

Genetics and Family Risk



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the *Guide to Understanding
Genetics and Family Risk*.

Thank you

for helping Living Beyond
Breast Cancer improve our
programs and services.

Is this guide for you?

This guide is about genetic counseling and testing for people diagnosed with breast cancer and their family members. Genetic testing is only recommended for people who may be at high risk of developing breast cancer. Not sure if you're considered high risk? See *Risk Factors in Families* on page 8.

Dear Friend:

At Living Beyond Breast Cancer, we know that many women seek as much information as possible about their and their family's health histories and the benefits and limits of genetic testing, to help them make the important decision about whether to pursue it.

Our *Guide to Understanding Genetics and Family Risk* explains how inherited gene mutations are related to breast cancer and the risk of a second breast or ovarian cancer. We discuss the traits that families with a high risk of developing those cancers generally share, how to decide whether and when to be tested, and the ways test results may impact your emotions and your family.

What you read in this brochure should help you to decide whether genetic testing is right for you and your family. We hope that you share this information with your family and friends, whether or not they have been diagnosed themselves.

Warmly,

Jean A. Sachs, MSS, MLSP
Chief Executive Officer



LIVING BEYOND BREAST CANCER®

With you, for you.

Toll-Free Breast Cancer Helpline
(888) 753-LBBC (5222)
lbbsc.org/helpline

All people pictured in this guide
are LBBC volunteers whose lives have been
affected by breast cancer. We thank them
for sharing their experiences.

SECTION 1

Genetics and Breast Cancer	4
Genes Related to Breast Cancer	7
Risk Factors in Families	8
How to Find Out if You Are at Risk	9
Understanding the Past	10

SECTION 2

Genetic Counseling and Testing: What to Expect	12
What if a Genetic Counselor Isn't Available?	16
The Testing Process	16
Tests You Can Get	17
Making a Decision About Testing	19

SECTION 3

Understanding Test Results	22
What the Results May Mean	23
Test Results and Treatment Decisions	25
What Your Results May Mean for Your Family	34

SECTION 4

Genetic Testing and Your Emotions	36
Shared Family Risk	37
Intimate Relationships	39

SECTION 5

Sharing Your Results	42
Sharing With Family	43
Sharing at Work	46

SECTION 6

Paying for Testing	48
Health Insurance	49

SECTION 7

Looking Toward the Future	54
----------------------------------	----

SECTION 8

Resources	56
Words to Know	60

Genetics and Breast Cancer

After being diagnosed with breast cancer, you may wonder “Why me?” or “What caused this?” These are common questions that, for many women, go unanswered.

According to the National Cancer Institute, 1 in 8 American women will develop breast cancer in her lifetime. Certain **genes**, small pieces of your DNA, can cause breast cancer to grow when they have a **mutation**, or error. Most breast cancers are caused by **somatic mutations**, which are not passed on to you from your parents and cannot be passed on to your children. They form on their own during your lifetime and what triggers them is not always known.

But a small group of women will be diagnosed each year with breast cancer considered to be **hereditary**. Mutations that cause hereditary cancer may be passed on to you from your parents in the same way that traits like height or eye color are.

Having breast cancer does not mean you have an inherited mutation. And, having a hereditary gene mutation does not mean that you will definitely get breast cancer if you are not already diagnosed. These gene mutations only put you at greater risk of developing cancer than women who don’t carry them. Most people with breast cancer do not have inherited gene mutations. Men with breast cancer are more likely to have a mutation.

Throughout this brochure, “gene mutation” is used to mean “hereditary gene mutation,” for which testing is available.

GENE MUTATIONS AND INCREASED RISK

Researchers have identified many mutations associated with increased risk for breast cancer, located on different genes that exist in every human body. Some of these mutations, like *BRCA1* and *BRCA2*, increase your risk significantly, while others increase it only slightly.

A genetic counselor will be able to tell you which mutations you test positive for and if you can take any medical action to help lower your risk of developing breast or ovarian cancer. Not all mutations will lead to preventive measures like surgery or risk-reducing medicine.



Genes Related to Breast Cancer

Researchers know of many hereditary gene mutations that raise the risk for breast and ovarian cancer. Some are more likely than others to lead to cancer. You may have heard of mutations to *BRCA1* and *BRCA2*, the two genes most commonly linked to hereditary breast cancer. Only a small percentage of all breast cancers are thought to be caused by them.

Other genes we know are related to breast cancer risk are

- ATM
- CDH1
- CHEK2
- PALB2
- PTEN
- STK11
- TP53

For most of these genes, researchers don't quite know by how much they raise the risk of breast cancer. But recent studies showed that women who have a mutation in one, *PALB2*, may have a 33 to 58 percent chance of getting breast cancer by age 70. Women who have *BRCA* mutations have a 45 to 85 percent chance, and women with no mutations have about a 12 percent chance.

Risk Factors in Families

Certain patterns in your family's health history may suggest that you or your relatives carry a gene mutation linked to breast cancer.

Research shows your family may carry a gene mutation if:

● **You were young at diagnosis.** Typically, breast cancer occurs in older women. The younger you are at diagnosis, the more likely the breast cancer is related to a gene mutation. National guidelines recommend BRCA testing if you were diagnosed at or before age 45, even if you don't have a family history of breast cancer.

● **You have a certain type of breast cancer.**

Triple-negative breast cancer, especially when diagnosed at a younger age, may be associated with a gene mutation.

● **You had two separate breast cancer diagnoses.**

If you had breast cancer in the past and were later diagnosed with a second, new breast cancer, a gene mutation might play a role.

● **You have breast cancer and a strong family history of breast or ovarian cancer.** Women with BRCA mutations are at risk for both breast and ovarian cancer. If there is a strong history of either in your family, an inherited mutation might be the cause. A strong family history includes:

- Several relatives on your mother's or father's side with breast or ovarian cancer
- One or more **first-degree relatives** with breast or ovarian cancer, especially if diagnosed at young ages. First-degree relatives are your parents, brothers, sisters or children
- Family members with both breast and ovarian cancer

- Any cases of breast cancer in men in your family
- You have ovarian cancer. Between 10–15 percent of ovarian cancers are associated with a BRCA mutation

● **Your family is of a certain ethnic origin.** One in 40 people of Ashkenazi (Central-Eastern European) Jewish descent will carry a BRCA gene mutation. This risk is higher than in people of other ethnic backgrounds.

How to Find Out if You Are at Risk

Not everyone who has one of these risk factors will have a gene mutation. In fact, even if someone in your family already has a known mutation, you may not.

We inherit two sets of genes from our parents: one from our mother, and one from our father. This means that if your father's side of the family has a mutation, you have a 50 percent chance of inheriting it if your father carries the mutation himself. The same is true of your mother's side of the family. Mutations can be passed on from either your father or mother, or both.

