



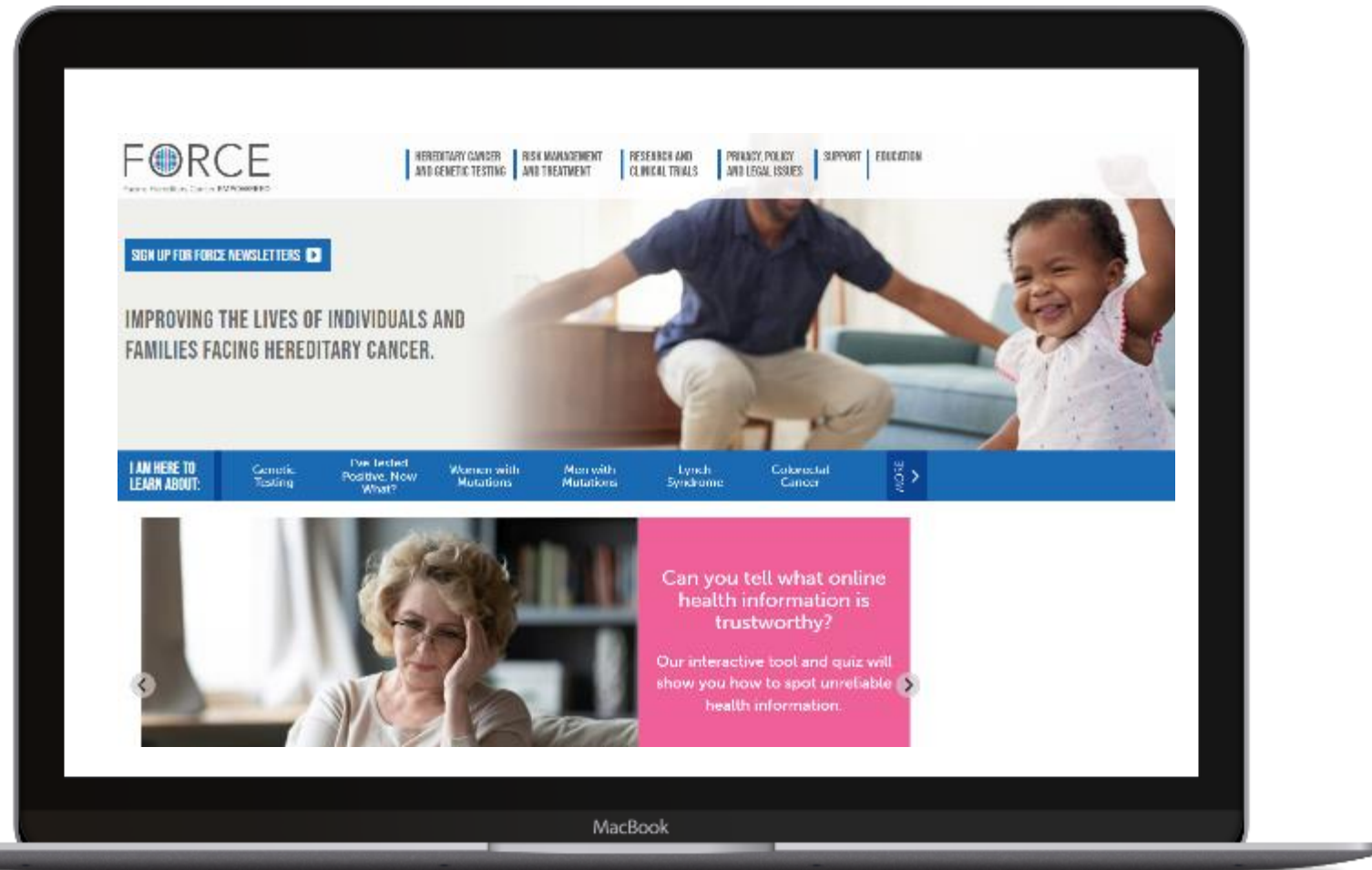
Hereditary Cancer: What You Learn Can Protect Your Family

