University Hospitals
Seidman Cancer Center

What You Need to Know About Genetic Testing for Cancer Risk

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This booklet is about:

- Genetic testing for cancer risks that run in a family
- What happens during a visit with a genetic counselor
- How genetic testing may help you, your family and your doctors

Genetic Testing for Cancer Risk

Most cancers happen by chance, meaning the cause is unknown. These are known as "sporadic" cancers. Some families have more cancer than would be expected by chance alone. These cancers may happen because of shared lifestyle habits, such as smoking. For other families, these cancers may happen because of shared genes. Still other families have cancer due to both shared environment and shared genes.

Genes tell our bodies how to work. Many of our genes help keep cancers from growing. When there is a change in a gene, it may not work the way it should to prevent cancer. These gene changes are called mutations.

We get half of our genes from our mother, and half of our genes from our father. Hereditary cancer happens when a gene that is not working the way it should is passed down from a parent. Having a gene change causes a higher risk for cancer. It doesn't mean that a person has cancer or will get cancer.

Genetic testing looks for gene changes that can cause hereditary cancers in families. Genetic testing can help determine a person's chances for getting cancer, but it cannot tell if someone has cancer.

Cancer may run in a family when:

- One or more family members have cancer before age 50
- Two or more family members have the same kind of cancer
- A family member has more than one type of cancer
- Family members have types of cancer that can happen together, such as breast and ovarian or colon and uterine cancer
- A family member has a rare cancer, such as a man with breast cancer

What are some reasons to meet with our cancer genetics team?

If you have cancer. Genetic testing may help decide the best treatment plan for you. Testing may also help find out if you have a higher chance of getting a second cancer. You may also want to know if your family members are at risk for cancer.

If a family member has cancer. You may want to learn if you have a higher risk for cancer. Evaluation and testing can help find out your risk and how to prevent cancer or find cancer early.

Our cancer genetics team will talk to you about genetic testing for you and your family. It's up to you to decide if testing is right for you. We work with people who:

- Have cancer now
- Have had cancer in the past
- Do not have cancer but have one or more family members with cancer

What happens at a cancer genetics visit?

At your first visit, you will meet a genetic counselor and/or a genetics doctor. They will talk with you about:

- Your personal and family history of cancer
- If cancers in your family appear to be hereditary (follow a pattern of being passed down)
- Ways to lower your and/or your family members' chances of getting cancer
- If and how genetic testing might help you and your family

Genetic testing may not be right for each family. Even if testing is offered, you may choose not to have it done. The choice is yours. If you do decide to have genetic testing, a blood sample will be taken. Sometimes tumor tissue from a past surgery is also tested. Results will be ready in about four weeks. You will return for a follow-up visit to talk about your test results.

What happens at a cancer genetics follow-up visit?

Your genetics team will:

- Tell you your test results
- Discuss the risk of cancer for you and your family
- Tell you how you can lower your chance of getting cancer and/or find cancer early
- Discuss if other family members should be tested

Your genetic information will be part of your medical record. All medical records are protected by federal privacy laws. Talk with your genetics team if you have any questions.

Does health insurance cover the cost of genetic testing?

Most health insurance covers this testing but not all plans are the same. Your genetic counselor will help you find out how much your insurance will cover and how much you may need to pay.

What hereditary cancers can be tested for?

Genetic testing can be done for:

- Breast cancers
- Ovarian cancers
- Uterine cancers
- Colorectal cancers
- Certain rare cancers

What should I know about hereditary breast and ovarian cancer?

Some women have a type of breast or ovarian cancer that is passed down through the family. Changes found in the BRCA1 and BRCA2 genes are the most common cause of hereditary breast and ovarian cancer. Other less common types of gene changes can also cause breast or ovarian cancer to run in the family.

Gene changes can be passed down from your father's family or from your mother's family. If a gene change is passed down through your male family members, there may not be a lot of breast or ovarian cancers in your family. That's why your genetic counselor looks at the cancer history on both sides of your family.

You should think about having genetic testing if:

- Women in your family have had breast cancer before age 50
- Women in your family have had ovarian cancer
- Men in your family have had breast cancer
- Two or more people on the same side of the family have had breast and/or ovarian cancer
- Your family is of Icelandic or Ashkenazi (Eastern European) Jewish ancestry and members have had breast or ovarian cancer
- Members of your family have had genetic testing that shows a higher risk for breast and ovarian cancer

What should I know about hereditary colorectal cancer?

Gene changes can be passed down from your father's or your mother's family.

You should think about having genetic testing if:

- You or a family member have had colorectal, uterine or ovarian cancer before age 50
- You or a family member have had a colon polyp before age 50
- Two or more people on the same side of the family have had:
  - Colorectal cancer
  - Uterine cancer
  - Ovarian cancer
  - Colon polyps
- You or a member of your family have had 10 or more colon polyps
- Members of your family have had genetic testing that shows a higher risk for colorectal cancer

What other cancers or tumors can be passed down through the family?

Some cancers and tumors that may be caused by changes in a person's genes are:

- Melanoma (skin)
- Gastric (stomach)
- Neurofibroma (nerve)
- Retinoblastoma (eye)
- Medullary thyroid cancer
- Pancreatic cancer
- Pheochromocytoma (adrenal gland)
- Leukemia (blood)
- Renal cancer or Wilms tumor (kidney)

How can I learn more?

You can meet with a genetic counselor at many University Hospitals locations.

To schedule a visit or ask questions, call the **Center for Human Genetics** at **216-844-3936**.

To give feedback about this booklet, call the UH Seidman Cancer Center Information Service at 216-844-5432 or 1-800-641-2422.

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