If you have any of the risk factors on page 8 and above, your doctor may suggest you meet with a **genetic counselor**. Genetic counselors are trained health professionals who, in a process called **genetic counseling**, discuss your and your family's health history to help you decide if genetic testing may be useful to you.

Genetic testing is the process of finding gene mutations in your DNA that raise your risk of breast and ovarian cancer as well as other cancers. They are found through a blood or saliva (spit) sample test. If a genetic counselor thinks a gene mutation may run in your family, he or she may recommend testing. If your doctor doesn't mention genetic counseling or testing but you are interested, it's OK to ask for information.

“My genetics counselor was so informative. She asked if I had questions or concerns throughout the process and explained everything I needed to know. She was wonderful.”

—MONIQUE

Understanding the Past

Genetic counseling and testing allow you to look at patterns of illnesses that occur throughout your family's history. With the help of your healthcare provider, you can estimate your own risk of developing those illnesses. If you are newly diagnosed with breast cancer, knowing whether you carry a gene mutation may help you make important treatment decisions. See page 25 for more information about how your genetic test results may impact treatment options.

If you have finished treatment, you might think genetic testing isn't necessary. You may see it as an extra test because your results can't change the treatments you've had already.

While this may be true, many women choose to have genetic testing even after they complete treatment to better understand their risk for a second breast cancer or ovarian cancer. Testing can also help family members know more about their own risk of developing these cancers.

Knowing whether you carry a hereditary gene mutation can inform other people in your family about their risk of carrying it, too.

Having a family member who carries a gene mutation greatly increases the chance that you do—so your test results may tell your siblings, children or grandchildren that they may be at high risk for breast cancer

themselves. If you test positive for a mutation, your family members' insurance providers may be more likely to cover the cost of genetic testing, especially if they have not been diagnosed with breast cancer already (for more on financial concerns, see page 48).

Learning your hereditary cancer risk after you complete treatment may allow you to consider risk management options to help protect you from new cancers. Some women choose to have risk-reducing surgeries after learning they carry a gene mutation. See page 25 to learn more about these and other treatment options.

Getting tested can also help scientists understand more about how mutated genes relate to developing breast cancer and to its treatment. Women who have gene mutations are needed to participate in breast cancer research that may one day shape new treatments or aid in prevention.

“I needed genetic testing for my own peace of mind. Once I knew there was a test to find out if my breast cancer was genetic, I wanted that test. It helps you and your other family members, too.”

—ELSABE

Genetic Counseling and Testing: What to Expect

When you first meet with a genetic counselor, your discussions will focus on your and your family's health and cancer histories. Your counselor will use this information to help you decide whether to have genetic testing.

If you go to a genetic counselor, you **are not required** to have genetic testing. The goal of genetic counseling is to help you understand your risk and decide if testing is best for you.

During the first appointment, your counselor will ask for details about your diagnosis, such as the breast cancer's type and how old you were at the time of diagnosis. He or she may also ask you to list any other major medical conditions you have now or had in the past.

Then your counselor will create a family tree, also called a **pedigree**. It will list all of your relatives through three or four generations, or everyone in your family from your children through your grandparents, including aunts, uncles and cousins. For each person you list, the counselor will want to know whether he or she had any cancer.

If the person did, the counselor will want to know:

- What type of cancer they had
- How old they were at diagnosis
- How long they lived and their cause of death if they died

You may find it hard to collect medical information on all your relatives, especially if you are not in touch with your family or do not know your biological family. It's OK if you can only give parts of someone's cancer or health history. Try to find as much information as you can before your first appointment by searching for medical records or by talking with family members you are in touch with. The genetic counselor will work with what you have to evaluate your risk as best as possible.

The most difficult part for me was awkward family dynamics that made it difficult to get all the information I needed about the family history of cancer.”

—HILLARY

For some women, preparing for the first appointment may be overwhelming. If you begin to feel stressed or anxious, consider asking a close friend or family member to help you pull together the information you need. Many women also ask someone to come to the appointment with them to take notes or give support.



10 REASONS PEOPLE CHOOSE GENETIC TESTING

- 1 To be proactive about their health
- 2 To make informed treatment or prevention decisions
- 3 To hand down information to their sons and daughters
- 4 To inform immediate family such as sisters, brothers, aunts, etc. of the possibility of inherited gene mutations
- 5 To make decisions about family planning that might be impacted by treatment or ovarian cancer
- 6 Because they have a family history of breast cancer, and want to know more
- 7 Because they were young at diagnosis, and the cancer is aggressive
- 8 Because others in their family want to know about their own risk
- 9 Because their doctor or genetic counselor recommended it
- 10 Because sometimes, knowing more means fearing less

What if a Genetic Counselor Isn't Available?

Most major cancer centers and large hospitals have genetic counselors available. If not, your oncologist or another member of your healthcare team may be able to recommend one to you.

Those living in rural areas or far from large hospitals may have less access to genetic counselors. Try not to worry if this is true for you. You can still have genetic testing. One of your doctors may have experience with genetic testing and be able to order the test and interpret its results for you.

If you cannot find a genetic counselor, or if traveling for counseling may be difficult, you can access services online and by phone that may be covered by your health insurance. The process is the same as it would be in person, but you will talk with the counselor via an on-line chat or over the phone. You will still need to visit a clinic to have your blood or saliva taken to a lab, if you choose to have testing.

For a list of phone-based genetic counseling services, see page 58 of the Resources section.

The Testing Process

The testing process for breast cancer-related gene mutations is a simple blood or cheek-swab test. A saliva (spit) sample also may be collected.

Blood may be drawn at a lab or at your doctor's office or hospital. It is taken by needle, usually from a vein on the inside of your elbow. If you have a cheek-swab test, your doctor will roll a cotton-tipped swab along the inside of your cheek to collect a sample. If you are asked for a spit sample, you will cleanse your mouth with mouth wash and spit into a cup.

Your sample will then be sent to a lab that will search for gene mutations. A report will be returned to your doctor or genetic counselor in 2 to 3 weeks or so. If you are newly diagnosed or need your results to make treatment decisions, you may be able to rush the test results.

Tests You Can Get

There are several types of tests to search for mutations thought to cause breast cancer. Most will look for mutations to the BRCA genes, or another gene called PALB2. Testing can be done in a few different ways. Your genetic counselor can explain which type of testing is best for you depending on your personal and family history of cancer.

The three most common tests are

- **Comprehensive testing** of a whole gene, such as *BRCA1* or *BRCA2*
- **Single-site testing** for a mutation already known to be in your family
- **Gene panel tests**, which look for many mutations in many genes, all at once

Important things to keep in mind when deciding whether to have testing include

- Whether the test results will provide information that you can act on and that changes your medical care
- The chance of getting unclear results
- The usefulness of a positive result if little is known about the hereditary cancer risk

If certain conditions in your or your family's health history suggest there may be a mutation in a specific gene, testing of just that gene may be done.

