 when the doctors found her cancer and the moment when she gathered my sister and me on the living room sofa, both of us in our 20s, and grasped our hands tightly. "I have bad, bad breast cancer," she said, her voice breaking. She died a mere 13 months later, after being diagnosed with inflammatory breast cancer, a rare and virulent form of the disease. She was three weeks from her 58th birthday.

My confession today is that it has taken me nearly two years from the time my doctor recommended a mammogram for me to actually get one. I delayed making an appointment for more than a year, the prescription sitting in a stack of junk mail. Months later, I arrived for the visit and discovered I had left the prescription at home. While I pondered my missing paperwork, an older woman next to me beseeched the desk clerk to check the book again for her apparently missing appointment. I quickly offered her my slot and scheduled another one five months down the road.

Now my reprieve is over.

I am well insured, well informed—I oversee the health coverage at SELF—and well aware of the lifesaving difference early detection can make. The only thing standing in my way has been a mix of scary emotions: fear of a poor result, denial of my above-average risk, dread of having to talk with strangers about what happened to my mother, sadness to be walking in her footsteps. It's a toxic cocktail that has brought on my paralysis.

For many women, a little anxiety is a helpful kick in the pants. Numerous studies show that the greater a woman's perceived risk for breast, cervical and other cancers, the more likely she is to get tested for them. Some research, however, suggests that those who are most fearful may actually be the least likely to get screened, according to experts at the Fred Hutchinson Cancer Research Center in Seattle. You already know which camp I fall into. And there are a lot of us: women who by all rights should know better. According to a 2007 Harris Interactive survey for the American College of Obstetricians and Gynecologists in Washington, D.C., one in five American women does not want

FROM LEFT: COURTESY OF SUBJECT. SONJA PACHO; STYLING, ABBY JOHNSON; HAIR AND MAKEUP, ANGELA HUFF FOR MARK EDWARD; PROP STYLING, SONIA NIKI.

to know if she has cancer. The number was a notch higher for those who had a family history. "For a subset of women, the fear is real and intense, and it can be disabling," says psychiatrist Mary Jane Massie, M.D., director of the Barbara White Fishman Center for Psychological Counseling at Memorial Sloan-Kettering Breast Center in New York City. Physicians say younger women whose doctors recommend an early cancer screening may be more likely to fall into that anxious group because tests such as mammograms and colonoscopies are not yet a routine part of their medical care.

During the years I avoided my mammogram, I thought of my relative youth as a license to stall—growing older, I rationalized, is the highest risk factor for breast cancer. But because younger women often have faster growing, more aggressive tumors, early detection is critical for them. "If you are going to put off getting screened, when you are younger is certainly not the time to do it," notes Mary Mahoney, M.D., director of breast imaging at the University of Cincinnati.

There is in fact no good time to put it off. Cancer caught through routine screenings tends to be at an earlier, highly treatable stage. When breast and skin cancers are found early, five-year survival rates reach 98 percent, reports the American Cancer Society in Atlanta. If the cancer has had time to spread to nearby organs or lymph nodes, however, the survival rate drops to 84 percent for breast tumors and to 65 percent for melanoma. "The type of patient that worries me is the one who knows she has cancer but sits at home until she has advanced disease," Dr. Massie says. "It is a tragedy, and we certainly have seen women who very much know what's happening in their body and can't force themselves to get checked."

More sophisticated tests and early-detection campaigns have helped increase screening rates and saved lives. Yet these developments also might give women the willies. "We are aware of breast cancer, and that's great," says Elizabeth A. Poynor, M.D., a gynecologic oncologist in New York City. "But because we hear about breast cancer daily, some women feel they are just waiting to get it." Meanwhile, the move to digital mammography from film machines has created an adjustment period for radiologists and patients. "The resolution is so improved that we're picking up more," Dr. Mahoney says. Yes, tumors are being detected earlier, but more women with healthy breasts are also enduring nerve-racking follow-up tests.

Other patients, particularly those at high risk and those with younger, denser breast tissue, may be asked to undergo additional ultrasound or MRI screenings even if their mammograms are clean. And any time a woman gets a call to return to the doctor, alarm bells ring. "We can tell women that the vast majority of these [callbacks] turn out not to be anything of real importance," Dr. Mahoney says. "That's all well and good until it's you. Women are understandably concerned because they know so much and know what the possibilities are."

Genetic testing has added another layer of anxiety. A test for gene mutations linked to breast cancer is even more distressing than a mammogram. A negative result, which indicates you do not carry the mutation, doesn't put you in the clear, and a positive result could mean a lifetime spent wondering if this is the day that turns into the worst day of your life. "Some women have significant anxiety from that, and if somebody is not going to act on the results, and if her quality of life is affected, then she shouldn't undergo testing," Dr. Poynor says.

My mother's cousin died of breast cancer in her 40s. No one is sure what my great-grandmother died of, but Mom suspected breast cancer. That's not enough evidence to make my doctors recommend a gene test—and given how a mammogram terrifies me, I'm grateful. I'd like to think that if information about my family tree changed, I'd opt for genetic counseling. But how long do you think it would take me to follow up on that referral? Denial about the issue runs high, Dr. Massie says. Some women in her care who test positive have sought out family members to pass along what could be lifesaving information, only to have the door slammed in their face.

Doctors and researchers have devoted relatively little attention to helping women like me move past our screening hang-ups, yet doing so could effectively promote early detection. It turns out that psychosocial factors—what we're afraid of, how we manage our emotions, the support we get from others—can have an effect on breast cancer screening behavior that is equal to that of income, education and age, according to an analysis of research by psychologists at Long Island University in Brooklyn, New York. "Knowledge alone is not enough—we know a lot of things are good for us and we still don't do them. But if you tap into the psychological factors, you can spark real change," says Nathan Consedine, Ph.D., research assistant professor in the psychology department at LIU.

More medical centers need to make tests as palatable as possible to patients, and some have already taken steps to do so. Doctors, nurses and technicians can play a key role by walking women through the process before it starts and telling them how equipment works—explaining, for instance, why compressing the breast (the source of the worrisome ow! factor) makes mammogram results so much more accurate. Shorter wait times for appointments and quick turnarounds on results mean patients aren't left waiting and wondering. When

Your skipped-screening excuses busted!

