Hereditary Cancer Risk

Who should be tested first?

You are asking about genetic testing to learn if you have a high cancer risk. You may be surprised when testing is recommended for someone else in your family first. Here's why that might happen.

Genetic testing does not always find a mutation.

Genetic testing can find many genetic changes (mutations) that cause a high risk of cancer. However, testing does not always find a mutation, even with a history of cancer in the family.

- Some mutations are not detected by standard genetic testing.
- Some families have cancers that are not caused by mutations in a cancer risk gene.
- Some people do not inherit the mutation that runs in their family.

Genetic testing is more likely to find a mutation in someone who has had cancer

We recommend starting with a person who has had cancer

The best way to **start** genetic testing is to test someone in your family who had cancer. If there is a cancer gene mutation in your family, then it is more likely to be found in a person who has had cancer. However, testing could be done on a close relative if there is no one with cancer available to test. A genetic specialist can help identify the person most likely to have a genetic mutation in your family.

Genetic testing can help a person who has already had cancer

Testing a person with cancer helps determine if a cancer risk gene is not working correctly. If a mutation is found, then it can explain how cancer runs in the family. It can also help predict that person's risk for other types of cancer or a second cancer of the same type. The test result may help guide medical care for their cancer. The doctor may also recommend ways to lower the chance of getting another cancer or find a future cancer at an early stage.

Test results are more meaningful when a family mutation is known

Genetic testing does not always give clear answers. Testing someone with cancer helps find out whether or not genetic testing will be useful for other family members. When a family mutation is known, testing can better determine the cancer risk for someone who has not had cancer.

- **Positive result**: A positive test result means a mutation was found in a cancer risk gene and confirms a hereditary cancer risk. A person who has had cancer is usually the most likely one in the family to get a positive result. When a mutation is found in a cancer risk gene, other family members (with or without cancer) can be tested for the same mutation.
- **Negative result**: A negative test result means that no mutation was found. Negative results do not always give a complete answer about cancer risk. A negative result in a person who has had cancer can happen for two reasons:
    - The genetic test cannot detect the family's specific mutation

      OR
    - The cancer is not caused by a cancer risk gene

  A negative result does not help explain why the cancer happened. It also means that testing family members *without* cancer will not help determine their cancer risk.

  When a family mutation is known, a negative result means that person did not inherit the mutation and is not at high risk for cancer.
- **Variant of Uncertain Significance (VUS) result**: A "VUS" result means that a genetic change was found but it is not clear if it causes a risk for cancer. Many genetic changes are harmless. This result means that testing family members *without* cancer will not help determine their cancer risk.

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