A NOTE ON AT-HOME TESTING

In recent years, **direct-to-consumer genetic tests** have become available.

You may see these tests advertised on TV or available online. They can be delivered directly to you by mail and depending on the company, may not need to be ordered by a doctor or other healthcare professional. An at-home genetic test may require you to visit a health clinic to have a blood sample taken and sent to the lab that sells the test, or it may only ask you to send a saliva sample to the lab by mail, without seeing a doctor first.

An at-home test may cost less or feel like less of a burden. But if you choose at-home testing, you will not have guidance from a specially-trained professional when you get your results. Having a genetic counselor available to discuss whether you need testing and how your test will be carried out can help you make treatment decisions and navigate emotional reactions once your results are back.

At-home tests for the *BRCA1* and *BRCA2* genes as well as others that may increase the risk of certain cancers are available from a few companies as of 2016. But experts have questioned how well some of these tests work and still recommend going to a genetic counselor. A genetic counselor can help you understand the results and consider other factors such as your environment, lifestyle and family history.

If you have questions or concerns about at-home testing versus testing in the clinic, talk with your oncologist, or ask to speak with a social worker, genetic counselor or patient navigator at your medical center.

Making a Decision About Testing

After the genetic counselor considers your medical and family history, you will discuss the pros and cons of getting genetic testing and whether it is right for you.

Everyone handles results differently, so any result may affect you differently than someone else. Whether you've already been through treatment may influence what your test results mean to you. See pages 23 and 24 for a description of possible results and what they mean.

Your test results may help you make treatment decisions such as whether to have surgery, have screenings more often or take risk-reducing medicine long-term. It doesn't matter if you are newly diagnosed or several years out of treatment—you can choose some of these options at any time.



Getting a negative result may ease your worries about your siblings' and children's risk of developing breast cancer. It also often means you won't need more surgeries to prevent new breast cancers or more screenings than are part of typical treatment. For these reasons, many people hope for a negative test result.

Though you may hope for a negative test result, some people find comfort in knowing that they do carry a mutation. Testing positive for a gene mutation offers some people a concrete reason why they were diagnosed with breast cancer. A positive result may also offer relief from any uncertainty you may be feeling about your own health or the health of your family members. On the other hand, a positive result may lead to feelings of anger, uncertainty, fear or depression.

If you come from a family with a very strong history of breast and ovarian cancer, your results may impact the way you identify with your relatives. It's possible that you might test negative, even if others in your family have already tested positive. You may feel like an outsider or experience **survivor guilt**, a sense of guilt or blame for not inheriting the mutation that negatively affects your loved ones.

Some women may receive an “uninformative” test result, which means it's possible the cancer is related to hereditary risk but the test did not find a specific mutation.

Uninformative test results can be frustrating or unsettling. They don't offer you a reason for your own diagnosis or your family's cancer history. Section 4 has more information on the emotional side of genetic testing and how to cope with your results (see page 36).

CHOOSING NOT TO TEST

You may decide after meeting with a genetic counselor that you don't want to have genetic testing. This is OK. Women choose not to be tested for many reasons, and all of those reasons are personal.

It may be that juggling treatment with genetic testing is too overwhelming. Or, you may not want to think about the risk of future breast or other cancers before you've handled the first. Your financial, family or relationship status may also play a part in deciding not to test.

Choosing not to test doesn't mean you can't test later. If you are unsure, it's OK to wait.



Understanding Test Results

When your test results are ready, your genetic counselor will meet with you to discuss what they mean.

Your results will tell you whether you are **positive** for a gene mutation, meaning you carry the mutation; **negative**, meaning a mutation was not found; or if you express a **variant of uncertain significance**, a change in the gene that may or may not increase your cancer risk.

What the Results May Mean

■ **Positive.** If you test positive for a BRCA mutation you have a greater risk of developing breast and ovarian cancer than women who do not carry the gene mutation. Experts believe undiagnosed women who carry BRCA mutations are up to 7 times more likely to be diagnosed with breast cancer in their lifetime than women who do not.

For women who are already diagnosed, a BRCA mutation means the risk of developing breast cancer in the other breast is about 2-3 percent per year.

With a *BRCA1* mutation, this risk is higher than with *BRCA2* in the first 5 years after diagnosis. The risk of ovarian cancer is also higher with a *BRCA1* mutation.

A positive result does not mean you will definitely develop a second breast cancer or ovarian cancer.

- A positive result also does not guarantee others in your family will develop either cancer
- Carrying a gene mutation does mean you have a 50 percent chance of passing that mutation on to each of your children

❖ **Negative.** If you are the first in your family to have genetic testing, a negative result may mean several things. You may not carry a BRCA mutation at all. If you have a strong family history of breast or ovarian cancer, you might carry a gene mutation that current testing can't identify, and your counselor may recommend more tests to look for mutations in other genes. Your genetic counselor will help make sense of the results.

When no one in your family has tested positive for a hereditary gene mutation, such as *BRCA1* or *BRCA2*, negative test results need to be interpreted with caution. We know that mutations in the BRCA genes do not explain all hereditary patterns of breast and ovarian cancer. Your counselor may speak with you about other genes researchers are exploring.

❖ **True Negative.** A person who tests negative for a specific gene mutation that someone else in his or her family has already tested positive for is considered to receive a **true negative** test result. True negatives are usually found through single-site testing (see page 17).

❖ **Variant of Uncertain Significance (VUS).** Though we know of several gene mutations associated with a higher risk of breast cancer, your family may carry a genetic change that is not well understood. In this case, your results may come back as **inconclusive** or **uninformative**.

A **variant of uncertain significance** means a change was found in one of your genes but it wasn't clear whether that change could cause cancer. You may learn more about the VUS as other people in your family are tested and as the lab gathers more information on the VUS. As more research is done on the genetic causes of breast cancer, it is possible doctors may find the VUS you have is related to breast cancer. It may also be harmless. Your genetic counselor will

be able to update you on these findings if the lab that runs your test has a program to contact counselors when a variant's meaning is found. Your counselor may recommend you call the office every year to see if any new information is available.

“It seemed odd to be diagnosed so young but to test negative for a BRCA mutation, especially with my aunt's diagnosis, too. I do believe there's another, unidentified gene mutation there.”

—APRIL

Test Results and Treatment Decisions

Whether you are newly diagnosed or post-treatment, your genetic testing results may impact treatment decisions you make now or in the future. Positive, negative and uncertain results each affect decision-making in their own way.