Women have all sorts of rationalizations for sidestepping mammograms, Pap tests and skin checks. Among the biggies:

YOUR EXCUSE	THE FACTS
I'm flat-chested, so my breast cancer risk must be low.	Breast size has no bearing on your risk for breast cancer—which is why basic screening recommendations are for women of all cup sizes.
Mammograms hurt too much.	The pain (if it hurts at all) is closer to a quick finger pinch than natural childbirth. A technician who helps you relax can minimize discomfort.
My last Pap test was fine, so I'm still in the clear.	Only after you're older than 30 and have had three normal Paps in a row can you postpone the test. Even then, you should get your M.D.'s OK first.
My dark skin means I'm safe from skin cancer.	Light-skinned people are certainly at above-average risk, but no one is entirely safe. Get a skin check annually from your dermatologist.
I'm too busy to squeeze in the appointment.	"Women are notorious for putting themselves last," says Mary Mahoney, M.D., of Cincinnati. "But you can't help others if you aren't healthy!"

LOG ON TO SELF.COM and visit Hot Topic to comment on this article or share your own screening anxieties.

the new breast-imaging center at the University of Cincinnati opened this year, even the decor, which includes a soft green color scheme, aimed to soothe anxious patients. "We tried to make it as spalike as you can get in a hospital," Dr. Mahoney says.

Primary care physicians also need to do more than rip off a referral slip for the test once a year; they should acknowledge to women that a screening might prompt anxiety even as they underscore its importance. If your doctor doesn't take the time to ask, you need to volunteer how anxiety-provoking cancer tests are for you. "It's important to have a good dialogue," Dr. Poynor says. "Ask, 'What can I expect? What if it's positive? What if it's negative?'"

Few of her patients who have skipped their tests are willing to fess up to the full reasons why, Dr. Poynor adds. And doctors are hard-pressed to guess, because our fears are so individual. Younger women without much sexual experience may find a Pap daunting, for example, whereas other women avoid mammograms out of fear of pain or embarrassment. Others' greatest worry is being alone when they discover they have cancer, so they neglect self exams.

Talking to your doctor about your fears can help the two of you find the best way to cope. "If I know a patient is scared it will hurt, I can explain the process so she knows what to expect," Consedine says. If you need more hand holding, get it literally: Schedule screenings with someone who can comfort you and keep you honest. "I work with women who arrange to have a mammogram done at lunch with a girlfriend," Dr. Massie says. "Then they go out afterward and turn it into a pleasant experience." If you can't take someone along, focusing on your loved ones can motivate you to make—and keep—the appointment, she suggests. "I really look at it as an obligation. We are obligated to ourselves and to the people who love us to do this."

I gave birth to a daughter this summer, so Dr. Massie's advice hit home with me. What do I owe my little girl? And what do I owe her maternal grandmother? I think about how much better things might have been if the cancer had been detected earlier. Inflammatory breast cancer is notoriously hard to catch, because it rarely produces a telltale lump, so probably nothing could have been done. To ask Mom post-diagnosis if she had kept up with her mammograms would have been cruel and pointless.

Still...I know my mother had no love for doctors or for facing up to bad news. In her hospital room after her double mastectomy, the two of us unwillingly overheard a psychologist's ham-fisted attempts to counsel my mother's dying roommate. Mom looked me in the eye and made me swear that, if there came a time when she couldn't speak for herself, I would never allow a therapist to try the same with her. (When the hospice sent someone to our house in her last days, I kept my promise.) She hid her illness from her 91-year-old mother for far too long, out of fear of breaking her heart and from denial that she didn't have more time. Fear and denial: I am my mother's daughter. But would she be proud of my following in these particular footsteps?

> "Focusing on loved ones can motivate you to make an appointment."

One day, my daughter will, like me, be forced at nearly every doctor's appointment to confront her grandmother's illness and her own higher risk. But I need her to know that fear of breast cancer is not my mother's only legacy. She passed on a love of storytelling and the South. She taught me to value my vote and to hold those running the country accountable when they let us down. She loved reading and thrived in her job as a reference librarian. She taught me how to make a French braid and pecan pie.

Those are things worth living for, things I want to pass on. Certainly they are worth a few minutes of angst in a New York City screening center. I pull my hospital gown tight around me, gather myself and head out of the changing room. And I vow to actually change. ■

FACTS FOR LIFE

What is Breast Cancer?

Every day, cells in your body divide, grow and die. Most of the time cells divide and grow in an orderly manner. But sometimes cells grow out of control. This kind of growth of cells forms a mass or lump called a tumor. Tumors are either *benign* or *malignant*.

Benign [bee-NINE] tumors
Benign tumors are not cancerous. But left untreated, some can pose a health risk, so they are often removed. When these tumors are removed, they typically do not reappear. Most importantly, the cells of a benign tumor do not invade nearby tissue or spread to other parts of the body.

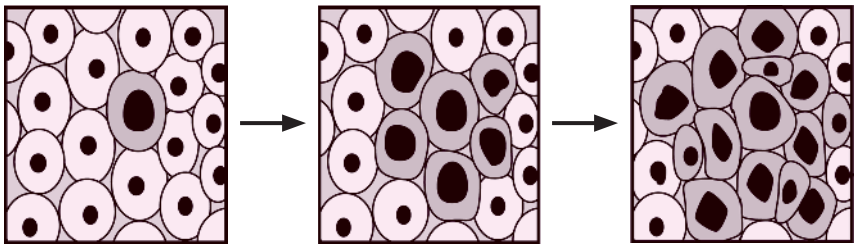
Malignant [ma-LIG-nant] (cancerous) tumors
Malignant tumors are made of abnormal cells. Malignant tumor cells can invade nearby tissue and spread to other parts of the body. A malignant tumor that develops in the breast is called breast cancer.

How does breast cancer grow and spread?

