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SECTION ONE: INTRODUCTION

More and more women today want to be partners with their doctors. They want to have a say in decisions about their health. So, they need accurate and up-to-date health information. As new facts come to light, medical advice will change.

You are part of a project called PRISM. (It's a program of Blue Cross and Blue Shield of North Carolina and the Duke University Medical Center with support from the National Cancer Institute.) As part of PRISM, we will give you information to help you decide when and how often you should have a mammogram. PRISM stands for "Personally Relevant Information about Screening Mammography."

*We've created this special booklet just for you from what you told us when we called. It's written by experts on breast cancer screening. The information in **your** booklet is based on the latest evidence from all over the world. It's unique, because you are unique. Nobody else will get the same booklet about breast cancer screening. It tells you who is at risk for breast cancer and gives you an estimate of your own personal chances of getting it. It talks about what's good about mammograms and some of the drawbacks. There are also some tips to help you overcome barriers to getting a mammogram.*

*You do not **have** to read the booklet all at once. You may first want to read the sections about the chances of getting breast cancer and then read the sections on mammography. You may want to read the decision making section by itself so you have time to think about the issues.*

Your Plans For Having Mammograms

You've never had a mammogram, but you're thinking about getting one in the next one to two years. Blue Cross and Blue Shield of North Carolina and the two largest cancer organizations, the American Cancer Society and the National Cancer Institute, now

*agree that women in their 40s should get mammograms every one to two years. Be sure to read the information about mammography for women your age in the section, **The Scientific Facts About Mammography.***

EXAMPLE

SECTION TWO: THE RISKS AND REALITIES OF BREAST CANCER

Breast cancer is the most common cancer among women. In 1997, about 180,000 women found out they had breast cancer.

Risk Factors For Breast Cancer

Anything that raises the chance of getting breast cancer is called a risk factor. Besides age and being a woman, the main risk factors that we know about for breast cancer include:

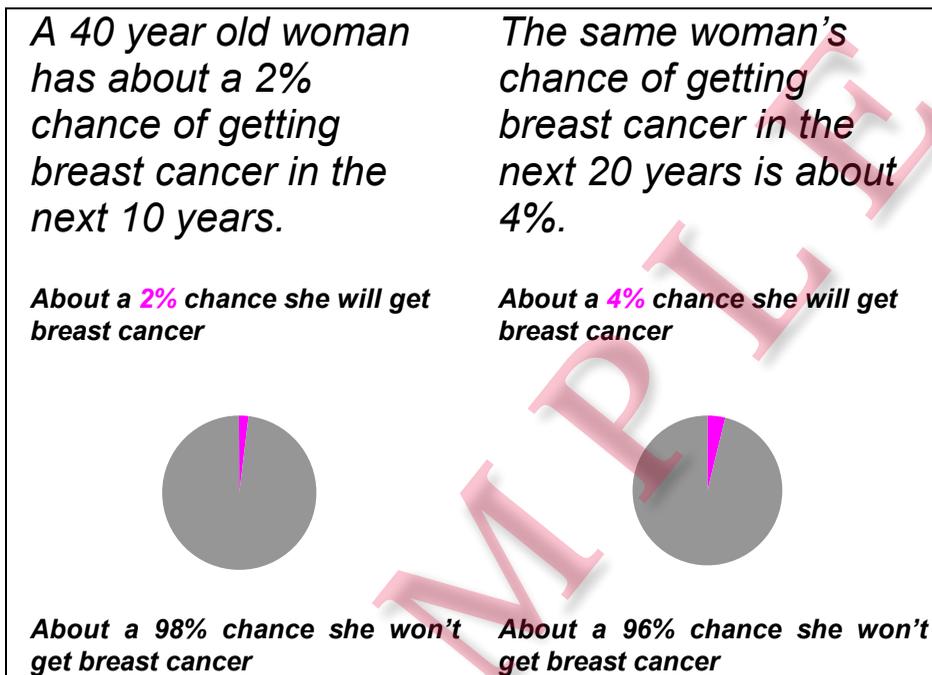
- *having had breast cancer,*
- *a gene alteration that makes the chance more likely,*
- *family members with breast cancer, especially if their breast cancer was diagnosed when they were younger than age 50,*
- *two or more breast biopsies that did not show cancer (benign),*
- *a lot of dense breast tissue that makes it hard for the doctor to read the mammogram,*
- *starting menstrual periods before age 12, and*
- *having a first baby after age 30. The chance of getting breast cancer increases slightly if a woman is older than 20 when she has her first baby. Her risk is even higher if she has her first baby after age 30.*

