

Cancer Genetic Testing

What you need to know before you test

Beth Israel Lahey Health



Beth Israel Deaconess Medical Center

Introduction

As part of your cancer care, we are offering you genetic testing.

Genetic testing may explain why you got cancer or help your doctors decide which treatments might work best for you. Genetic testing may also help family members learn more about their chance to get cancer.

Please review the information in this packet. It should take you less than 10 minutes.

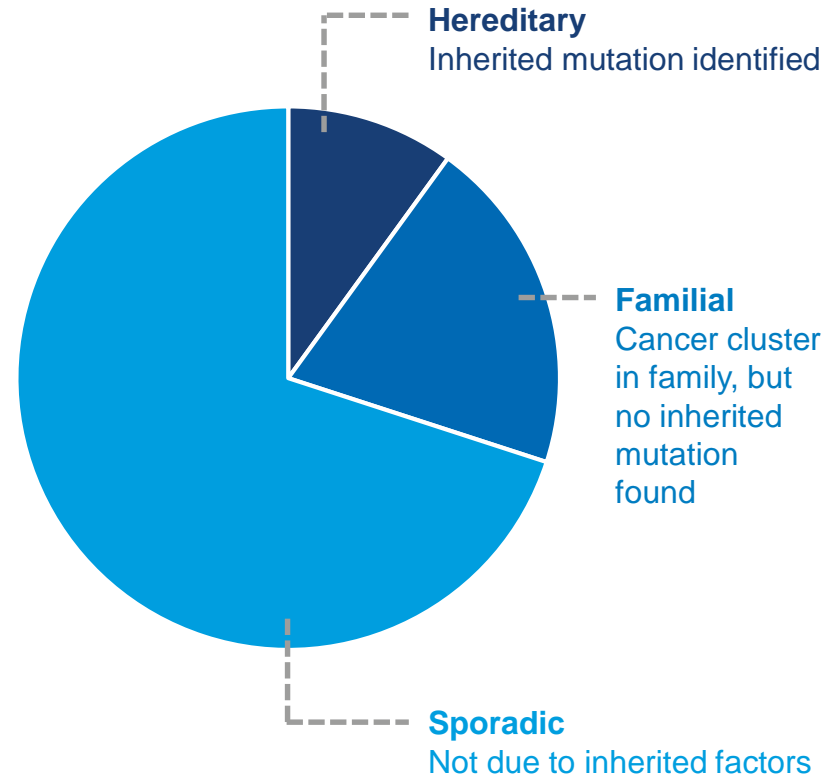
After reviewing the following information, you may choose to either:

1. Proceed with genetic testing
2. Ask for an appointment with a certified genetic counselor to get more detailed information about genetic testing
3. Decline genetic testing and counseling – you can always contact us later if you change your mind

Background

Most cancer occurs by chance, not due to any known cause. Less commonly (10-15% of the time), cancer in a family is related to a genetic mutation (mistake) that can be inherited and passed on in a family.

Not everyone who inherits a genetic mutation will develop cancer, but people who do inherit a genetic mutation related to cancer usually have a much higher chance to get cancer than most people.



Inherited Cancer Risk

A cancer gene panel test looks for mutations in multiple genes associated with hereditary cancers.

These genes relate to many different types of cancer, including ovarian, breast, colon, pancreatic, aggressive prostate and many more.

One of the most common causes of hereditary cancer are mutations in the BRCA1/2 genes, which increase the risk for breast, ovarian, pancreatic, prostate cancers, and melanoma.

Benefits of Genetic Testing

This information could provide **helpful information for your medical management**, which may include:

- Specific types of cancer treatments
- Increased screening for other cancers in the future
- Certain medication that may lower risk for future cancers
- Surgery to prevent cancer from developing

This information could also provide **helpful information for your family members**. Your healthcare team will talk to you about how to share this information with your family members, if needed.

Risks of Genetic Testing

You might learn **unexpected information** from these genetic testing results, including potential cancer risks for you or your family members.

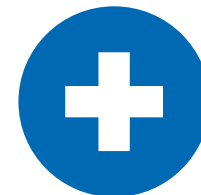
Sometimes learning this information causes **anxiety, distress or depression**.

Some family members, who have not already had genetic testing, may have questions about **genetic discrimination**. There are national and state laws that prevent genetic discrimination by employers and health insurers, based on this type of genetic test result.