To continue growing, malignant breast tumors need to be fed. They get nourishment by developing new blood vessels in a process called angiogenesis. The new blood vessels supply the tumor with nutrients that promote growth. As the malignant breast tumor grows, it can expand into nearby tissue. This process is called invasion. Cells can also break away from the primary, or main, tumor and spread to other parts of the body. The cells spread by traveling through the blood stream and lymphatic system. This process is called metastasis. When malignant breast cells appear in a new location, they begin to divide and grow out of control again as they create another tumor. Even though the new tumor is growing in another part of the body, it is still called breast cancer. The most common locations of breast cancer metastases are the lymph nodes, liver, brain, bones and lungs.

Breast cancer growth

The light circles represent normal breast cells and the dark-shaded circles represent cancerous breast cells. As the cancerous cells grow and multiply, they develop into a malignant tumor within the breast.



For more information, call Susan G. Komen for the Cure® at 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org.

Why does breast cancer grow?

We all have genes that control the way our cells divide and grow. When these genes do not work like they should, a genetic error, or *mutation*, has occurred. Mutations may be inherited or spontaneous. Inherited mutations are ones you were born with — an abnormal gene that one of your parents passed on to you at birth. Inherited mutations of specific genes, such as the BRCAI and BRCA2 genes, increase a woman's risk of developing breast cancer. Spontaneous mutations occur within your body during your lifetime. The actual cause or causes of mutations still remains unknown. Researchers have identified two types of genes that are important to cell growth. Errors in these genes turn normal cells into cancerous ones. The table below provides a description of each.

Type of gene	How it should work	How it works when damaged
Oncogene	It "turns on," or starts normal cell division and growth.	The gene does not stop when it should and cell growth continues out of control.
Tumor suppressor gene	It "turns off," or stops normal cell division and growth.	The gene does not work and cell growth continues out of control.

But remember...

Cells may be growing out of control before any symptoms of the disease appear. That is why breast screening to find early changes is so important. The sooner a problem is found, the better a woman's chances are for survival. Experts recommend that women 40 years and older have a mammogram every year. If you have a history of breast cancer in your family, talk with your doctor about risk assessment, when to start getting mammograms and how often to have them. If your mother or sister had breast cancer before menopause, you may need to start getting mammograms and yearly clinical breast exams before age 40. It is important for all women to have clinical breast exams done by a health care provider at least every three years starting at age 20 and every year after age 40.

Resources

Susan G. Komen for the Cure®
1-877 GO KOMEN (1-877-465-6636)
www.komen.org

American Cancer Society
1-800-ACS-2345
www.cancer.org

National Cancer Institute
1-800-4-CANCER
www.cancer.gov

Related fact sheets in this series:

- Ductal Carcinoma in Situ
- Genetics & Breast Cancer
- Types of Breast Cancer

Developed in collaboration with the Health Communication Research Laboratory at Saint Louis University. Item No. 806-368a 8/08

FACTS FOR LIFE

Breast Cancer Risk Factors

What affects your risk of getting breast cancer?

The causes of breast cancer are not fully known. However, researchers have identified a number of factors that increase one's chances of getting breast cancer. These are called risk factors. Risk factors are not necessarily causes of breast cancer, but are associated with an increased chance of getting breast cancer. Some women have many risk factors but never get breast cancer. Some women have few or no risk factors but do get the disease. Being a woman is the number one risk factor for breast cancer. Talk to your health care provider about your personal risk.

There are some risk factors you can control, and others you cannot. Remember, even if you do not have any of these risk factors, you can still develop breast cancer.

Age: a major factor

A woman's chance of getting breast cancer increases with age. Your chance by your current age is:

age 20	1 in 1,837
age 30	1 in 234
age 40	1 in 70
age 50	1 in 40
age 60	1 in 28
age 70	1 in 26
Lifetime	1 in 8

Source: American Cancer Society Breast Cancer Facts and Figures 2007-2008

Factors that may increase your risk of breast cancer

- being a woman
- getting older — the older you get, the greater your risk of breast cancer
- having an inherited mutation in the BRCA1 or BRCA2 breast cancer genes
- having a previous biopsy showing hyperplasia or carcinoma in situ
- a family history of breast cancer
- having high breast density on a mammogram
- being exposed to large amounts of radiation, such as having very frequent spine X-rays for scoliosis or treatment for Hodgkin's disease at a young age
- a personal history of breast or ovarian cancer
- starting menopause after age 55
- never having children
- having your first child after age 35
- high bone density
- being overweight after menopause or gaining weight as an adult
- having more than one drink of alcohol per day
- currently or recently using combined estrogen and progesterone hormone replacement therapy (HRT)
- being younger than 12 at the time of your first period
- current or recent use of birth control pills

Get the facts on breast cancer

Because the causes and cures of breast cancer are not yet fully known, many people have misconceptions about the disease. Here is what we know for sure:

Myth	Fact
I'm only 35. Breast cancer happens only in older women.	While the risk of breast cancer increases with age, all women are at risk for getting breast cancer.
Women with a family history of breast cancer typically get breast cancer.	Actually, most women who get breast cancer have no family history of the disease. However, a woman whose mother, sister or daughter had breast cancer has an increased risk. Having a male relative with breast cancer, although rare, can also increase your risk.
If I don't have a mutated BRCA1 or BRCA2 gene, I won't get breast cancer.	Just because you do not have a mutated BRCA1 or BRCA2 gene, you can still get breast cancer. About 90 to 95 percent of women who get breast cancer actually do not have an inherited form of breast cancer, or a mutated BRCA1 or BRCA2 gene.[1]
Women with more than one risk factor typically get breast cancer.	Most women diagnosed with breast cancer have no known risk factors except being a woman and getting older. All women are at risk.
You can prevent breast cancer.	Because the causes of breast cancer are not yet fully known, there is no way to absolutely prevent it. However, the drugs tamoxifen or raloxifene can help reduce the risk.
If I had a mammogram every year, I would be exposed to too much radiation, and that would cause cancer.	The small level of radiation from mammograms is believed to be safe, with the benefits outweighing the risks.[2]
Breastfeeding can increase my risk of breast cancer.	Breastfeeding may decrease a woman's risk of getting premenopausal breast cancer.