Being a woman and getting older are the most important risks for breast cancer. This means age makes a difference in how likely it is a woman will get breast cancer. But the known risk factors don't explain all breast cancers. So, there is still a lot to be learned.

The Average Woman's Chance Of Getting Breast Cancer

Let's look at an average woman's chance of getting breast cancer in her lifetime. When a baby girl is born she has a 1 in 8, or 13%, chance of getting breast cancer at some point during her life, which

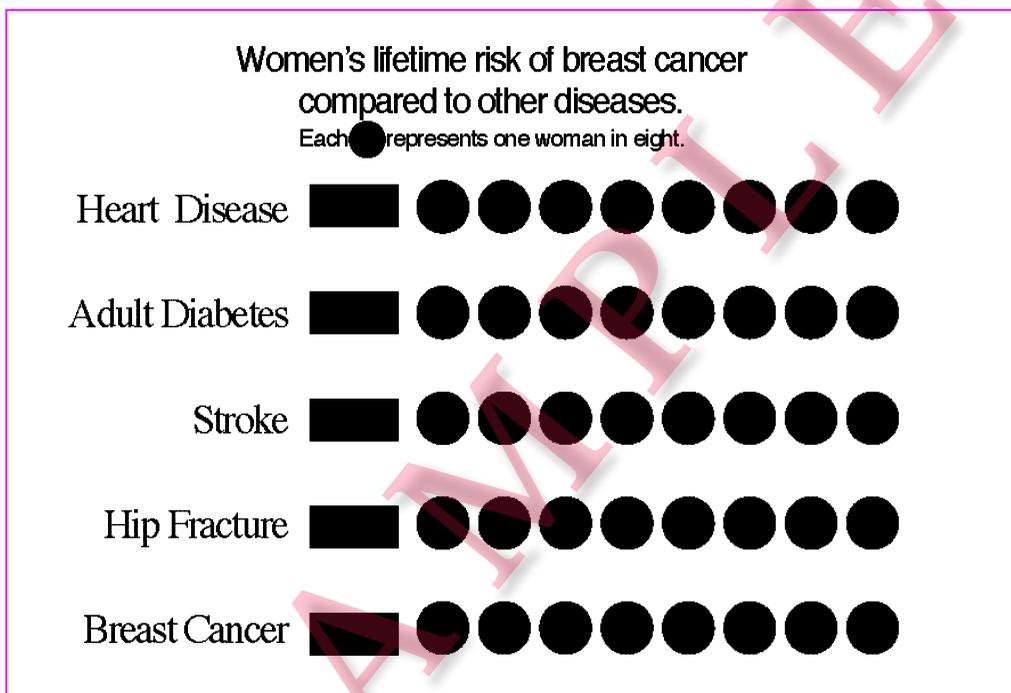
means some time from birth through age 95. Another way of looking at risk is based on how old you are.



For most women, the chance of getting breast cancer at any one point in their life is much smaller than 1 in 8. This is because the chance of getting breast cancer changes with age. Your age affects your breast cancer risk. **Age makes a difference! The older you are, the greater your risk.** The average 40 year old woman has less than a 2% chance of getting breast cancer in the next 10 years. This means that of 100 women who are age 40, fewer than 2 of them will get breast cancer by the time they turn 50. The good news is that this chance is a lot less than most women think. But since we do not know for sure who will and who will not get breast cancer, all women in their 40s should get regular mammograms. So, just take action!

