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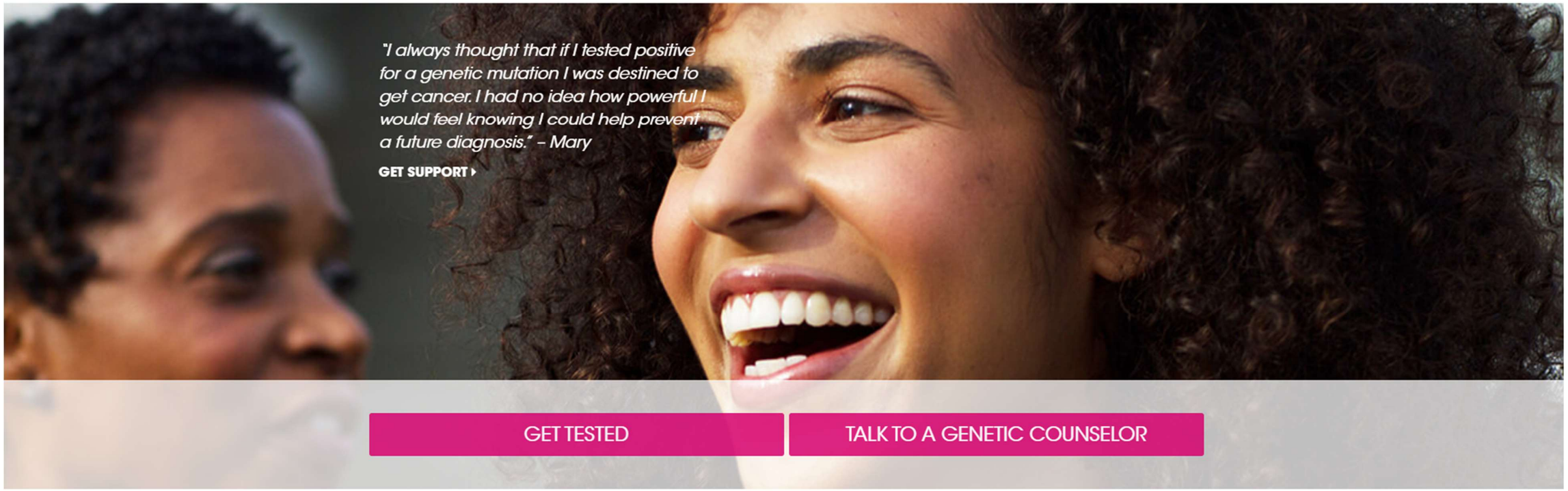
Attachment C3: Materials for Testing with African American Young Women

exploreyourgenetics
by bright pink

THE GENETIC LINK | THE CHOICE TO GET TESTED | HOW TO GET TESTED | SUPPORT | TAKE ACTION



What Do Genes Have To Do With Me?

They make you uniquely you. Genes carry information that determines things you can see, like hair color, and things you can't see, like your risk for breast and ovarian cancer. Bright Pink wants all women to be empowered to make important decisions about genetic testing and their health. It all starts by exploring your genetics.

UNDERSTAND THE GENETIC LINK ▸

Myth

BRCA1 and *BRCA2* are the only gene mutations associated with breast and ovarian cancer.

Reality

While *BRCA1* and *BRCA2* are the most well-known and common genes for breast and/or ovarian cancer, many other gene mutations are also associated with these diseases.

LEARN MORE ▸

Myth

Genetic testing is only for people who haven't had cancer.

Reality

Genetic testing can be really helpful in understanding if a cancer diagnosis was sporadic or due to an inherited mutation and if you may have an increased risk for other cancers. Your loved ones also benefit in knowing if there is an inherited mutation in your family tree.

LEARN MORE ▸

Myth

If you have a gene mutation, you will get cancer.

Reality

While it's true that if you have a gene mutation you have a higher risk of developing breast and/or ovarian cancer during your lifetime, a mutation DOES NOT guarantee you will develop cancer.

LEARN MORE ▸

ASSESS YOUR RISK

Decide if testing is right for you
Learn more about the reasons for getting tested and the experts you can work with.

GO ›

Understand how to get tested
Find out about your testing options – and why cost doesn't have to be a barrier.

GO ›

Find Support
From women just like you to genetics professionals, you have incredible support options.