For more information about risk factors go to www.komen.org/riskmatrix

Related fact sheets in this series:

- Breast Cancer Detection
- Genetics & Breast Cancer
- How Hormones Affect Breast Cancer

1 American Cancer Society, Breast Cancer Facts & Figures 2007-2008.
2 American College of Radiology, www.radiologyinfo.org/content/mammogram.htm/.

FACTS FOR LIFE

Young Women & Breast Cancer

Why do "young" women get breast cancer?

When it comes to breast cancer, "young" usually means anyone younger than 40 years old. Breast cancer is less common among women in this age group. In the United States, less than 5 percent of all breast cancer cases occurred in women under age 40.[1]

However, women who are diagnosed at a younger age are more likely to have a mutated BRCA1 or BRCA2 gene. These genes are important in the development of breast cancer. Women who carry defects on either of these genes are at greater risk of developing breast and ovarian cancer. If a woman carries a defective BRCA1 or BRCA2 gene, she may have a 30 to 85 percent chance of developing breast cancer in her lifetime. In addition, having a mother, father, daughter or sister who has or had breast cancer also increases a young woman's risk of developing breast cancer. So while the risk of breast cancer is generally much lower for young women, there is still a high risk for some.

If you are concerned about your genetic risk, ask your doctor to refer you to a genetic counselor who will discuss in detail what your risk may be. You can talk about genetic testing, risk reduction or other screening tests, like MRI, that might be right for you.

Diagnosing breast cancer in young women can be more difficult because their breast tissue is often denser than the breast tissue of older women. By the time a lump can be felt in a young woman, it is often large enough and advanced enough to lower her chances of survival. In addition, the cancer may be more aggressive and less responsive to hormone therapies. Delayed diagnosis in young women is a problem. Because it is rare for a young woman to get the disease, they are often told to wait and watch a lump. Tell your doctor if you notice a change in either of your breasts, and think about getting a second opinion if you are not satisfied with his or her advice.

If you have had breast cancer, you still may be able to have children.

A helpful tip for young women

Clinical breast exams are recommended for all women beginning at the age of 20, at least every three years, or every year if you are age 40 or over. If you are under age 40 with a family history or other risk factors you should talk with your health care provider about risk assessment, when to start getting mammograms and how often to have them.

It is important to know how your breasts normally look and feel. Breast self-exam (BSE) is a tool that may help you learn what is normal for you. BSE includes looking at and feeling your breasts. If you discover a lump or notice any changes in your breasts, see your health care provider right away. (For step-by-step breast self-exam instructions, go to www.komen.org/bse.)

1 American Cancer Society, Breast Cancer Facts & Figures 2007-2008.

Hearing the pitter-patter of little feet?

Some treatments for breast cancer can affect a woman's ability to have children. If you think you would like to become a parent after breast cancer, talk with your doctor about your options before deciding on treatment.

In the past, doctors would advise women who have had breast cancer not to have children. Doctors thought that the added estrogen and progesterone during pregnancy may promote the growth of breast cancer. Yet, there are no studies that have clearly shown a link between pregnancy and recurrence of breast cancer. Today, many doctors say it is fine for women who are free of cancer and not undergoing treatment to become pregnant. Some suggest waiting 2 to 5 years after diagnosis — the most likely period of recurrence — to assure that breast cancer has not returned.

Some women around age 40 who are closer to menopause find that after chemotherapy, their periods do not return. For those who are in their 20s and 30s and who still have their periods after chemotherapy, the ability to have children may be unaffected. If you are hoping to have children after cancer treatment, talk with your doctor about your options.

For mothers with breast cancer

If you are a mother of young children and you have breast cancer, it can be hard to tell your children what you are going through. Remember that children can pick up on their parents' feelings, and may be confused if you do not talk to them about your condition. Telling your children in simple terms about your cancer and sharing some of your feelings will help them understand the changes around them. Every mother is different, and your parenting style may be different from someone else's. But in your own way, try to share with your children what you are going through. Also, trying to maintain your usual routine may help your children adjust to the changes. Talking about your breast cancer can help both you and your children cope with the disease.

Resources

Young women with breast cancer may have special concerns that are different from those of older women. Finding the right support group can bring strength and friendship through sharing your thoughts and feelings. Many larger hospitals have or can refer you to cancer support groups in your area. Or you can contact these organizations for more information:

Organizations

Susan G. Komen for the Cure®
1-877 GO KOMEN, www.komen.org for these booklets:
What's happening to me?
What's happening to the woman I love?
What's happening to mom?
What's happening to the woman we love?

American Cancer Society
1-800-ACS-2345
www.cancer.org

Fertile Hope
1-888-994-HOPE
www.fertilehope.org

Young Survival Coalition
1-646-257-3000
www.youngsurvival.org

Breast Cancer™ Network of Strength
1-800-221-2141 (English) or
1-800-986-9505 (Spanish)
www.networkofstrength.org

Related fact sheets in this series:

- Genetics & Breast Cancer
- Talking With Your Children
- When You Discover A Lump

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FACTS FOR LIFE

Inflammatory Breast Cancer

What is inflammatory breast cancer?

Inflammatory breast cancer (IBC) is rare and the most aggressive form of breast cancer. It is called inflammatory breast cancer because its main symptoms are swelling and redness of the breast. Unlike other forms of breast cancer, IBC often lacks a distinct lump or tumor. Instead, cells grow in sheets that spread through the breast. IBC is not usually found by mammograms or ultrasounds unless there is a defined lump. If no lump is present, it can be hard to diagnose. Because IBC cells spread easily to other parts of the body, it requires prompt diagnosis and treatment.

Who is at risk?

IBC accounts for about one to five percent of all breast cancer cases in the United States. The average age at diagnosis in the U.S. is younger for both Caucasian and African American women.[1]

- It is slightly more common in African American women. As many as ten percent of new breast cancer cases in African American women are IBC, compared to six percent of breast cancer cases in Caucasians and five percent of other races.
- It is more common in younger women than other forms of breast cancer. It has been seen in women who are pregnant and in women who are breastfeeding.
- Like other forms of breast cancer, it has also been seen in men.