The Average Woman's Chance Of Getting Other Diseases

You also may want to know how the chance of getting breast cancer compares to the chance of getting other diseases. The chart shows an average woman's lifetime chance of getting some common diseases.



Most Women Don't Die Of Breast Cancer

Women have a greater chance of **getting** breast cancer than they do of **dying** from it. This is because many women are either cured of their breast cancer or live a long time with it. A 40 year old woman with average risk has less than a 1% chance of dying of breast cancer over the next 10 years. Her chance of dying of breast cancer after that is about 4%. This means that there are very good reasons to get mammograms.

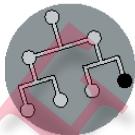
More white women than African American women get breast cancer. But African American women are twice as likely to die from it as are white women. This may be due partly to some African

American women being diagnosed with breast cancer at a later stage, when it is harder to treat. As an African American woman, it is especially important that you consider getting regular mammograms.

How We Can Estimate Your Chance of Getting Breast Cancer

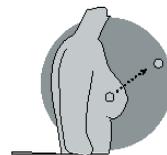
We also can use some of your personal risk factors to figure out your chance of getting breast cancer. This is done using a mathematical model called the Gail Model. Dr. Gail is a senior physician scientist at the National Cancer Institute who created this model by studying thousands of women. This model is not perfect because doctors don't know everything that causes breast cancer. But the Gail Model gives a good estimate based on what doctors know today. It's a "best guess", because no one knows for sure who will get breast cancer and who will not. Besides, **over 70% of women who get breast cancer have no known risk factors for it.** There are several risk factors that are used in the Gail Model when determining a woman's risk. These include her family history of breast cancer, if she has had breast biopsies, the age she had her first baby, and the age when she started her period. Her current age is also part of the model. The risk factors are not equal in strength, and some do not affect breast cancer risk very much.

One of the biggest risks for breast cancer is age. How old you are affects your breast cancer risk. As you get older, your chances go up. So the older you are, the greater your risk. About 1 out of 4 breast cancers are found in women younger than age 50. So, it's important for you to think about your age when you think about breast cancer risk. **Age makes a difference!**



If someone in your immediate family -- your mother, sister(s) or daughter(s) -- has had breast cancer, your chance of getting it is higher. This is especially true if she had it in both breasts or if she got it before she was 50 years old. The more blood relatives you have with breast cancer, the higher your own risk.

Your chance of getting breast cancer is higher if you have had one or more breast biopsies that did not show cancer (benign). During a biopsy, a doctor takes

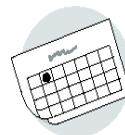


some cells from the breast and sends them to a lab to see if there is cancer. The biopsy itself doesn't cause breast cancer or increase the risk of getting it. But the problem that caused a woman to need the biopsy may increase her risk. Women who have had a biopsy have 1½ times the chance of getting breast cancer as women who have not had biopsies. A biopsy for a breast problem called atypical hyperplasia is one that increases your chance of getting breast cancer even more.