IF YOU TEST POSITIVE

If you are newly diagnosed, you may consider how your treatment plan will not only treat the current cancer, but also help prevent a second, new breast or ovarian cancer. If you've already completed treatment for breast cancer, you may already have taken some of these steps toward preventing a recurrence or a second breast cancer.

SURGERY

❖ **Lumpectomy and Mastectomy**

Depending on your treatment plan and genetic test results, you may have one of three kinds of surgery. In **lumpectomy**, only the tumor and a small area of healthy tissue around it are removed. In **single**

mastectomy, only the breast with the tumor is removed. Some women need or choose to have both breasts removed in **bilateral mastectomy**, also called **double mastectomy**. If you have tumors in both breasts your doctor may recommend a double mastectomy. If you have cancer in only one breast and know you carry a breast cancer gene mutation, you can also choose to have both the breast with the tumor and the healthy breast removed. This is called a **prophylactic mastectomy**.

The decision to have a prophylactic mastectomy is very personal. Having the surgery may affect you physically as well as emotionally. Mastectomies are major surgeries and may require a good amount of rest and recovery. Removing your breasts also may cause worry or sadness over lost femininity or other body image concerns. Or, you may welcome the idea of surgery because lowering your risk may rid you of some fears and anxieties. Be sure to talk with your healthcare team about the side effects and recovery time involved in surgery. See section 4 for more on your emotions.



If you were treated with a single mastectomy in the past and have just learned you have a BRCA mutation, it's OK to talk with your doctor about removing the other breast. Depending on your level of cancer risk, the hormonal status of the cancer and your comfort, you may choose to have more screening tests or take hormonal therapy instead of having a risk-reducing mastectomy.

Oophorectomy

BRCA mutations are known to be related to an increased risk of both breast and ovarian cancer. In some families, there is also an increased risk of melanoma, pancreatic and prostate cancers. Studies have shown that the ovarian cancer risk is higher in people who carry *BRCA1* mutations than in those who carry *BRCA2* mutations.

Many women with mutations in either gene have a **risk-reducing salpingo-oophorectomy**, surgery to remove the ovaries and fallopian tubes. The risk of ovarian cancer increases with age, especially after age 40 if you carry a BRCA mutation.

Removing the ovaries greatly reduces the risk of developing ovarian cancer. It also stops the body from making the estrogen that fuels certain kinds of breast cancer. For some women, ending estrogen production greatly lowers the risk of breast cancer recurrence. Some research suggests that when done before menopause, oophorectomy may also lessen the risk of a new breast cancer.

Talk with your doctor about the benefits, risks, and timing of removing your ovaries before making a decision. When the ovaries are removed, you can no longer become pregnant naturally and your body goes into **surgical menopause**. If you plan to have children in the future, you may wish to wait until later in your life to have an oophorectomy.

HORMONAL THERAPY

Breast cancers in women who carry *BRCA2* mutations are more likely to be estrogen receptor-positive (ER-positive) than in women who carry *BRCA1* mutations.

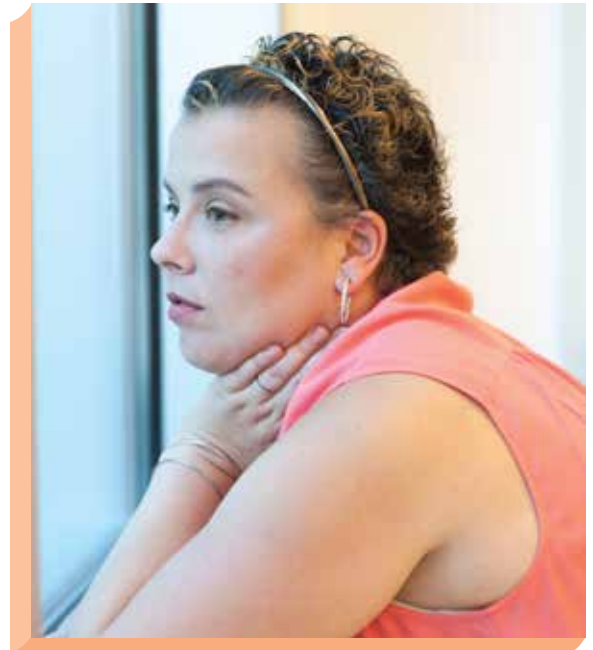
ER-positive breast cancer grows with the help of **estrogen**, a female hormone that occurs naturally in the body.

Hormonal therapy is medicine that blocks or lessens the amount of estrogen in the body so that it can't fuel cancer growth. Blocking estrogen can have the same effects on your body as oophorectomy. You may have symptoms of menopause, such as hot flashes or bone loss. It can interrupt your monthly period by making it irregular or stopping it entirely.

You may already be familiar with **tamoxifen**, the standard anti-estrogen hormonal therapy for women who are **premenopausal**, or who still have their monthly or an occasional period. **Postmenopausal** women, those who have stopped having their period, are often given **aromatase inhibitors** (AIs) instead of tamoxifen. AIs block an enzyme called **aromatase** that works to convert certain enzymes into estrogen when the body stops making it.

If you have an ER-positive breast cancer, your doctor may recommend 5 to 10 years of a daily hormonal therapy pill. Which medicine you take will depend on your age and menopausal status. Taking hormonal therapy for 5, and sometimes 10, years has been shown to reduce the risk of recurrence and second breast cancers.

Your oncologist will be able to tell you whether the cancer is hormone sensitive and if hormonal therapy is an option for you.



IF YOU TEST NEGATIVE

If you test negative for a gene mutation already identified in your family, your result is considered a true negative (see page 24). This result means you can feel confident following the standard breast cancer treatment and follow-up screening in national guidelines. Your risk of recurrence and of being diagnosed with a second, new breast cancer is the same as a woman whose family does not carry a *BRCA* gene mutation.

Some women will test negative for *BRCA* mutations despite a strong family history of breast and ovarian cancer. If this describes your situation and you are the first in your family to have genetic testing, your doctor may suggest following a screening schedule based on your family history of cancer.

IF YOU TEST INCONCLUSIVE, UNINFORMATIVE, OR SHOW A VARIANT OF UNCERTAIN SIGNIFICANCE

If you receive one of these test results, your genetic counselor may recommend you have mammograms, clinical breast exams and gynecologic visits more often than women at average risk. If you're young or at very high risk, your doctor may also recommend breast MRIs.

If your family has a strong history of breast or ovarian cancer, you are likely considered at "high risk" even though your test wasn't positive. Talk with your doctor about the risks and benefits of surgery and other preventive measures.



My positive result was a blessing, because it meant I could make preventive decisions. Our family had a strong history, and you can get cancer whether you know you carry a mutation or not. For me, knowing what I was facing gave me power.”