FORCE

Facing Hereditary Cancer **EMPOWERED**

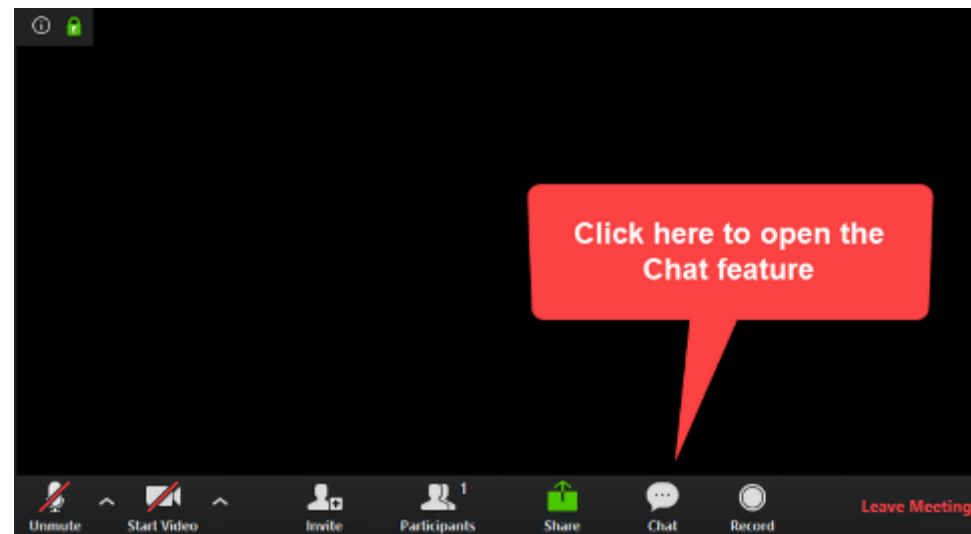
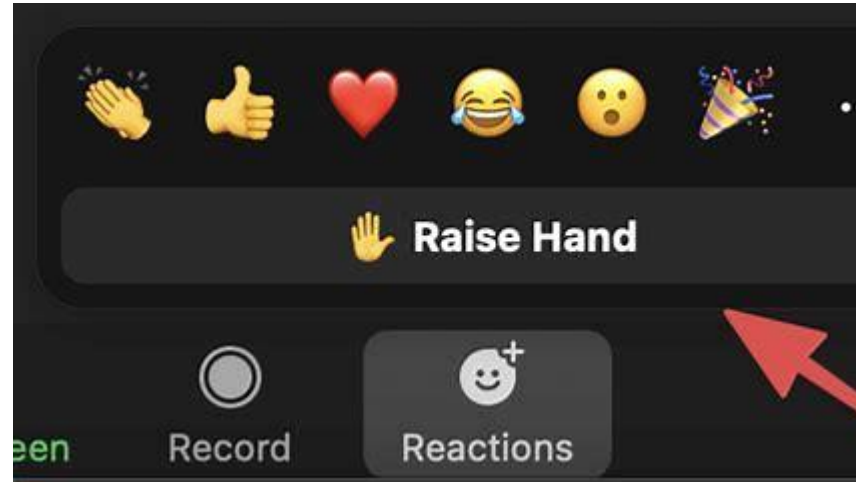
About **FORCE**

FORCE serves people and families affected by Lynch syndrome or an inherited mutation in BRCA, ATM, PALB2, CHEK2, PTEN or other gene linked to cancer. We accomplish this through our education, support, advocacy and research programs.



Poll Questions

Using Zoom's raise hand and chat features.



Why we are here

We are here to:

- provide facts and dispel myths about hereditary cancer and genetic testing
- share personal stories
- provide you with resources



Definitions: Inherited mutation and hereditary cancer risk

- Inherited mutations are changes in genes that can be passed on from parents to children.
 - Some inherited mutations can increase people's risk for cancer.
- Cancers caused by inherited mutation are called "hereditary cancers."
 - "Hereditary cancer risk" describes the chance of developing certain types of cancer.



Disparities in cancer genetics referrals

Compared to other groups:

Hispanic people are equally likely to have inherited mutations linked to cancer.



But Hispanic people are much less likely to be referred by their doctor for genetic counseling/testing.

Cancer is a common disease.