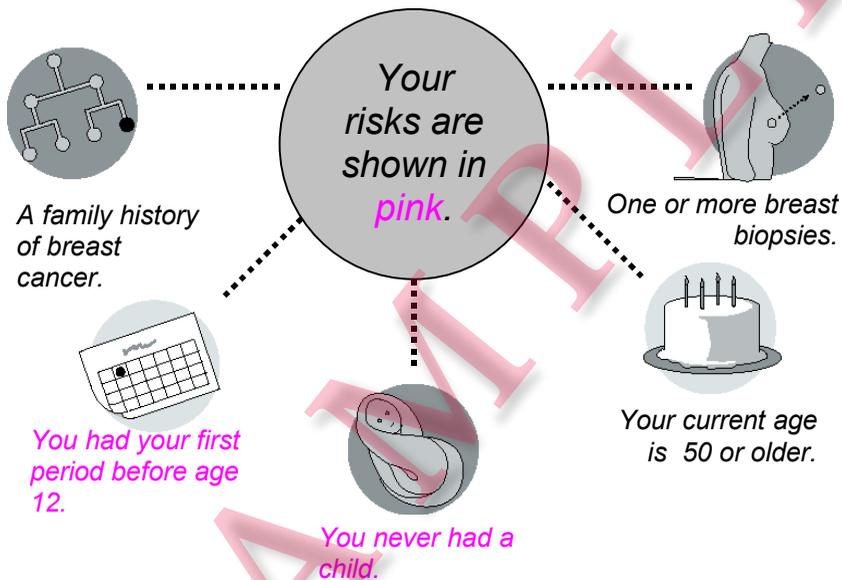
The age when a woman has her first baby, if she has one, also affects her chance of getting breast cancer. Having a baby before age 20 is protective. Your chance of getting breast cancer increases slightly if you are older than age 20 when you have your first baby. Your risk is even a little higher if you have your first baby after age 30 or never have children. Doctors aren't sure why this is. They think hormonal changes that are a normal part of pregnancy play a role.

Finally, when you had your first period is another risk factor for breast cancer. If you started at a young age (younger than 12), your chance of getting breast cancer is a little higher. Doctors think this may be because the female hormone, estrogen, affects when you start your period.



SECTION THREE: TAYLOR D. FORTEE'S PERSONAL RISKS

Your chance of getting breast cancer is based on your own risk factors. The picture shows the risk factors used in the Gail Model. **The figure has been created just for you based on your risk factors. The factors that increase your risk at this point are shown in pink.** The others do not increase your risk or may even lower it.

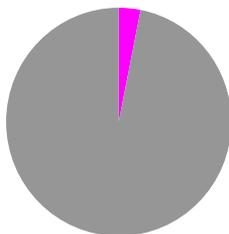


We have used the Gail Model and the information you gave us over the phone to estimate your own chance of getting breast cancer. Based on this information, Ms. Fortee, your chance of getting breast cancer in the next 10 years is 2.6%. This also means you have a 97.4% chance of **not** getting breast cancer in the next 10 years. Keep in mind that this estimate is a “best guess” about your chance based on what we know today and the facts you gave us.

You told us you thought your chance of getting breast cancer in the next 10 years was 0%. Our estimate using the Gail Model is 2.6%.

Your chance of getting breast cancer in the next 10 years

Based on the Gail model, your estimated chance of getting breast cancer in the next 10 years is **2.6%**.



Your chance of not getting breast cancer in the next 10 years is **97.4%**.

The estimate you made of your chance of getting breast cancer

You estimated your chance of getting breast cancer in the next 10 years to be **0%**.

The pie chart shows the Gail Model estimate of your risk. The Gail Model score is higher than your own estimate. Keep in mind that this is only an estimate. Several factors go into the Gail Model score, and you may not have thought about all of them. Of course, no one can tell for sure who will get breast cancer and who will not. But the Gail Model score gives you a rough idea, a best guess. Because your risk may be higher than you thought, it is especially important to get regular mammograms, just to be on the safe side. You may also want to compare your Gail Model estimate to the score of a woman your age with no risk factors for breast cancer. Based on the Gail Model, a 43 year old woman who has no risk factors has a 1.6% chance of getting breast cancer in the next 10 years. Your breast cancer risk is affected by the fact that you:

- *had your first period before you were 12 years old*
- *never had children.*

EXAMPLE

SECTION FOUR: THE SCIENTIFIC FACTS ABOUT MAMMOGRAPHY

What Is Mammography?

A mammogram is a low dose x-ray of the breast. The purpose of a mammogram is to find breast cancer early. That's when breast cancer is most likely to be cured, and when women have more choices of treatment. Mammograms cannot prevent breast cancer. But they can reduce the chances of dying from breast cancer. The picture shows how the x-ray is taken. Two views are taken of each breast. Getting a mammogram takes less than 30 minutes.