GO ›

The Choice to Get Tested

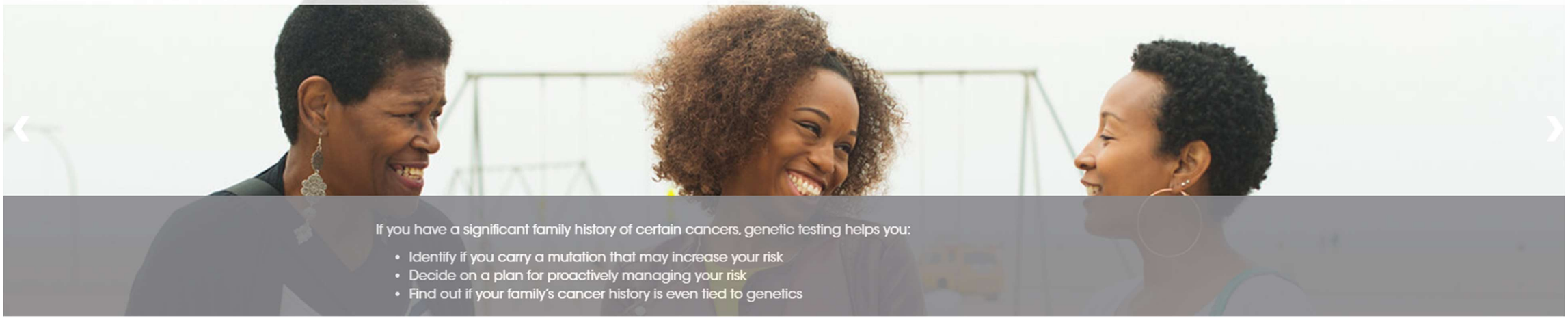
Undergoing genetic testing is a powerful way to take charge of your health. There are lots of reasons to get tested, and knowing what to expect and who to talk to throughout the process will help you make informed choices that are right for you.

Reasons to Get Tested

Learn more about the different risk factors that should inform your decision whether to undergo genetic testing and find out how you can assess your own risk.

EVALUATING YOUR SITUATION ›

Tiffany's mom and aunt were both diagnosed with breast cancer before they turned 50.



If you have a significant family history of certain cancers, genetic testing helps you:

- Identify if you carry a mutation that may increase your risk
- Decide on a plan for proactively managing your risk
- Find out if your family's cancer history is even tied to genetics

Take Action

Now that you've got the information and the tools to help you move forward, turn your awareness into action. There are a few ways to get started.

Get Started on Your Own

Work with a genetic testing lab that lets you begin the process online.

GO ›

Get Tested with Your Healthcare Provider

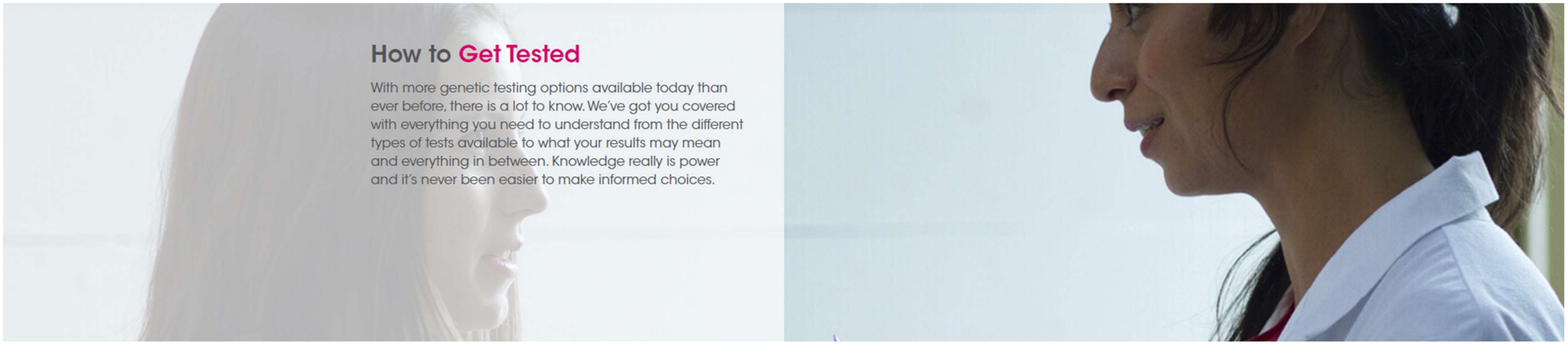
Visit your provider to get started with genetic testing.

GO ›

Talk to a Genetic Counselor

Work with a genetic counselor to determine what's right for you.