17
MILLION

PEOPLE living with
CANCER in the
UNITED STATES



3.0
MILLION

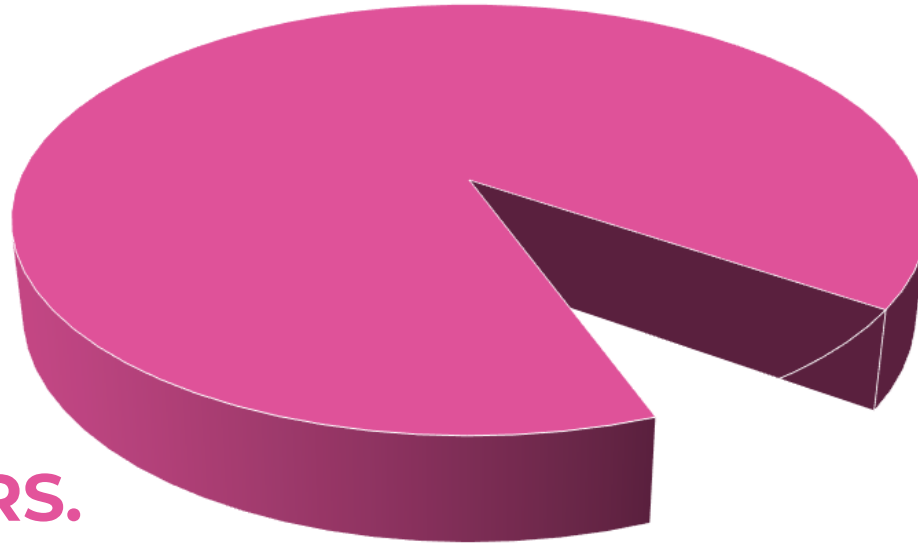
HISPANIC PEOPLE
living with **CANCER** in
the **UNITED STATES**

This much cancer is sporadic.

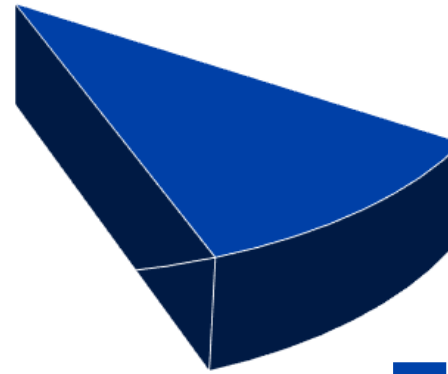
90%

of all **CANCERS** are
NOT CAUSED BY
inherited mutations.

These are called
SPORADIC CANCERS.



What makes this 10% so important?



10%

of all **CANCERS**
are **CAUSED BY**
inherited
mutations.

These are called
HEREDITARY CANCERS.

How familiar are you with genetic testing for hereditary cancer risk?



- Not at all familiar with it at all
- Somewhat familiar with it
- Very familiar with it

My story

August 24, 2020

MI HISTORIA FAMILIAR HISPANA DE BRCA

A Hispanic BRCA1 Family Story

By Marisol Rosas

I watched my mother fight breast cancer for several years when I was very young, only to lose her when I was eight years old to ovarian cancer. Since then, I always feared I would one day have those same fights.

First, there was fear

I first learned about hereditary breast and ovarian cancer genetic testing more than 16 years ago, when my cousin who had breast cancer tested positive for a BRCA1 mutation. At that time, I was single and eager to ignore this information. However, it was always in the back of my mind. I didn't want to undergo genetic testing, because I was afraid of what I would find out.



Benefits of genetic testing for inherited cancer risk

Provides information about:

- Cancer in the family
- Personal cancer risk
- Cancer risks to relatives

Guides decisions about:

- Cancer screening
- Risk-reduction
- Cancer treatment
- Childbearing or fertility options

BRCA1 and BRCA2

BRCA1 and BRCA2 are two common genes linked to breast cancer

1 in 400 people carries a BRCA mutation



INCREASED lifetime risk for*:

- breast
- male breast
- ovarian
- pancreatic
- prostate



OTHER GENES linked to these cancers*:

- ATM
- BRIP1
- CHEK2
- PALB2
- RAD51C/RAD51D
- others

*Note: Cancer types and level of risk vary by gene

Genetic testing for inherited cancer risk

Genetic testing uses blood or saliva to find gene mutations linked to an increased risk for hereditary cancer.