Helping You Decide About Mammography

Most experts now agree that women in their 40s should have mammograms every one to two years. That would reduce deaths from breast cancer among women in their 40s by about 17%. But not every medical organization advises women in their 40s to get mammograms. We want to give you the facts, so you and your doctor can talk. Then you can decide what's right for you. The doctors at Blue Cross and Blue Shield of North Carolina hope you will get regular mammograms. But they want you to know the facts.

What Scientists Say About Mammography For Women Your Age

Over the past 30 years, more than 180,000 women age 40-49 and 320,000 women age 50 and older around the world took part in several large studies of mammography. In 1997, the National Institutes of Health brought together a group of scientists to look at these studies. The strictest way scientists measure the success of a cancer screening study is by asking if it lowers cancer deaths in women who are screened. They ask if death rates are lower in women who are screened

compared to those who are not screened. They also make sure the results are statistically significant, that the results show an answer that could not have occurred by chance alone.

When all the studies were combined, cancer deaths for women who entered the studies in their 40s were reduced by about 17%. But some of the studies found no benefit, some found fewer deaths and some found more deaths from breast cancer among the women screened.

The benefits of mammograms for women in their 40s are about half that of women in their 50s. Also, the benefits for women in their 40s take at least seven years to appear. This means that much of the benefit occurs when women, who entered the studies in their 40s, are actually over 50. So, there is a benefit for women in their 40s as a group even though our science is not yet good enough to cure every woman of breast cancer.

Both the National Cancer Institute and the American Cancer Society advise women in their 40s to get mammograms every one to two years. Blue Cross and Blue Shield of North Carolina advises women in their 40s to get mammograms every other year.

The Limitations Of Mammography

No medical test is perfect. Every test has some limitations. In order to make a good decision about mammography, you need to know what possible limitations or drawbacks it carries with it.

Mammograms miss more cancers in women younger than age 50 than in women age 50 and older. As many as 25% of breast cancers may be missed in women in their 40s. These are called **false negatives**. That means the mammograms were read as normal, but cancers were really present. **If you have a lump or other changes in your breast and your mammogram does not find anything, make sure you talk with your doctor about what other tests need to be done.**

A **false positive**, on the other hand, means that the mammogram found a problem, but further tests showed it was not cancer. These are also called false alarms. There are also more false positives for women in their 40s.

It has been estimated that if a woman had a mammogram once a year in her 40s, she has a 30% chance of getting a false positive result. This means a woman would need other tests and sometimes a surgical biopsy to rule out breast cancer. Some women say this experience is stressful and affects their short-term quality of life. For most, any negative effects go away within about three months.

The Benefits of Mammography

Mammograms may reduce the chances of dying of breast cancer by 17% for women in their 40s. Early detection also means that there may be more treatment choices. Often, women can have surgery that saves the breast and treatment with drugs is easier.

Advice For Women In Their 40s

Every woman in her early 40s should talk with her doctor about breast cancer and mammography. Based on your family and personal health history, your own preferences, and the advice of your doctor, you can decide at what age you should begin screening and how often you should have mammograms. The best evidence we have in 1997 shows that average risk women should begin screening some time in their 40s. Blue Cross and Blue Shield of North Carolina doctors advise women in their 40s to have mammograms. Blue Cross and Blue Shield of North Carolina pays for mammograms every other year for women in their 40s. If you don't know where to get a mammogram, please contact Member Services at Blue Cross and Blue Shield or talk with your doctor about how to find a participating mammography provider in your area.

SECTION FIVE: WEIGHING YOUR OWN CHOICES ABOUT BREAST CANCER SCREENING

Ms. Fortee, we have given you the facts about breast cancer and who gets it. We've reviewed the benefits and limitations of mammography for women your age, and have given you specific information about your own risks. This section will help you put all this together so you can decide for yourself about mammograms.

What You Need To Think About

We want you to think about both the possible benefits and limitations of mammography. The picture below shows the possible benefits and limitations of mammography for women in their 40s.