1 Merajver SD, Sabel MS. Inflammatory breast cancer in Harris JR, Lippman M, Morrow M and Osborne C. Diseases of the breast Philad Lippinolt Williams & Wilkins, 2004.

Symptoms of inflammatory breast cancer

There are many symptoms of inflammatory breast cancer. It is important to see your doctor if you have any of these symptoms:

- one breast becomes much larger than the other one (often sudden)
- warmth and swelling in the breast (often sudden)
- redness or pinkness that may look like an infection
- itching or pain in the breast that won't go away
- dimpling of the skin that may look like the skin of an orange (called peau d' orange)
- ridges or thickened areas of skin
- nipple discharge
- nipple retraction or flattening
- change in the color of the areola (the dark skin around the nipple)
- a bruise that does not go away
- swollen lymph nodes on the neck or under the arm
- a lump (although often there is no lump)

Photo courtesy the Inflammatory Breast Cancer Research Foundation

Enlarged right breast with nipple retraction. Peau d' orange on underside of breast not visible in the photo above is shown in the next photo.

For more information, call Susan G. Komen for the Cure® at 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org.

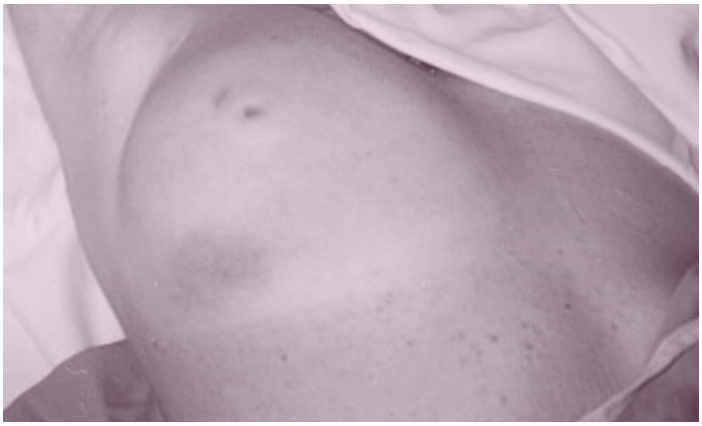

Photo courtesy the Inflammatory Breast Cancer Research Foundation

Peau d'orange on underside of breast, not visible when standing. The small irregular red spot at the 11 o'clock position in this photo is the scar remaining from a skin biopsy, not a symptom of inflammatory breast cancer.

The symptoms of IBC are not always the same. It is often misdiagnosed as a breast infection. Any of these symptoms may be a sign of either IBC or a benign breast infection (not cancer). If the symptoms last longer than a week after starting antibiotics, insist that your doctor do a biopsy to see if cancer cells are present. If you do not feel that your doctor listens to your concerns, get a second opinion.

Treatment for inflammatory breast cancer

Treatment for inflammatory breast cancer often starts with several rounds of chemotherapy, hormone therapy or both. These systemic treatments affect the whole body. They are used to kill or control any cancer cells that might have spread to other parts of the body. Then local treatments, such as radiation therapy and surgery, are used to target the remaining cancer cells in the breast and under the arm. Sometimes systemic treatments are used again after the local treatments. Systemic treatments used at follow-up may include chemotherapy, hormone therapy and targeted therapy.

If you have been diagnosed with inflammatory breast cancer, know that there is hope. Advances in the treatment of breast cancer have improved the 5-year survival rates of women with IBC and new research is ongoing. Staying positive is vital to your quality of life. Ask your doctor about sources of help and support in your area.

Resources

Organizations

Susan G. Komen for the Cure®
1-877 GO KOMEN (1-877-465-6636)
www.komen.org

American Cancer Society
1-800-ACS-2345
www.cancer.org

IBC Research Foundation
1-877-STOP-IBC
www.ibcresearch.org

National Cancer Institute
1-800-4-CANCER
www.cancer.gov

Young Survival Coalition®
1-877-YSC-1011
www.youngsurvival.org

Internet

IBC Support
www.ibcsupport.org

Related fact sheets in this series:

- Biopsy
- Treatment Choices — An Overview
- Types of Breast Cancer
- What is Breast Cancer

Developed in collaboration with the Health Communication Research Laboratory at Saint Louis University. Item No. 806-03202a 8/08

FACTS FOR LIFE

Breast Cancer Detection

Breast cancer screening methods

Mammogram — A mammogram is an X-ray picture of the breast. It is done with a special X-ray machine designed for this purpose. The picture is stored on film (standard) or into a computer (digital). A mammogram can find many cancers before they can be felt.

Clinical breast exam — A breast exam by a health care provider should be part of your regular medical checkup. If it is not, ask for it. A clinical breast exam includes a visual examination and carefully feeling the entire breast and underarm area. If you are 40 or older, schedule your mammogram close to the time of your clinical breast exam.

Breast self-exam (BSE) — Is a tool that may help you learn what is normal for you. BSE includes looking at and feeling your breasts. Many women have a pattern of lumpiness in their breasts, which is normal. But if you feel any change or a new lump in your breasts or underarms, ask your doctor to examine the area. (For step-by-step BSE instructions, go to www.komen.org/bse.)

Now is the best time

Believe it or not, the best time to check for breast cancer is when your breasts feel fine. If you find cancer early, there are more treatment options and a much better chance for survival. Mammography is the best screening method used today to find breast cancer early. However, it is not perfect. But, when mammography is combined with clinical breast exam your chances for finding cancer are even greater.

Remember, even if you feel healthy now, just being a woman and getting older puts you at risk for breast cancer. Getting checked regularly can put your mind at ease. And finding cancer early may save your life.

Find your age on the chart below to see which screening methods you should use and how often. Women under age 40 with either a family history of breast cancer or other concerns about their personal risk should talk with their health care provider about when to start getting mammograms or other tests, such as breast MRI, and how often to have them.

Age 20-39	Frequency	Age 40 and older	Frequency
clinical breast exam	at least every three years	mammogram	once a year
BSE is a tool that can be used to learn what is normal for you. Women at higher risk may need to get screened earlier and more frequently than recommended.		clinical breast exam BSE is a tool that can be used to learn what is normal for you.	once a year

For more information, call Susan G. Komen for the Cure® at 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org.