It's important to talk with your relatives about your family medical history



Inherited mutations cause cancer to run in families by being passed down from parents to children



"Breast cancer is the most common cancer among Latinas, who also tend to be diagnosed at more advanced stages. My mother and three aunts each passed away from metastatic breast cancer. I, too, was diagnosed with Triple Negative Breast Cancer prior to learning that I had a BRCA1 gene mutation. Now, I want to help spread awareness about hereditary cancer. The more we talk and learn, the more lives we can save."

- DEBBIE DENARDI,
BRCA1 Breast Cancer Survivor

Including yourself, going back 2 generations, how many people in your family have had cancer?



- 0
- 1 or 2
- 3-5
- More than 5
- I don't know my family's medical history

Inherited mutations affect both men and women



Watch Out Men, Breast Cancer Gene Can Get You Too

By Karen Iris Tucker
August 10, 2016 | Courtesy of Angel Moses

FORCE volunteer, Angel Moses and her father were the subject of a FORWARD article about genetic testing in men

True or False?

Genetic testing is only helpful for people with a lot of cancer in their family.



- True
- False

Genetic testing is only helpful for people with a lot of cancer in their family.





While genetic testing is helpful for people with a lot of cancer in their family, sometimes even one person with cancer in the family can be enough to recommend genetic testing.

Genetic testing can help people with and without a lot of cancer in their family.

If you or a close relative has been diagnosed with any of the following, genetic counseling and testing are recommended:

- ✓ breast, colorectal or endometrial cancer at age 50 or younger
- ✓ triple negative breast cancer at any age
- ✓ breast cancer in both breasts or more than once
- ✓ ovarian cancer, pancreatic or male breast cancer at any age
- ✓ metastatic (advanced cancer that has spread) prostate cancer

One rare cancer in the family is enough to seek genetic counseling and testing: Male breast cancer

Beyoncé's father Mathew Knowles opened up about his breast cancer journey one year after sharing his diagnosis