There are many things for you to think about when making a decision about getting mammograms. One of the most important viewpoints is that of your doctor. Blue Cross and Blue Shield of North Carolina doctors advise women your age to get mammograms every other year.

You are 43. Doctors agree that women your age should get regular mammograms. Review the information about your breast cancer risk. Discuss your Gail Model score and risk factors with your doctor. Then, you and your doctor can decide together the mammography schedule that is best for you.

So you should consider taking the following steps:

- *Plan to discuss your Gail Model score with your doctor. To make this easier, take this booklet with you.*
- *Weigh the benefits and limitations of mammography for yourself.*
- *Think about the reasons you would or would not get a mammogram.*
- *Overcome your roadblocks to screening.*
- *Review the questions to ask your doctor and add your own.*

Your Reasons To Get A Mammogram And Your Concerns

The following chart shows the benefits and limitations that matter to you, Ms. Fortee, as well as other reasons you would or would not get mammograms. You can add new items on either side or cross out items that do not matter to you now. You may want to discuss these with your doctor at your next appointment.

YOUR POINT OF VIEW ON MAMMOGRAPHY

<p><input checked="" type="checkbox"/> Your Reasons To Get Mammograms</p> <p><u>No test is perfect, but it's better to be on the safe side.</u> You would rather get a test even if there were only a small chance it will help you. Keep in mind that no test is perfect. Mammograms do miss some breast cancers.</p> <p><u>You may be able to have breast-sparing surgery if breast cancer is found early.</u></p> <p><u>You believe mammograms save the lives of women in their 40s.</u> There is now new evidence that mammograms can reduce deaths from breast cancer for women in their 40s.</p>	<p><input checked="" type="checkbox"/> Your Concerns About Mammograms</p> <p><u>You are worried about having a false negative result.</u> (See the Limitations of Mammography section.)</p> <p><u>You are torn between getting and not getting a mammogram in the next year or two.</u> Talk with your doctor about your health history and preferences so you can make an informed decision about mammography for yourself.</p> <p><u>They cost too much.</u></p> <p><u>You feel uncomfortable with your mammography facility.</u></p>
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OVERCOMING YOUR ROADBLOCKS TO SCREENING!

You told us you have some concerns that are keeping you from getting a mammogram.

They cost too much. Blue Cross and Blue Shield of North Carolina will pay for your mammogram every other year. So cost should never stand in the way of protecting your health!

You feel uncomfortable with your mammography facility. If you are not satisfied with the mammography facility you went to before, you can use a different one. Check your directory of Blue Cross and Blue Shield of North Carolina Providers or call Member Services for another facility near you.

Questions To Ask Your Doctor

We hope we have covered some of your concerns about mammography. But you may still have some questions.

Your doctor is an important partner in helping you decide about whether to get regular mammograms. If you have any questions about breast cancer and your chance of getting it, or about mammography, please talk with your doctor. You may want to ask some or all of the questions listed below.

- ✓ How often do I need to have a mammogram?
- ✓ Will you refer me to a mammography facility for a mammogram?
- ✓ How can I be sure my mammogram is of good quality?
- ✓ How can I be sure the interpretation of my mammogram is of high quality?
- ✓ Is there anything I should do to prepare for my mammogram?
- ✓ Who gets the report of my mammogram? How do I get the results? When will I hear? Can the report be sent to other doctors who treat me?
- ✓ How long will it take to get the mammography report?
- ✓ How often will you do a physical breast exam?

- ✓ *If my health care provider or I find an abnormality in my breasts: Do I need to have a biopsy? If yes, why? What kind? What is involved? If no, why not?*

Add other questions you now have.

Don't Forget: You Also Need A Yearly Breast Exam By A Health Professional

You also need routine physical breast exams by a doctor or other trained health care provider. They are a central part of breast cancer screening. Because mammography is not perfect, all women your age need breast exams by a provider every year. A thorough breast exam can find some cancers missed by mammography, even very small ones.