—LAURIE

Waiting for your results to come back may feel overwhelming, especially if you need them to move forward with your treatment plan. Talk with your genetic counselor about the time frame for getting your results. If you don't hear at that time, it's OK to call for an update.

ACTION TO TAKE FOR NON-BRCA GENE MUTATIONS

Without knowing more about each breast cancer-related gene mutation, it's hard for doctors to suggest you take any steps to prevent breast cancer if you are not yet diagnosed. But, new guidelines from the National Comprehensive Cancer Network recommend:

- **MRI screening.** For ATM, CDH1, CHEK2, PALB2, PTEN, STK11, TP53, and both BRCA genes
- **Risk-reducing oophorectomy.** For both BRCA genes, BRIP1, RAD51C, RAD51D and Lynch syndrome

NCCN also recommends you talk with your doctor about:

- **Risk-reducing mastectomy.** For CDH1, PALB2, PTEN, TP53, and both BRCA genes

WHAT IF I DON'T HAVE BREAST CANCER?

If you received this guide from a family member, you may be concerned about your own risk of getting breast or ovarian cancer. You may already know a gene mutation exists in your family and wonder if you carry it yourself.

National testing guidelines recommend that the first person who gets tested in a family already be diagnosed with breast cancer. If that first person tests positive, other family members may then choose to have testing themselves. Yet, if you and your healthcare provider believe there are other reasons to test, you may wish to do so.

If you test positive for a gene mutation, your genetic counselor will likely recommend that you have screening more often than the average woman your age who is not at high risk. The National Comprehensive Cancer Network recommends women of average risk start getting yearly mammograms and exams starting at age 40. For women with a BRCA mutation they suggest:

- Starting annual breast imaging tests based on the youngest age of diagnosis in your family.
 - NCCN recommends getting a yearly MRI starting at 10 years before the youngest age of diagnosis in your family, but no younger than age 25. For example, if your aunt was 45 when she was diagnosed, you would start yearly MRI screenings at age 35.
 - Yearly mammograms too should begin 10 years before the youngest diagnosis but not before age 30.

- Go for a clinical breast exam every 6–12 months.
- Consider risk-reducing actions like an oophorectomy (usually by age 40 and after you are done having children).

If your doctor follows American Cancer Society guidelines, they may recommend a different, but similar, schedule. It's OK to ask why he or she chooses one or the other.

Depending on your family history, you may also choose to have surgery or take medicine to help lower your risk of developing cancer. When you do not have breast cancer, choosing to have mastectomy or oophorectomy is considered **prophylactic**, or preventive. Treatment with a medicine like tamoxifen or raloxifene is also an option, and is known as **chemoprevention**.

For more on these surgeries and tamoxifen, see the “If You Test Positive” section on page 25.



What Your Results May Mean for Your Family

Because gene mutations are passed from parents to children, your test results may have a direct impact on members of your family.

IF YOU TEST POSITIVE

- Each of your children has a 50 percent chance of inheriting the mutation, whether male or female.
- Any first-, second-, and third-degree relatives, both men and women, are at higher than average risk and should consider meeting with a genetic counselor to discuss testing. It is recommended that the most closely-related family members, such as parents and children, be tested first, to find out which family members are most likely to have a mutation.


IF YOU TEST NEGATIVE OR UNCERTAIN

- Each member of your family should follow an individual plan of recommended screening. A doctor can tell them if they should follow high-risk screening standards.

Talking with family about genetic testing can sometimes be difficult. Your family members may or may not want to know their own results, or may have strong opinions about how you handle yours. See section 4 (page 36) for more on the emotional impact of testing and how to talk with your loved ones.

10 MYTHS ABOUT GENETICS AND BREAST CANCER

- 1 Testing positive for an inherited gene mutation means that I will definitely get cancer.
- 2 Having a family history of breast cancer means I will test positive for an inherited gene mutation.
- 3 Having no family history of breast cancer means I can't test positive for an inherited mutation.
- 4 Testing now, after I already have breast cancer, won't make a difference.
- 5 The *BRCA1* and *BRCA2* genes cause breast cancer.
- 6 Only women carry gene mutations related to breast cancer risk.
- 7 *BRCA1* and *BRCA2* are the same mutation.
- 8 *BRCA1* and *BRCA2* are the only mutations associated with breast cancer risk.
- 9 If I carry a gene mutation my children will definitely carry it, too.
- 10 If I find out I'm at high risk for breast cancer, I will have to have surgery to prevent it.



Genetic Testing and Your Emotions

You may have been thinking about your family risk for a long time, or this may be the first time you've wondered if your history of cancer is related to gene mutations. No matter your situation, taking the first step to see a genetic counselor, or moving forward with genetic testing, may leave you feeling everything from empowered to anxious.

Your emotional reaction will be unique to you, and also may surprise you. There are no "wrong" reactions. Remember your genetic counselor is available to talk with you about these emotions and how to deal with them. He or she can also recommend other useful resources.

Shared Family Risk

If your family has a strong history of breast and ovarian cancer, you may have grown up with relatives going through diagnosis and treatment. Watching their experiences may have left you with your own worries. Or, you may see breast cancer as a disease that you are prepared to face, as your family members have.

In some families, a shared gene mutation may have a bonding effect. Knowing you have the same mutation may bring family members together because of common worries or challenges. Screening, diagnosis and treatment might even feel more communal. The women in these families can face breast cancer, or risk of breast cancer, together. Testing negative may leave you feeling isolated or uncomfortable around people in your family who test positive.

Mixed feelings are common if you learn you do not carry a gene mutation that is in your family. Some women even feel guilty about it because they believe they've escaped something their relatives could not—a reaction known as survivor guilt (see page 20). It's common to feel this way. Try talking with people in your family about your feelings. You will likely find they are relieved to hear your risk is lower than their own.

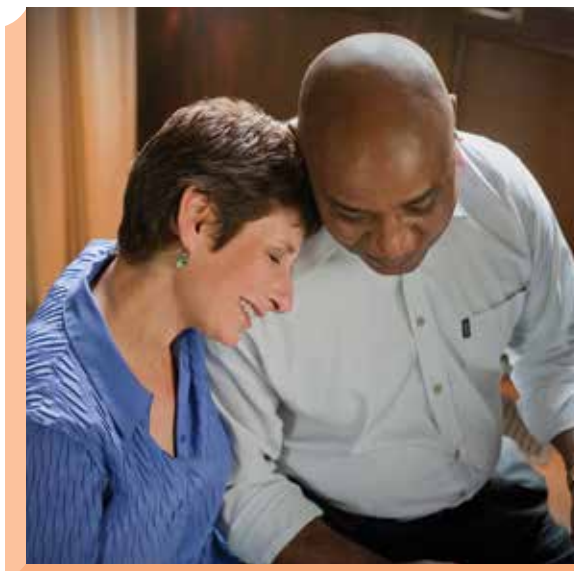
I knew my mother's family—an Ashkenazi Jewish family—carried a BRCA mutation, so when I was diagnosed with breast cancer I assumed I also had it. Then I tested negative. I was a little disappointed, which is a strange way to think about it. It's a very emotional thing.”