Questions to ask

Talk with your health care provider about your risk of breast cancer. Ask which screening methods are right for you.

Here are some questions you might want to ask:

1. What is my personal risk for getting breast cancer?
2. Do I need a mammogram? If not, why not?
3. Where can I go to get a mammogram?
4. What if I cannot afford a mammogram?
5. How often should I get a mammogram?
6. How often do I need a clinical breast exam?
7. What is the best way to do a breast self-exam?
8. Should I consider additional tests related to my risk?

Resources

You can receive information about mammograms and clinical breast exams by contacting the organizations listed on this page. You may also go to www.komen.org/bse for step-by-step BSE instructions.

Susan G. Komen for the Cure®
1-877 GO KOMEN (1-877-465-6636)
www.komen.org

American Cancer Society
1-800-ACS-2345
www.cancer.org

National Cancer Institute's Cancer Information Service
1-800-4-CANCER
www.cancer.gov

Trouble signs that should not be ignored

Be aware of possible problems in your breast or underarm area. If you notice any of the following signs, make an appointment with your health care provider right away.

- lumps, hard knot or thickening in any part of the breast
- swelling, warmth, redness or darkening that does not go away
- change in the size or shape of your breast
- dimpling or puckering of the skin of your breast
- itchy, scaly sore or rash on the nipple
- pulling in of your nipple or other parts of the breast
- nipple discharge that starts suddenly
- new pain in one spot that does not go away

Related fact sheets in this series:

- Benign Breast Changes
- Breast Cancer Facts
- Mammography
- When You Discover a Lump

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FACTS FOR LIFE

Treatment Choices — An Overview

Choosing your treatment

Step 1: Learn all you can
Take some time to learn all you can about your type of breast cancer and your treatment options. Try not to let anyone pressure you into making a decision about your course of treatment before you are ready. Your breast cancer took a long time to develop and it is not going to get worse overnight. You have time to get the information you need to make the right decision. Visit the library, search the Internet, request pamphlets from health care providers and organizations that help cancer patients and ask your doctor(s) all your questions so you may understand your options.

Step 2: Get a second opinion
It is very common to seek a second, or even a third opinion from other specialists. Some insurance companies and HMOs actually require you to get a second opinion. Most doctors will not be offended that you want a second opinion. After all, it can only add to your knowledge about your breast cancer.

Step 3: Get a medical team
Finding good doctors to work with you is the best way to decide what treatments are right for you. Most insurance plans will provide you with a list of doctors to choose from. Call the local office of the American Medical Association or go online at www.ama-assn.org to find out more about the doctors in your area. Most women with breast cancer need to make decisions about what type of breast surgery to undergo; whether to undergo radiation therapy, chemotherapy or hormonal therapy; and whether to undergo breast reconstruction. All women with breast cancer should talk with a medical oncologist to discuss their specific treatment needs, a specific treatment plan and identify who will speak for them should they be unable to speak for themselves.

Questions to ask your doctor

- How long do I have to make a treatment decision?
- What procedures will my insurance cover?
- Which form of treatment offers me the best chance of survival?

- Where will my surgical scars be and what will they look like?
- What is my prognosis?
- Will I need a blood transfusion? Can I donate my own blood?
- What side effects can I expect during each stage of treatment? How can they be managed?
- How long will I have to stay in the hospital? How much work will I miss?
- How many of my axillary nodes are involved?
- Will I need radiation therapy, chemotherapy, hormone therapy or biological therapy? Why or why not?

For more information, call Susan G. Komen for the Cure at 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org.

Types of treatment

Surgery and **radiation therapy** are *local treatments* because they treat a small area of the body. Studies have shown that breast conserving therapy and mastectomy are equal in terms of their effectiveness.

- **Breast conserving surgery** involves surgical removal of only the cancerous area of the breast and some surrounding normal tissue. Usually, underarm lymph nodes are also removed. This procedure is often called a *lumpectomy*. Side effects can include temporary loss of arm movement, numbness and lymphedema (fluid build-up that causes swelling in the arm and hand on the surgery side). Although there is a chance that not all the cancer will be removed, the breast is saved, the surgery is less invasive and an overnight stay in the hospital may not be required. Radiation therapy is generally required to decrease the chances of recurrence.

- **Mastectomy** involves surgical removal of the entire breast and usually some underarm lymph nodes. Side effects may include temporary soreness, loss of arm movement, numbness and lymphedema. Mastectomy is an invasive procedure, requires a short stay in the hospital and can have an emotional impact. However, radiation therapy often is not required and there are several options for reconstruction. There is a small chance that not all the cancer will be removed with a mastectomy.

- **Radiation therapy** involves using high energy X-rays to destroy cancer in the breast, chest and axillary lymph nodes. It is most often used with breast conserving surgery, but may also be recommended after a mastectomy for women with four or more positive lymph nodes or women with breast cancers over 5 cm. in size or those with close or positive margins (cancer cells close to or at the edge of the surgically removed breast.) Side effects may include fatigue, soreness and swelling in the breast area and lymphedema that may develop later. It is a *local treatment* because it treats a small area of the body.

Adjuvant therapy is used *after* local treatment to kill any cancer cells that may have escaped from the breast and spread to other parts of a woman's body. Adjuvant therapy includes chemotherapy, hormone therapy and biological therapy.

- **Chemotherapy** involves using drugs to kill cancer cells that may be in a woman's body. The treatment is given 1 or 2 times a month for 3 to 6 months. Side effects can include hair loss, nausea, fatigue, early menopause, hot flashes and lowered blood counts for a short time. It is a *systemic treatment* because it treats the entire body.

- **Hormone therapy** involves using drugs to prevent your body's hormones, especially estrogen, from promoting the growth of any cancer cells that may remain after surgery. The therapy may involve taking a drug, like tamoxifen, for several years, or it may involve drugs to decrease the body's production of estrogen. Side effects can include hot flashes, vaginal dryness, weight gain and rarely, depression. It is a *systemic treatment* because it treats the entire body.