Taylor Ardrey Oct 5, 2020, 3:21 PM EDT

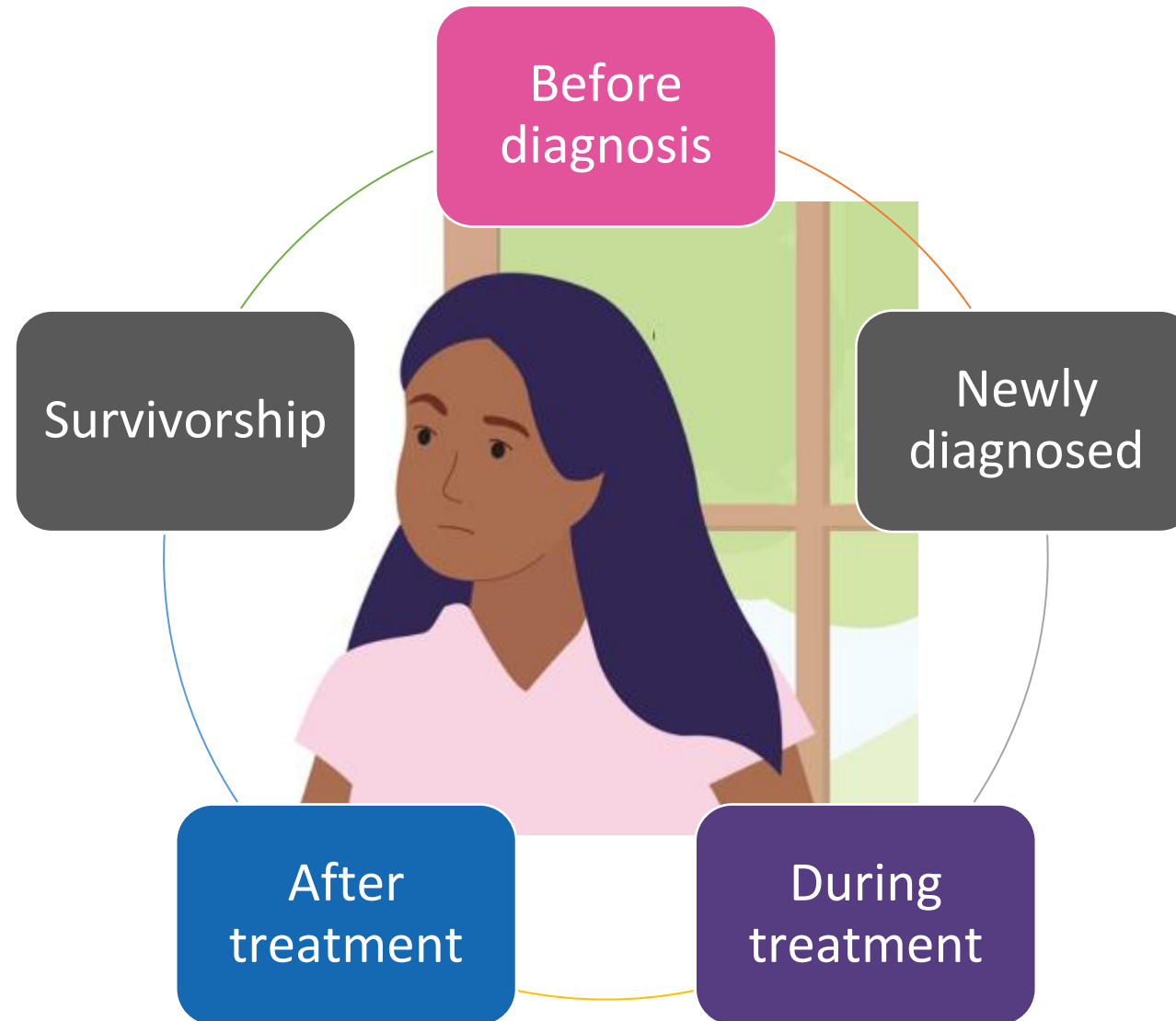


Allen Berezovsky/WireImage & Bauzen/GC Images

Knowles announced he had breast cancer on "Good Morning America."

Since his diagnosis, Knowles underwent a mastectomy to remove his left breast and found out through a genetic test he had a BRCA2 gene mutation.

Genetic testing can be helpful at different times



Genetic counseling before and after testing

Genetic counselors:

- Collect family history to assess risk for hereditary diseases like cancer
- Discuss benefits, risks and limitations of genetic testing
- Interpret test results
- Discuss next steps and medical options



True or False?

Genetic testing costs thousands of dollars and insurance won't usually pay for it



- True
- False

Genetic testing costs thousands of dollars and insurance won't usually pay for it.