—ELLEN

You may feel alone or confused if you are the first person in your family to have testing. As the first, you are likely learning a lot very quickly. If you are newly diagnosed you may feel pressure to make your treatment decisions while also educating your family about their potential risk. You may want to take time to process your thoughts before talking with your family. Or, you may choose to talk with only a few relatives at a time so that it is less overwhelming. Making treatment decisions should be your first priority.

On the other hand, many women find their role as a source of information to their family empowering. The ability to help other family members through the genetic testing process can be very rewarding. Discovering the reason your family has seen so much cancer may ease their stress.

If you are uncomfortable informing your family, a genetic counselor can help you educate family members or meet with them if they want to learn more.



Intimate Relationships

A breast cancer diagnosis, as well as genetic testing, may affect your intimate relationships in unexpected ways. The status of a current relationship, the treatments you choose and your age may all play a part in how you feel.

If you test positive, you may choose to have a double mastectomy or have your ovaries removed to reduce your risk of **local recurrence**, ovarian cancer or of a second breast cancer (see page 25). Local recurrence is breast cancer that comes back in the breast; this is different from **metastasis**, which is when breast cancer spreads to distant parts of the body.

No matter your relationship status, both surgeries can have a strong effect on body image. These parts of your body are often closely connected to your feelings of femininity and sexuality. You may worry that you or your partner will lose interest in your physical relationship, or, if you are single, that dating will be more difficult.

There is no simple way to predict how others will react to your test results. Communicating clearly about your worries and fears is key to how both you and your partner respond to facing this challenge together.

Because a mutation can be passed to your future children, it's important to keep your partner informed. Your partner may want to see the genetic counselor with you to both support you and to help understand what a mutation means. Giving your partner an active role in counseling and testing may strengthen your relationship.

If you plan to have children in the future, you may worry about fertility. Some of the preventive treatments for positive test results (see page 25) may delay or end your ability to get pregnant. You may feel pressure to plan for your future family—and that pressure may come on suddenly. It can feel overwhelming to have the plans for your future changed because of something beyond your control.

Know that many family planning options are available to help you make decisions about building your family while lowering your cancer risk. Talk with your genetic counselor, a social worker or your oncologist about preserving your fertility. LBBC also offers a *Guide to Understanding Intimacy and Sexuality* that may be helpful to you as you make decisions.



Sharing Your Results

Though genetic testing is highly personal, it may be important to you or your family to share what you've learned from your results. Communicating such important and sensitive information can be stressful, but it can also offer you relief by sharing your burden. If you tested positive, telling family members who may also carry the mutation can be empowering.

Sharing With Family

TALKING WITH YOUR SPOUSE OR PARTNER

In relationships, diagnosis, treatment and genetic testing are often joint experiences. Be sensitive to your partner's concerns while you share your own. Invite your partner to appointments with you to take notes, support you and learn along the way. If your partner feels overwhelmed or anxious, he or she may wish to seek individual emotional support, whether through private therapy, your religious community or elsewhere.

TALKING WITH CHILDREN

If you carry a gene mutation you have a 50 percent chance of passing it on to your children. Your children — sons as well as daughters — may want to consider genetic testing themselves.

National guidelines recommend high-risk screening begin at age 25 for women and 35 for men. Still, some young adults may choose to test as young as age 18. Your genetic counselor can schedule a time to meet with you and your adult children to talk about

their risk, or schedule individual appointments for each adult.

It is possible your children will be uncomfortable talking about testing or unwilling to be tested. As a parent, that may distress or even anger you. You want the best for your children, and you want them to understand how their family background may affect their health.

Everyone deals with things differently. Like you, your children may need time to consider the risks and benefits of knowing if they carry a gene mutation. They may choose not to have testing done now but change their minds later. One way to be there for your children is to give them as much information about genetic risk and breast cancer as you can, and leave it with them to think about.



When I got my positive result, I felt like I was trying to be the mom, the nurse, and the cancer patient. My daughter didn't want to talk about it, and I had to respect her choice. I gave her all the relevant information, told her what her choices were, and let her decide what to do."

—TERESA

If you have very young children, you may not need to tell them about the gene mutation until they are older. Preteens, teenagers and young adults who have seen you go through cancer treatment will likely have questions about your test results and how it might impact them.

When to tell your children about the mutation is up to you and your partner or spouse (if you have one), but your children will value an honest talk about their risk when they are ready. Let them know that your mutation means they have a 50 percent chance of carrying the mutation themselves, but that it does not mean they will definitely get cancer.

If your young adult or adult children have many questions, it may be a good idea to take them with you to a genetic counselor. They can learn about when to start screening and testing.

TALKING WITH IMMEDIATE FAMILY

Your siblings, parents, aunts, uncles, and cousins are all potential carriers of gene mutations if you test positive. Depending on your family, it may be easy or difficult to discuss your results. If you have many distant relatives or don't know some relatives well, communication can be more challenging.

The first step may be asking your family if they want to know your results. Even if you would choose differently,

it's important to respect the choices your family members make. Some may not want to know. Be sensitive to their feelings.

For those family members who are interested, preparing a list of useful information may make talking with them easier. Offer the basic facts of your results, what those results mean for them individually, and the name of your or other nearby genetic counselors.

In some cases, you may want to tell relatives who live far away or who you don't know well. Talking by phone may not be an option or could be uncomfortable. It's OK to tell your relatives about your results by letter or email. Be sure to ask first if the information is something they want. Some nonprofit organizations offer pre-written sample letters for how to share your news. Genetic counselors and social workers are also a good resource for communicating with family.

“Some members of my family thought my decisions to have a double mastectomy and hysterectomy were extreme, but I knew what I was going to do and I did it. Don't let others' opinions sway you, especially if they don't have experience behind what they're saying.”

—LAKSHMI

Sharing at Work

Though you may need to take time off for genetic testing just as you would for a doctor's appointment, you don't have to share your medical or genetic information with your employers. Your results, as well as the testing process, are personal.

The only time you may need to disclose medical information is to use disability benefits, change your

work hours or take time off for longer procedures like surgery. In such cases, your employer only needs information about the treatment or surgery—not your genetic test results. If you need to disclose medical information, talk with your company's human resources representative, who is required by law to keep your information private.