- **Biological therapy** involves using the body's immune system to fight cancer and reduce the side effects that are caused by other treatments. These therapies are relatively new and many are still being studied in clinical trials. Herceptin is a biological therapy that targets breast cancer cells that have high levels of a protein called HER2. Herceptin has been approved by the FDA to treat early stage breast cancer and certain metastatic breast cancers that contain high levels of HER2 (20 to 25 percent of breast cancer).

Neoadjuvant chemotherapy is sometimes used *before* surgery to help shrink the size of the tumor. The side effects are the same as for adjuvant chemotherapy.

Related fact sheets in this series:

- Breast Surgery
- Chemotherapy
- Hormone Therapy
- Radiation Therapy
- Lymphedema

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FACTS FOR LIFE

Life After Treatment

When breast cancer treatment begins, many women think that their last day of treatment will signal the end of this challenge in their lives. But most women report ongoing physical and emotional issues that they did not expect. Lasting side effects of treatment and emotional concerns are normal. It helps to know what to expect after treatment ends.

Emotional effects of treatment

The last day of treatment
Visions of cake and celebration often go along with thoughts about the last day of treatment. But many women report that they feel let down, sad, tired and anxious. One way to help ease into this change is to do something special to mark the day. You may not feel like having a big party, but a quiet dinner with your loved ones or a special outing may be good ways to celebrate.

Will I ever feel normal again?
You may wonder when you will feel like your old self again. Friends and family often think that just because your active treatments are over, you are fully recovered. Plan on it taking at least as long as you were in treatment to recover physically, sometimes longer. Take the time you need before agreeing to new obligations. If you find you have trouble saying "no" it may help to have a script ready. Practice saying, "No thanks, I'd rather not take on anything extra right now."

One source of anxiety is that you are now very aware of every ache and pain in your body. Each trouble brings with it the fear of the cancer's return. This is normal and will ease with time. If you are concerned about any symptoms, contact your doctor instead of worrying.

The anxiety of medical tests

Follow-up tests, though necessary, can bring the fear of a return of the cancer. This is normal. It can help to schedule your tests so that you have the results that same day or the next. Bringing a co-survivor (friend or family member) with you may also help. Some women like to schedule an appointment with their doctor to go over the results, either in person or over the phone, so they do not have to wait for the office to call them.

The fear of the cancer returning
The fear that breast cancer may return is a normal reaction. Most women report that, as time goes by, they think of it less and less often. Getting support from co-survivors (friends, family, clergy, therapists or support groups) are all ways to help handle this anxiety. If you find that your fears are not easing over time or that they interfere in your daily life, you should talk to your doctor. You may be suffering from depression. Getting the support and treatment you need is important for your health and the quality of your life.

For more information, call Susan G. Komen for the Cure at 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org.

Physical effects of treatment

Surgery

After surgery you may be faced with getting used to the way your breasts look. There may be scars, changes in shape or the absence of breast tissue. If you have had a mastectomy you may be thinking about wearing a prosthesis or having reconstructive surgery. No matter what you decide, there is no need to rush. If you are thinking about reconstruction, take the time to find an experienced surgeon and talk over the risks and benefits of your options. It is also possible to have reconstruction done on the same day as the mastectomy.

If you had surgery that removed lymph nodes under your arm you may be at risk of lymphedema [lim-fa-DEE-ma]. This is a swelling of the arm and hand due to the build-up of lymphatic fluid. It can occur shortly after surgery or even years after treatment. Ask your surgeon about what to look for and how to reduce your risk.

Chemotherapy

After ending chemotherapy you may be looking forward to having your hair grow back. Hair grows about a half-inch per month so it may take some time before you are able to style it as you did before. Sometimes when it grows back in, it is a different color and texture.

Chemotherapy can cause sudden menopause. The closer a women is to her natural menopause, the more likely this is to happen. This sudden physical change comes with all of the symptoms of menopause. Hormone replacement therapy (HRT) is not an option for managing these symptoms due to the role hormones play in breast cancer. However, your doctor can help you find other ways to manage these symptoms. In younger women, the menopause caused by chemotherapy can be temporary or it can be permanent and result in infertility.

Chemotherapy may also lead to memory problems. This is sometimes called "chemobrain," and is a general sense of mental "fuzziness" and short-term memory problems. Most women say that these symptoms improve with time, although no one is sure if they ever return to pre-treatment levels. Talk to your doctor to rule out side effects from medicines or depression.

Weight gain is a common side effect of chemotherapy. Exercise, even just walking, can help with weight loss and can also help relieve stress. It is also very important to eat a healthy diet. Not only will this help with weight loss, it helps your body heal.

Radiation therapy

Radiation therapy may cause fatigue and skin changes. These changes usually start to get better once treatment ends. Some breast changes like soreness, swelling, firmness and color changes can last for up to a year or longer.

Hormone therapy

Most side effects from hormone treatments end once treatment is over. Some women though, continue to take tamoxifen (Nolvadex) or an aromatase inhibitor (Arimidex or Femara) to reduce the chance of the cancer returning. The most common side effects of tamoxifen include hot flashes, vaginal dryness or discharge, weight gain, mild nausea, fatigue, depression and decreased libido. The side effects of the aromatase inhibitors include bone pain, hot flashes, fatigue, joint pain, osteoporosis and fractures. Your doctor may prescribe another medication along with an aromatase inhibitor to prevent osteoporosis.

Related fact sheets in this series:

- Follow-up
- Breast Reconstruction and Prosthesis
- Complementary Therapies
- Lymphedema
- Tamoxifen

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FACTS FOR LIFE

Breast Health Resources

If you need more resources...

This fact sheet lists some credible resources to help you. For many people, the Internet is a valuable source of breast cancer information. If you use the Internet for this purpose, make sure the information you are getting is reliable and trustworthy. Is the source reputable? Is the source affiliated with a university, health foundation or government health agency? Before you take any health actions based on something you find on the web, check it out with your health care provider. Get at least one other opinion, then decide what is best for you.