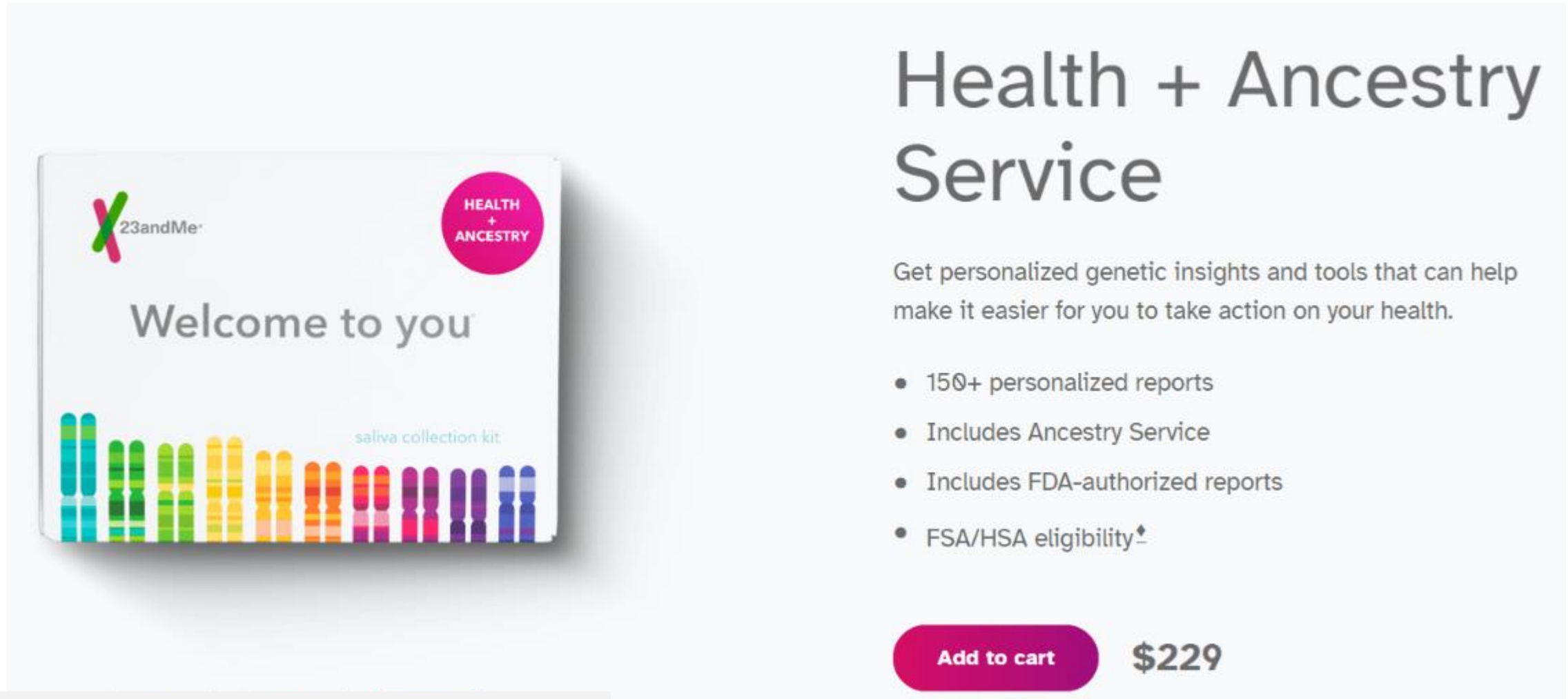




Genetic testing costs are covered by most health plans. Most people can get testing for \$250 or less.

Do not use ancestry DNA tests for medical decisions

- Ancestry testing should not be used for medical decision-making



The advertisement features a product box for the 23andMe Health + Ancestry Service on the left. The box is white with a colorful graphic of human chromosomes at the bottom. Text on the box includes the 23andMe logo, a pink circle with 'HEALTH + ANCESTRY', 'Welcome to you', and 'saliva collection kit'. To the right of the box, the title 'Health + Ancestry Service' is displayed in large, bold, dark grey font. Below the title, a paragraph states: 'Get personalized genetic insights and tools that can help make it easier for you to take action on your health.' A bulleted list follows, listing features: '150+ personalized reports', 'Includes Ancestry Service', 'Includes FDA-authorized reports', and 'FSA/HSA eligibility*'. At the bottom right, there is a pink 'Add to cart' button and a price tag of '\$229'.