You're on schedule for your breast exam by a doctor or nurse. Be sure to have the exam every year. Few studies have looked at how well clinical breast exams alone find cancers. So even if you get breast exams, you should still consider getting regular mammograms.



HERE IS THE STORY OF ANOTHER WOMAN WHO DECIDED TO GET A MAMMOGRAM AND HOW SHE MADE HER DECISION.

Julia, who is 43 years old, works for a major company. She has just been promoted and is juggling her new responsibilities and raising a family. She also cares for her aging father. Lately, she's been thinking about getting a mammogram.

"I've never had a mammogram before, but lately I've been thinking that maybe I should get one. I'm not sure if women my age are supposed to get mammograms. I hate to go through all the hassle

of making an appointment and getting one unless I really need a mammogram. I just don't have the time."

"Even though I'm really busy, if I do get breast cancer, I could get really sick or even die... Maybe a mammogram is worth it."

"I'm going to ask my doctor if he thinks I need a mammogram. I feel like I owe it to myself and my family to make sure I'm doing all I can to take care of my health -- just in case."

EXAMPLE

SECTION SIX: TO YOUR GOOD HEALTH!

Regular mammograms can save the lives of some but not all women diagnosed with breast cancer in their 40s. The National Cancer Institute, the American Cancer Society, and Blue Cross and Blue Shield of North Carolina advise women in their 40s to get regular mammograms. Be a good consumer. Know the benefits and the limitations. Talk with your doctor. Together, you should plan what's best for you. No two women are the same.

Your feelings about screening, your risk for breast cancer, and your preferences should be part of your decision. Relax. Yes, breast cancer is a serious disease. But it's not nearly as common as most women think. Research shows that mammograms save lives. It's your life. Protect it!

One of our women's health advisors, Linda James, will be calling you in the next two weeks. She will be able to answer any questions you may have after reading the booklet.



Looking Into Other Sources For Information



Below you will find other breast cancer and mammography resources. Breast cancer organizations can give you information and up-to-date lists of suggested books for further reading. Your local library also has books and other materials about breast cancer. We cannot guarantee the accuracy of information from any source except the National Cancer Institute.

Cancer Information Service (CIS) of the National Cancer Institute



(800) 4-CANCER

CIS is a nationwide program for health professionals, patients, and the general public. Trained CIS information specialists are available Monday through Friday, from 9:00 a.m. to 4:30 p.m. to answer questions and provide materials about cancer, in both English and Spanish.

American Cancer Society (ACS)



(800) ACS-2345



<http://www.cancer.org/>

ACS is a nationwide, voluntary organization that provides programs and materials about cancer and shares information about local services and activities.

Breast Cancer Lighthouse



<http://commtechlab.msu.edu/CTLprojects/breastcancerlighthouse/DDMam.html>

This Internet site includes information about mammography, women's personal experiences, and links to other resources on the World Wide Web.

CancerNet of the National Cancer Institute (NCI)



<http://cancernet.nci.nih/>

Internet users can use CancerNet to quickly and easily access current cancer information from the NCI's computer database.

National Alliance of Breast Cancer Organizations (NABCO)



(800) 719-9154



<http://www.nabco.org/index.html>

NABCO distributes fact sheets, articles, and a newsletter addressing breast cancer issues.

National Women's Health Network



(202) 347-1140

National Women's Health Network provides newsletters and position papers on women's health issues.

OncoLink

<http://oncolink.upenn.edu>

Accessible via Internet, this World Wide Web site includes a collection of support groups, peer-reviewed journals, and other online resources.

Personal Health Advisor of Blue Cross and Blue Shield of North Carolina (BCBS)

(800) 999-1629

BCBS members can call the Personal Health Advisor, 24 hours, 7 days per week, to access an Audio Health Library, information about health care resources, and the advice of a registered nurse.

Women's Information Network (WIN) Against Breast Cancer

(619) 488-6300

WIN provides information about breast cancer, including treatment, support, and other resources.

Y-Me

(800) 221-2141

Y-Me supports women who have had breast cancer by providing information about survival.

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