Still, many people find supportive relationships in their coworkers or peers. If you choose to tell someone you trust at work about your genetic test results, you do not need to worry about your employers finding out about your medical background. Laws, like the 2008 Genetic Information Nondiscrimination Act (GINA), protect you. Employers are not allowed to ask you about your genetic information, ask you to take leave, fire you or change your work duties because you carry a genetic mutation that may lead to a health risk. It's also illegal for potential employers to ask for genetic information during interviews or to choose not to hire you if they know about genetic test results.



Paying for Testing

Whether you choose to have genetic testing likely depends on many factors, including the cost. In the United States today, the Affordable Care Act considers testing for *BRCA1* and *BRCA2* mutations in undiagnosed people at high risk a preventive service, which most insurance plans cover. If you are already diagnosed, not high risk, or your insurance doesn't offer coverage, testing can cost anywhere from a few hundred to a few thousand dollars. Testing an entire gene or multiple genes typically costs less than full sequencing. The cost of testing may change over time. Discuss it with your genetic counselor.

Your health insurance provider may cover the cost of genetic testing if you meet certain conditions. Whether you have private insurance through an employer or insurance through a government program such as Medicare or Medicaid may also make a difference in what's covered.

Contact your provider and ask to speak with a case manager about what's covered under your plan. For information on Medicare and Medicaid, visit the Centers for Medicare and Medicaid Services at [cms.gov](https://www.cms.gov).

Health Insurance

PRIVATE INSURANCE

Private insurance coverage of genetic testing varies by plan. How long you've had your insurance, as well as your personal and family history of breast cancer, will also play a part in whether genetic testing is covered. Some labs have special plans to cover testing for those who don't have insurance coverage.

The Affordable Care Act (ACA) of 2010 states that all private healthcare plans started **after March 23, 2010**, must pay the full cost of **preventive services** like annual physical exams and genetic tests for some people.

However, the ACA **does not** require private insurance to cover genetic testing if you are already diagnosed with breast or ovarian cancer, or if you already know of a mutation in your family. Though it's not required by law, some plans will still cover genetic tests even if you are diagnosed. It's also important to note that though the ACA makes sure insurance companies offer plans that cover BRCA testing, employers don't have to offer those plans to their employees.

Plans that existed on or before March 23, 2010 may also choose to cover preventive services. Talk with your health insurance provider to find out if your plan covers genetic counseling and testing.

If you are not diagnosed with breast cancer

In 2013, the U.S. Department of Health and Human Services recommended that genetic counseling and testing should be paid for under the ACA if a woman is **undiagnosed with breast or ovarian cancer and**

- Is of Ashkenazi Jewish descent and has one first-degree or two second-degree relatives with breast or ovarian cancer, or
- Has two first-degree relatives with breast or ovarian cancer, and one was diagnosed before age 50, or
- Has three or more relatives with breast or ovarian cancer, regardless of age at diagnosis, or
- Has one first-degree relative with breast cancer in both breasts, or
- Has a first-degree relative with both breast and ovarian cancer, or
- Has a male relative with breast cancer



GOVERNMENT HEALTH COVERAGE

Depending on your age and financial situation, you may have access to one of two healthcare programs offered by the U.S. government: Medicare and Medicaid.

MEDICARE

Medicare, a health insurance program offered to Americans over age 65, offers limited coverage of genetic testing for breast cancer. To qualify, you must already be diagnosed with breast cancer and have other risk factors recognized as high-risk by Medicare. To learn more about how the Medicare program may cover genetic testing, visit medicare.gov.

MEDICAID

Medicaid is health insurance offered to low-income people and is funded by both the federal government and state governments. Because each state runs its own Medicaid program, where you live may determine whether genetic testing is covered. To learn about your state's program and what it offers, visit medicaid.gov.

WHAT IF I DON'T HAVE INSURANCE?

You may want to consider joining a plan through your employer or applying for Medicare or Medicaid before you begin genetic counseling and testing. You can also consider buying an insurance plan through your state's Health Insurance Marketplace/Exchange.

The state marketplaces are a service formed by the ACA (see page 50) that offers plans with different monthly costs and that cover different medical needs so that you can choose a plan that works best for you. No matter what plan you buy, preventive services should be covered. And, as of 2014, you can't be denied insurance because you are already diagnosed with an illness. **This means that no insurance company can refuse to enroll and cover you simply because you have, or have had, breast cancer.** Be aware that these protections only extend to health insurance; if you have questions about your eligibility for life, disability or long-term care insurance, talk with a social worker or individual insurance policy providers.

See the Resources section (page 56) for organizations that offer financial assistance for genetic testing and counseling. You may also be able to access genetic tests through [clinical trials](#), research studies that test methods of screening, prevention and treatment. A social worker, patient navigator or your oncologist may be able to help you find a trial near you.

LEARN MORE

To learn more about the ACA and other financial concerns, read our *Guide to Understanding Financial Concerns*.



Looking Toward the Future

Researchers are learning more about how specific gene mutations direct cells to grow and divide abnormally, leading to breast and other cancers. There are many gene mutations identified and under study that may be associated with the disease.

Choosing to have genetic testing may help you find the answers you are looking for. It may also leave you feeling like you've hit another bump in the road, if your results are not what you expect. Remember that all research takes time, and every day scientists are learning more about how human genes affect the body and the disease.

Genetic testing techniques may change as researchers learn more. Consider checking with your genetic counselor every few years as the understanding of hereditary cancer risk and genetic testing evolves. Newer tests may help you learn more even if you've tested negative for a mutation in the past. Visit LBBC.ORG to see the latest updates.

GENE PATENTING AND THE SUPREME COURT

In the summer of 2013, the U.S. Supreme Court ruled that human genes cannot be patented, which means that no lab or person may hold exclusive rights to working with specific human genes. The ruling has allowed new labs to offer genetic testing. Talking with a genetic counselor is the best way to know how the costs and availability of genetic testing will change as time goes on.

Resources

Information is current as of September 2016 but may change.