Health + Ancestry Service

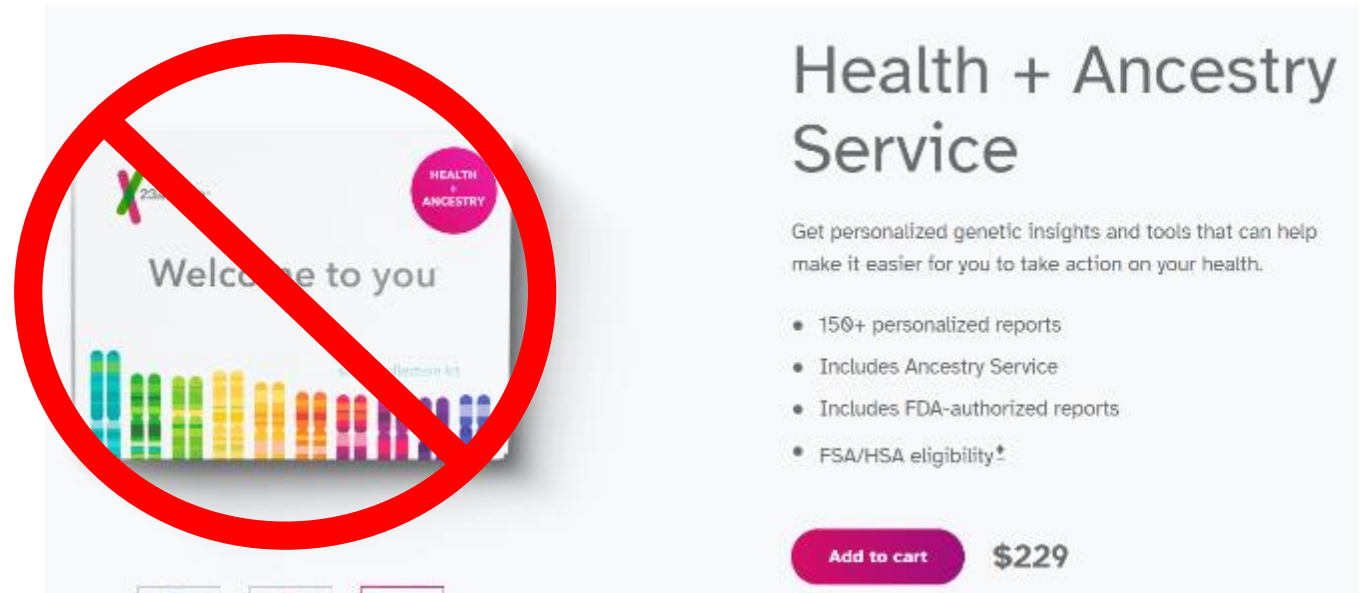
Get personalized genetic insights and tools that can help make it easier for you to take action on your health.

- 150+ personalized reports
- Includes Ancestry Service
- Includes FDA-authorized reports
- FSA/HSA eligibility*

Add to cart **\$229**

Do not use ancestry DNA tests for medical decisions

- Not recommended for medical decision-making
- See a genetic counselor



Find a Genetic Counselor



FindaGeneticCounselor.org

True or False?

If you test positive for an inherited mutation linked to cancer risk, there's not much you can do about it.



- True
- False

If you test positive for an inherited mutation linked to cancer risk, there's not much you can do about it.





People with increased cancer risk have access to more advanced screening and prevention options for many types of cancer.

Cancer screening and prevention



Screening in Men at High Risk of Developing Prostate Cancer

Clinicaltrials.gov identifier:
[NCT05608694](https://clinicaltrials.gov/ct2/show/study/NCT05608694)

Prevention

Screening using MRI for men at risk of developing prostate cancer



Testing a Vaccine for Cancer Prevention in People with a BRCA1 or BRCA2 Mutation

Clinicaltrials.gov identifier:
[NCT04367675](https://clinicaltrials.gov/ct2/show/study/NCT04367675)

Prevention

People with a BRCA1 or BRCA2 mutation

“Previving” cancer

I AM A PROUD PREVIVOR

By Ashley Dedmon



“I was 22 when I learned I was BRCA positive. My mother had metastatic breast cancer and lost her battle at the young age of 52. . .I felt the odds were stacked against me, having been born into three generations of women affected by breast cancer. Genetic counseling and testing may have saved my life”

True or False?

If you test positive for an inherited mutation, you could lose your job or health insurance.



- True
- False

If you test positive for an inherited mutation, you could lose your job or health insurance.





There are federal and state laws that protect people from losing their health insurance or job based on a genetic risk for disease.

These laws have some gaps.

Federal and state laws against genetic discrimination

GINA bans genetic discrimination in health insurance & employment

The Genetic Information Nondiscrimination Act (GINA) prohibits discrimination by health insurance plans and employers based on genetic information. "Genetic information" is defined as:

- Your genetic test results
- Your relatives' genetic test results (up to and including fourth-degree relatives), and/or
- Information about family history of any disease or disorder

Information about your participation in research that includes genetic testing, counseling, or education is also protected.



Exceptions

GINA does not apply to life, long-term care or disability insurance. These insurers are allowed to use genetic, personal or family health information to make coverage or premium decisions. Some states have their own genetic protection laws, providing additional security against genetic discrimination for these types of insurance.