GO ›



How to Get Tested

With more genetic testing options available today than ever before, there is a lot to know. We've got you covered with everything you need to understand from the different types of tests available to what your results may mean and everything in between. Knowledge really is power and it's never been easier to make informed choices.

Testing 101

Take a few minutes to learn genetic testing basics. Once you're armed with information on the different types of genetic tests available to you, the labs that run these tests, how insurance comes into play and the implications of your results, you'll feel empowered to start making informed decisions.

Test Options

Results

Test Cost/ Insurance

Different genetic tests, different testing labs

The specific test that the lab runs depends on things like your ancestry and personal risk factors for breast and ovarian cancer. It also depends on the types of products or tests that each given lab offers. Learn more about the difference between the various tests and the labs that perform them.

TEST OPTIONS ›

Costs & Health Insurance

The way you pay for testing may be a major factor in your decision, but it doesn't have to drive your decision. As testing becomes more common, some health insurers – and even some labs– are working to make genetic testing affordable for all women, no matter their financial situation.

PAYING FOR YOUR TEST ›

Results

Understanding what your results mean and what you can do next, gives you an opportunity to plan ahead and have meaningful conversations.

GETTING YOUR RESULTS ›

Myth

Genetic testing is expensive and is never covered by insurance.

Reality

With the Affordable Care Act, women with a family history of breast and/or ovarian cancer are eligible for counseling and testing at no cost due. Plus, many health insurance plans cover testing with very little or no out of pocket expenses. For women who are uninsured or want to bypass insurance, there are financial assistance programs and low-cost options.

LEARN MORE ▸

Myth

Genetic testing is painful

Reality

Most genetic tests can be done with a simple blood test. If needles make you queasy, using your salvia to test is another option!

LEARN MORE ▸

Myth

You have to go see your doctor to get tested.

Reality

While starting with your healthcare provider is good option, it may not work for everyone. There are options that allow you to start the testing process with a testing lab along with their network of physicians.

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What you should know about genes and cancer

FORCE
Facing Our Risk of Cancer Empowered

How can I learn if I have an inherited mutation?

Blood or saliva laboratory tests can tell if you have an inherited mutation. Most people do not inherit cancer-causing gene mutations, so genetic testing is not recommended for everyone. Medical experts known as genetic counselors can provide you and your family with information about genetic testing, cancer risk and medical options to help you stay healthy.

A genetic counselor will:

- help you to understand hereditary cancer
- review your family medical history to assess and explain your risk for cancer
- describe the benefits and limitations of genetic testing, and discuss whether it is right for you
- order the appropriate test if you choose to proceed with genetic testing
- interpret and explain what genetic test results mean for you and your family
- discuss how to manage your cancer risk and refer you to experts for follow-up care

There are many different types of genetic tests, so it's important to speak with a genetic counselor before genetic testing. Test results may affect health care decisions about cancer screening, prevention and treatment, so it's equally important to speak with a genetics expert after testing. Your test results may also make you eligible to participate in clinical trials. Sharing your test results with relatives can help them learn more about their own cancer risk and provide them with more medical options for staying healthy.

For more information on finding specialists, visit www.facingourrisk.org/specialists.

What do my genetic test results mean?

Different genetic tests look for mutations in different genes, and different gene mutations are associated with different cancer risks. The meaning of your test results depends on which test was ordered and whether or not a mutation was found in any of your genes. This is why speaking with a genetics expert before and after genetic testing is so important.

A positive test result means that an inherited gene mutation was found in one of your genes. Your cancer risk depends on which gene has the mutation, your gender, your age, your family history of cancer and other factors.

A negative genetic test result means that no mutation was found in any of the genes included in your test. Although this is good news, a negative genetic test may not provide clear information on your cancer risk. If you test negative for a mutation, your risk for cancer will vary depending on several factors, including your personal and family medical history.

Your genetic test results may provide your relatives with important information about their risk for cancer. Therefore, it is important to share information about your genetic counseling and testing result with your family members.

"FORCE is such a blessing. I am so grateful to benefit from the work of hereditary cancer pioneers like the people of FORCE who planted trees so the rest of us could sit in the shade—and so we could feel empowered enough to plant a few trees ourselves."
Frances Ratner, FORCE Constituent

What is genetic testing for cancer risk?

All humans inherit 23 pairs of chromosomes from their parents. Each of these chromosomes contain up to thousands of genes.