Organizations

Susan G. Komen for the Cure® — promises to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. For information and support, call 1-877 GO KOMEN (1-877-465-6636) or visit www.komen.org

American Cancer Society — provides medical information, treatment decision tools, news updates, and support resources. 1-800-ACS-2345, www.cancer.org

American Society of Clinical Oncology — has goals of improving cancer care and prevention and ensuring that all patients with cancer receive the highest quality care. 1-703-299-0150, www.asco.org

American Society of Plastic and Reconstructive Surgeons — to advance quality care to plastic surgery patients by encouraging high standards of training, ethics, physician practice and research in plastic surgery. www.plasticsurgery.org

CenterWatch Clinical Trials Listing Service™ — provides information on clinical trials and specific studies currently being conducted. www.centerwatch.com

Facing Our Risk of Cancer Empowered, Inc. (FORCE) — provides information for women whose family history or genetic status puts them at high risk of ovarian and/or breast cancer. 1-866-824-7475, www.facingourrisk.org

Fertile Hope — provides reproductive information, support and hope to cancer patients whose treatments present the risk of infertility. 1-888-994-HOPE, www.fertilehope.org

Food and Drug Administration Breast Implant Information Line — answers questions and registers complaints about breast implants. 1-800-532-4440, www.fda.gov/cdrh/breastimplants

Inflammatory Breast Cancer Research Foundation — dedicated to researching the cause of Inflammatory Breast Cancer (IBC), an advanced and accelerated form of breast cancer usually not detected by mammograms or ultrasounds. 1-877-786-7422, www.ibcresearch.org

Mautner Project, The National Lesbian Health Organization — provides education, support and other services to lesbians with cancer. 1-866-MAUTNER, www.mautnerproject.org

National Cancer Institute Cancer Fact Sheets — provides an index of all the National Cancer Institute Cancer Fact Sheets. www.cancer.gov/cancertopics/factsheet

National Cancer Institute's Cancer Information Service — provides information and resources for patients, the public and health care providers. 1-800-4-CANCER, www.cancer.gov

National Center for Complementary and Alternative Medicine at the National Institutes of Health — provides information on complementary and alternative health care. 1-888-644-6226, www.nccam.nih.gov

National Lymphedema Network — provides information on lymphedema. www.lymphnet.org

Sisters Network, Inc. — provides outreach and education on the impact of breast cancer in the African American community. 1-713-781-0255, www.sistersnetworkinc.org

Young Survival Coalition — provides information on breast cancer in young women. 1-646-257-3000, www.youngsurvival.org

Advocacy

Susan G. Komen for the Cure® Advocacy Alliance — launched I Vote for the Cure™ to educate voters and make breast cancer a priority by challenging candidates to support research, screening and treatment. www.ActNowEndBreastCancer.org

National Breast Cancer Coalition — grassroots organization with a mission to eradicate breast cancer through action and advocacy. 1-800-622-2838, www.stopbreastcancer.org

The Patient Advocate Foundation — provides legal and advocacy help with disputing insurance claim denials. 1-800-532-5274, www.patientadvocate.org

Support Programs and Services

American Cancer Society — the Reach to Recovery program has trained breast cancer survivors who visit newly diagnosed post-surgical patients. 1-800-ACS-2345, www.cancer.org

***Breast Cancer*™ Network of Strength** — to ensure, through information, empowerment and peer support, that no one faces breast cancer alone. 1-800-221-2141 (English) and 1-800-986-9505 (Spanish) or visit www.networkofstrength.org

Cancer*Care*® — provides free, professional support services to anyone affected by cancer. Services include counseling, education, financial assistance and practical help. 1-800-813-HOPE, www.cancercare.org

Gilda's Club — provides meeting places where men, women and children living with cancer, along with their families and friends, can join with others to build a network of social and emotional support. 1-888-GILDA-4-U or visit www.gildasclub.org

Kids Konnected — provides friendship, understanding, education and support for kids and teens who have a parent with cancer or have lost a parent with cancer. 1-800-899-2866 or visit www.kidskonnected.org Se Habla Espanol.

Financial Resources

There are many resources that can help with financial decisions. The first place that people can turn to for advice is a trusted health care provider. Physicians, nurses and social workers can all provide information and advice about financial questions. In addition, these resources may be helpful:

American Association of Retired Persons (AARP) — provides detailed information on a range of health issues for people over 50, including Medicare and other health insurance programs. 888-OUR-AARP (888-687-2277), www.aarp.org/health

Cancer*Care* Linking A.R.M.S.™ — offers qualified low-income, under-insured or uninsured people diagnosed with breast cancer financial assistance grants to cover the costs of oral chemotherapy and hormonal therapy medications, pain and anti-nausea medication, lymphedema supplies and medical equipment through a partnership with Susan G. Komen for the Cure®. 1-800-813-HOPE, www.cancercare.org

Corporate Angel Network — provides air transportation to treatment centers. 1-866-328-1313, www.corpangelnetwork.org

Hill-Burton program — hospitals receiving funds from the government for construction costs, etc. are required by law to provide services to persons unable to pay. 1-800-638-0742, or contact the Health & Human Services Department nearest you.

National Breast and Cervical Cancer Early Detection Program — provides access to critical breast and cervical cancer screening services for underserved women in the United States. 1-800-CDC-INFO, www.cdc.gov/cancer/nbccedp

National Patient Air Travel HELPLINE — provides air transportation to treatment centers. 1-800-296-1217, www.patienttravel.org

Partnership for Prescription Assistance — provides information on how to find pharmaceutical manufacturer assistance programs. 1-888-4PPA-NOW, www.pparx.org

Patient Advocate Foundation — offers a Co-Pay Relief Program that provides financial assistance to eligible patients who are being treated for breast cancer. 1-866-512-6861, www.copays.org

The National Financial Resources Guidebook for Patients — is a state by state directory of information for patients seeking financial relief for a broad range of needs including housing, utilities, food, transportation to medical treatment, and children's resources. 1-800-532-5274, www.patientadvocate.org

YWCA — offers ENCORE*plus*® breast and cervical cancer program that provides outreach, education and screening mammograms to women who are most in need and lack access to breast health services. 202-467-0801 or contact your local YWCA. www.ywca.org

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