ADVOCACY AND SUPPORT

- Bright Pink: brightpink.org
- FORCE: Facing Our Risk of Cancer Empowered: facingourrisk.org, (866) 288-7475
- Genetic Alliance: geneticalliance.org, (202) 966-5557
- Sharsheret: Your Jewish Community Facing Breast Cancer: sharsheret.org
- Young Survival Coalition: youngsurvival.org

CENTERS AND CLINICS

- Bassett Center for BRCA: penncancer.org/bassett
- Center for Jewish Genetics: jewishgenetics.org
- GeneTests: genetests.org

GENERAL INFORMATION

- American College of Medical Genetics and Genomics: www.acmg.net, (301) 718-9603
- American Society of Human Genetics: ashg.org, (866) 486-4363
- Centers for Disease Control and Prevention: cdc.gov/genomics/resources/diseases/breast_ovarian_cancer/testing.htm
- National Cancer Institute: cancer.gov/about-cancer/causes-prevention/genetics
- National Human Genome Research Institute: genome.gov/10000507

GENETICS LABS

- Ambry Genetics: ambrygen.com/tests/brca1-and-brca2
- City of Hope: cityofhope.org/clinical-molecular-diagnostic-laboratory, (626) 256-4673
- GeneDx: genedx.com
- Invitae: invitae.com
- Myriad Genetics: myriad.com
- University of Washington Genetics Lab: depts.washington.edu/labweb/Divisions/MolDiag/MolDiagGen/index.htm

GENETIC COUNSELING AND COUNSELORS

- American Board of Genetic Counselors: abgc.net
- Cancer Genetic Services Directory: cancer.gov/about-cancer/causes-prevention/genetics/directory
- National Society of Genetic Counselors: nsgc.org, (312) 321-6834

GENETIC COUNSELING BY PHONE

- Genetic Counseling Services: geneticcounselingservices.com, (888) 260-6543
- InformedDNA: informeddna.com, (800) 975-4819

ETHICS AND HUMAN GENETICS

- American Civil Liberties Union: aclu.org/free-speech-technology-and-liberty-womens-rights-association-molecular-pathology-v-myrriad-genetics
- Council for Responsible Genetics: CouncilForResponsibleGenetics.org, (617) 868-0870

FERTILITY AND PREGNANCY

- Hope for Two—The Pregnant with Cancer Network: hopefortwo.org, (800) 743-4471
- LiveStrong Fertility: livestrong.org/we-can-help/fertility-services
- MyOncoFertility: MyOncoFertility.org, (866) 708-3378
- Path 2 Parenthood: path2parenthood.org

FINANCIAL AND LEGAL HELP

- Cancer and Careers: cancerandcareers.org
- Cancer Legal Resource Center: cancerlegalresourcecenter.org, (866) 843-2572
- Center for Patient Partnerships: patientpartnerships.org, (608) 890-0321
- Patient Advocate Foundation: patientadvocate.org, (800) 532-5274

FOR WOMEN OF JEWISH DESCENT

- Hadassah: The Women's Zionist Organization of America: hadassah.org, (888) 303-3640
- JACOB International: jacobintl.org
- My Jewish Genetic Health: myjewishgenetichealth.com
- Sharsheret: sharsheret.org, (866) 474-2774

Words to Know

Ashkenazi Jewish. People of Jewish heritage whose families came from Central and Eastern Europe.

BRCA1 and BRCA2. Two naturally-occurring genes that normally help suppress cell growth. Mutations to either *BRCA1* or *BRCA2* increase a person's risk of developing breast and ovarian cancers, as well as others.

Chemoprevention. Taking medicine to try to lower the risk of developing a new cancer.

Clinical trial. A research study in humans.

Direct-to-consumer genetic test. Genetic tests that can be ordered online or through TV ads, and that are completed at home without a genetic counselor or doctor.

ER-positive breast cancer. Breast cancer that grows in the presence of estrogen.

Estrogen. A hormone with strong influence on the growth of some breast cancer cells.

First-degree relatives. Your parents, siblings, and children.

Full sequencing. Genetic tests that look at the full DNA of a gene to see if there is a mutation.

Gene. In a cell, the part that contains the directions (DNA) that tell the cell when and how to grow.

Gene panel. Genetic test that looks for several gene mutations all at once. Gene panels look for mutations in other genes as well as *BRCA*.

Genetic counseling. The process of meeting with a genetic counselor to discuss your family health history and whether genetic testing is right for you.

Genetic counselor. A healthcare provider trained to weigh the risks and benefits of genetic testing and to educate people about genetic test results.

Genetic testing. Tests that look for genetic mutations that increase the risk for developing diseases like breast and ovarian cancer.

Hereditary. Traits, genes, mutations and risks that are passed on to you from your parents, and can be passed on to children or shared with siblings.

Hormonal therapy. Treatment that lowers the amount of estrogen in the body or stops breast cells from absorbing estrogen.

Inconclusive. A genetic test result that means it is possible the cancer is associated with a gene mutation the test could not identify. Also called uninformative.

Mutation. When a cell has an error in its directions. As the cell makes more copies of itself, the copies will also have the error.

Negative. A genetic test result that means you may not carry a mutation.

Pedigree. Chart of a family's medical and cancer history.

Positive. A genetic test result that means you carry a mutation.

Postmenopausal. Describes women who have had no periods for more than 1 year.

Pre-existing condition. A medical condition you had before you joined your insurance plan.

Premenopausal. Describes women who have periods or menstruate.

Primary. A new breast cancer. Not a recurrence of breast cancer that has already been treated.

Prophylactic. Preventive.

Risk-reducing salpingo oophorectomy. Surgery to remove the ovaries and fallopian tubes to lessen the chance of developing ovarian cancer.

Single-site analysis. Genetic test that looks only for gene mutations already known to exist in your family.

Somatic mutations. Gene mutations that are not passed on to you from your parents or shared with siblings or children.

Surgical menopause. Menopause that is caused by having the ovaries removed by surgery.

Survivor guilt. A sense of guilt or blame for not inheriting the gene mutation that negatively effects your loved ones.

Tamoxifen. Hormonal therapy medicine that stops estrogen signals from getting to cells and causing them to grow. Lowers the risk of hormone-sensitive cancer returning.

True negative. A negative test result that occurs in a family with a known inherited gene mutation.

Uninformative. A genetic test result that means it is possible the cancer is associated with a gene mutation the test could not identify. Also called inconclusive.

Variant of Uncertain Significance (VUS). A change in either BRCA gene that may or may not increase your risk of developing breast cancer.



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More Resources

Visit LBBC.ORG or call (855) 807-6386 to order our other *Understanding* publications:

- ☐ **Guide for the Newly Diagnosed**
- ☐ Clinical Trials
- ☐ Complementary Therapies
- ☐ Fear of Recurrence
- ☐ Financial Concerns
- ☐ HER2-Positive Breast Cancer
- ☐ Hormonal Therapy
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- ☐ Lymphedema
- ☐ Treatment Decisions
- ☐ Triple-Negative Breast Cancer
- ☐ Yoga & Breast Cancer
- ☐ Your Emotions

Guides in our *Metastatic Breast Cancer* Series:

- ☐ **Guide for the Newly Diagnosed**
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- ☐ Treatment Options for Today and Tomorrow
- ☐ Understanding Palliative Care
- ☐ Understanding Symptoms and Treatment Side Effects

Guides in our *Breast Cancer InFocus* Series:

- ☐ Breast Cancer During Pregnancy
- ☐ Breast Cancer in Men
- ☐ Getting the Care You Need as a Lesbian, Gay or Bisexual Person



With you, for you.

This brochure is designed for educational and informational purposes only, as a resource to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

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