People who do not have a cancer diagnosis should be aware there are no clear protections in life insurance, long-term care or disability insurance. This topic can be discussed in more detail if a mutation is found in your family and genetic testing is recommended for people who do not have cancer.

Test Results – Positive

A positive genetic test result means that a gene, which is normally protective, is not working the way it should. We refer to this type of result as a mutation. This leads to an increased risk for certain types of cancer.



What does this mean for you?

Your oncologist will discuss if any treatment options are more effective based on your genetic results.

A certified cancer genetic counselor will discuss with you:

- Cancer risks related to your genetic test result
- Options available for cancer screening and prevention

You may also be referred to a physician with an expertise in cancer genetics.

Test Results – Positive (cont.)

What does this mean for your family?

If your results are positive, your family members may also have the same mutation. The most common gene mutations may be passed from both mothers and fathers to sons and daughters.

A certified cancer genetic counselor will discuss with you:

- Who else in the family should consider genetic testing
- Cancer risks for family members
- Options available for cancer screening and prevention for family members

Family members who live nearby can be seen through our program. We can also work to find cancer genetics experts where other family members live.

Test Results – Negative

A negative (normal) result means that no mutations were seen in the genes analyzed with this testing. Possible explanations for negative results include:



- You may have a mutation in a gene that was not analyzed
- You may have a mutation that was not detected with current technology
- Your cancer may be sporadic, even if you have cancer in your family

What does this mean for you?

Your medical care should be based on your personal health history and family history of cancer.

What does this mean for your family?

We would not recommend this testing for your children based on your cancer history. However, this testing may still be appropriate for other family members, depending on the family history.

Test Results – Variant of Uncertain Significance (VUS)

A VUS result means the lab found a genetic change in one (or more) of the genes analyzed, but this change may be a normal genetic difference between people and not necessarily a mistake related to cancer risk.



Most VUS are benign (not cancer-causing). If the lab learns more about your particular VUS, we will make every effort to follow up with you. However, we also encourage you and your healthcare team to check in with us on an annual basis to review the status of this VUS.

What does this mean for you?

A VUS result will not change your medical care. Your medical care should be based on your personal health history and family history of cancer.

What does this mean for your family?

We would not recommend this testing for your children based on your cancer history. However, this testing may still be appropriate for other family members, depending on the family history.

Insurance Coverage and Financial Responsibility

Cancer genetic testing will be billed to your insurance.

It is usually covered by private insurance and Medicare. However there may still be a cost to you, such as a co-pay or deductible.

The lab will provide a courtesy check of your insurance coverage. They will notify you (typically by a text message) if your out-of-pocket cost is estimated to be more than \$100. They will then offer a link to set up a patient portal to review all your financial options related to the cost of genetic testing.

MassHealth patients have access to testing through laboratory based coverage programs for no out of pocket cost.

Your genetic test is headed to Invitae.

Please make sure your provider has your email address and mobile phone number.

How billing works:

1. Invitae will work with your insurance company to determine your estimated out-of-pocket cost.
2. Most patients pay \$100 or less out-of-pocket. If your cost will be higher, you will receive an email and/or text from Invitae in the next few days. Click on the link to view your estimated out-of-pocket cost and choose how you want to pay:
 - Continue with insurance billing
 - Switch to patient-pay billing (see reverse side for pricing)
3. If you don't make a selection within the timeframe outlined in the email/text notification, Invitae will automatically bill your insurance.

Have questions?

Visit www.invitae.com/patient-billing for answers to commonly asked questions, including:

- I received an explanation of benefits from my insurance company. Is this a bill?
- What should I do if I receive a check from my insurance company?
- Do I qualify for Invitae's financial assistance program?
- What payment options are available?

Prefer to talk to a person?

Call Invitae Client Services at **800-436-3037** or email billing@invitae.com.

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Next Steps



Option 1 – Proceed with genetic testing

Please discuss this testing with your oncologist.

You can choose to have your blood drawn on the day of your visit. Your doctor will call you with your results in 2-3 weeks.

If your results are positive, we will schedule a follow up appointment with our Cancer Genetics and Prevention Program.

Option 2 – Ask for an appointment with a certified genetic counselor

We are currently offering telehealth genetic counseling visits.

Option 3 – Decline genetic testing and counseling

You can always contact us later if you change your mind.

Stay in touch!

Please update your healthcare team every year with any changes to your personal or family history. There also may be updated genetic testing in the future.

Cancer Genetics and Prevention Program

(617) 667-1905