Genes contain information that tells our bodies how to function, like an instruction manual. There can sometimes be errors in that information, like a misspelled word. These errors are called “mutations.”

Genetic tests for cancer risk look for mutations, or errors, in specific genes that increase the chance that someone may get cancer.

Are all genetic tests the same?

Not all genetic tests are the same. Genetic tests differ by how many errors or mutations they look for and where they look for them.

There are four types of genetic tests:

1) **Single site or selected variants tests** look for one or more specific mutations in specific locations on specific genes. These tests are best suited for those who already know there is a cancer-causing genetic mutation in their family; otherwise a single-site test will provide limited information. Most direct to consumer tests are selected variant tests.

2) **Comprehensive mutation tests** search in multiple locations for a specific type of mutation that can increase your chances of getting cancer. These tests are best suited for individuals who have talked with a genetic counselor about their family history of cancer and have a good sense of what types of mutations might run in their family.

3) **Multi-gene or panel tests** looks for several mutations in up to 30 genes that are all known to increase a person's chances of getting cancer. Panel tests are best suited for individuals who after talking to a genetic counselor are unclear about what gene(s) may be behind their family history of cancer.

4) **Whole genome sequencing** looks at every location in all of your genes. This is an uncommon type of testing that can be rather expensive.

Genetic tests can be accessed via three different routes: from a certified genetic counselor, from a medical doctor (i.e., your primary care provider or OB-GYN), or from a direct-to-consumer testing kit. Direct-to-consumer test kits are advertised and sold online and in stores. Consumers can take these genetic tests without the involvement of healthcare providers.

Key Differences Between Direct-to-Consumer Genetic Testing and "Traditional" Genetic Testing at Medical Facilities			
	Direct-to-consumer testing	Testing from a Medical Doctor	Testing from a Certified Genetic Counselor/Professional
What types of tests do they typically offer?	Single Site or Selected Variants Tests.	Comprehensive Mutation Tests, Multigene or Panel Tests.	Comprehensive Mutation Tests, Multigene or Panel Tests, Whole Genomic Sequencing (this is rare).
Who initiates the test?	You initiate the test.	A health care worker initiates the test.	A certified genetic counselor initiates the test.
How do individuals receive their results?	Results are delivered directly to you, likely via email or online report.	Results are delivered to your healthcare provider who then shares the results with you.	Results are delivered to you by the genetic counselor.
Who interprets the results?	You or someone you choose may help you interpret the results; typically these are not accredited medical or genetic counseling professionals.	Licensed or accredited healthcare professionals interpret the genetic information.	Licensed or accredited genetics professionals interpret the genetic information.
How are the results used?	Results can be used for multiple purposes, such as better understanding your ancestry, paternity, or health	Results inform your medical care	Results inform your medical care. A genetic counselor can also discuss implications of your results for family members.
How else can the results be used?	Companies can sell your data for profits.	Secondary uses are largely limited to health care research purposes.	Secondary use is not allowed without your permission.
How is pricing determined?	Intense competition may drive down product price.	Product price is tied to healthcare payment/insurance model. Some genetic test companies offer assistance with paying for genetic testing.	Product price is tied to healthcare payment/insurance model. Some genetic test companies offer assistance with paying for genetic testing.
Who regulates the testing?	Companies are regulated as consumer products.	Health care systems are regulated by industry-specific rules.	Health care systems are regulated by industry-specific rules.
Is there a quality control process for the test?	Test quality is largely unregulated.	Regulations and quality control systems are in place to assess test quality.	Regulations and quality control systems are in place to assess test quality.

What kinds of results could I get from genetic testing?

If you have genetic testing for cancer risk, there are three types of results you could get:

1) Negative – This means the test did not find a mutation that increases your risk for cancer, but a negative result doesn't mean you will never get cancer. A genetic counselor can help you understand your cancer risk after testing negative. Depending on the type of test used, additional genetic testing may be needed to confirm you are negative for a mutation.

2) Positive – This means the test found a genetic mutation that increases your chance of developing cancer. It does not mean you will definitely get cancer just that you are more likely. A genetic counselor or other medical provider can talk to you about ways to decrease your chance of developing cancer and additional tests that may be recommended for you.

3) Variant of Unknown Significance – This means that while the genetic test found a mutation, "researchers haven't yet confirmed whether this variant is a harmless change or a risk factor for cancer." As researchers continue to gather new information, variants of unknown significance may be reclassified and you may receive updated results.