In addition, GINA does not apply to:

- Members of the United States military
- Veterans obtaining health care through the Veteran's Administration
- Individuals using the Indian Health Service, or
- Federal employees enrolled in the Federal Employees Health Benefits program (FEHB)

However, the military and veterans' health care systems have their own policies that provide protections similar to GINA. Note that there are some exceptions for individuals joining the military. These can be found in the DoD [Medical Standards for Appointment, Enlistment, or Induction into the Military Services](#).

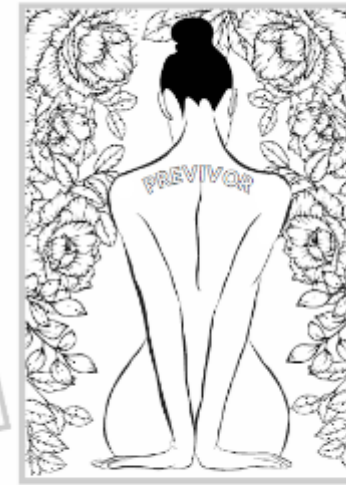
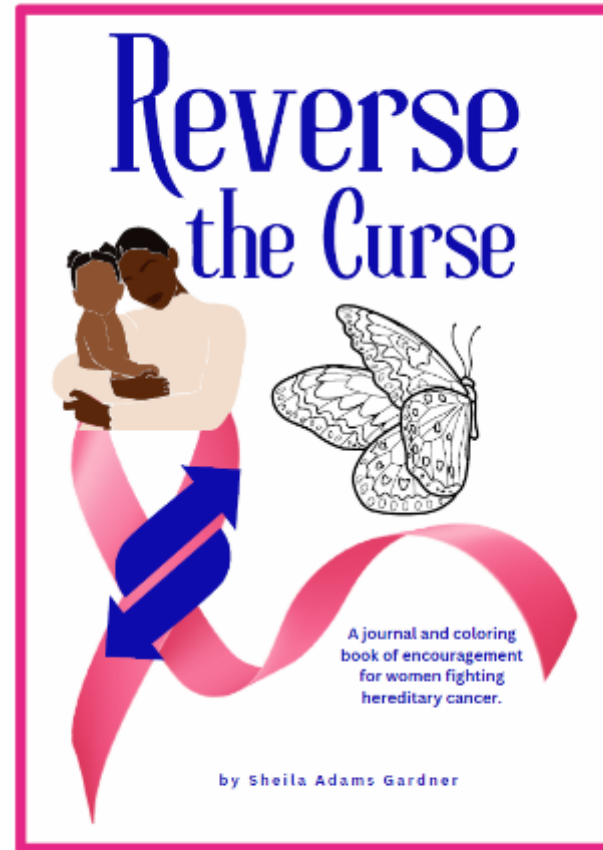
Federal employees are similarly protected under an [executive order](#).

Note: some states have laws that offer additional protections.

Most people are glad their relatives shared this information



Sheila Adams Gardner, Esq.



Tips for informing family about your genetic mutation:

- Acknowledge the gift of knowledge.
- Understand that sharing information happens many times and many ways.
- Keep the family health history and your genetic testing results handy.
- When the response is not what you hoped, have peace in knowing that you did your part in sharing the information.
- Keep being the family's example of how to navigate the previvor journey. You are awesome!

Reverse the Curse: A journal and coloring book of encouragement for women fighting hereditary cancer.
[amazon.com](https://www.amazon.com)

Tools for discussing medical information with relatives

“Let’s Talk” from the CDC helps people talk with relatives about cancer risk



Brochure –
“The Genes
Between Us”





Wrap up

- ✓ Hereditary cancers are caused by inherited mutations that can be passed on from parents to their children.
- ✓ Genetic testing can help you learn if the cancers in your family are caused by an inherited mutation.
- ✓ Genetic counselors are medical experts who can help you decide if testing is right for you and help you and your relatives get genetic testing.
- ✓ FORCE and BCRC have resources to help you and your family understand hereditary cancer, make decisions and get support.

Find support and information at FORCE



Website: FacingOurRisk.org

Get Social: FacingOurRisk

