

Information for Parents and Patients

HEREDITARY CANCER RISK ASSESSMENT CLINIC



Can risks for cancer be inherited?

Approximately one in every two men and one in every three women will develop some type of cancer in their lifetime; one in 300 during their childhood. About one in 10 people (including children) who develop cancer have had the diagnosis because of an inherited risk factor. In these cases, a person has a change in their genetic material that is either new in the individual or inherited from a parent. This change, or mutation, increases their chances of developing certain types of cancer and is found in small pieces of genetic material called genes.

How do I know if the cancer in my family is hereditary?

Your doctor or genetic counselor can help you determine if your family history suggests that you may have a hereditary risk for cancer. In general, the following situations increase the chances that an inherited form of cancer may exist in your family:

- Multiple family members diagnosed with cancer
- Cancer in multiple generations
- More than one cancer diagnosed in an individual
- Cancer in an individual who also has two or more congenital anomalies such as:
 - Birth defects
 - Abnormal growth and/or development
 - Other major medical issues unrelated to the cancer
- Rare or certain types of cancer, such as:
 - Adrenocortical carcinoma
 - Atypical teratoid and malignant rhabdoid tumors
 - Choroid plexus carcinoma
 - Endolymphatic sac tumors
 - Hemangioblastomas
 - Hepatoblastoma
 - Juvenile myelomonocytic leukemia
 - Malignant peripheral nerve sheath tumors
 - Optic pathway tumors
 - Paragangliomas
 - Pheochromocytoma
 - Renal cell carcinoma
 - Retinoblastoma
 - Thyroid cancer, especially medullary
 - Vestibular schwannomas



Contact Us

If you are concerned about your family history of cancer or would like more information about genetic counseling, please ask your CCBD medical care team or primary care provider about making a referral for genetic counseling and/or contact Kami Wolfe Schneider, MS, CGC directly at 720-777-2627.

What should I do if I think there is hereditary cancer in my family?

With a genetics consultation through the Center for Cancer and Blood Disorders (CCBD), you can investigate the possibility of hereditary cancer in your family. By talking with a genetic counselor, you will learn how cancer can be inherited and what steps can be taken to prevent and detect cancer as early as possible.

What can I expect from genetic counseling?

Genetic counseling is a confidential face-to-face communication process between you and your genetic counselor. Your genetic counselor will work with your physicians to make recommendations for you and your family regarding your medical care based on your evaluation. Genetic counseling may include:

- Discussion of cancer and how it develops
- Collection of information about your family history of cancer
- Individualized cancer risk assessment
- Recommendations for cancer screening and lifestyle changes for detecting and preventing cancer
- Options for genetic testing based on your history
- Exploration of the implications, risks and benefits of options in your situation
- Information about research studies relating to hereditary cancer

What is genetic testing and how is it done?

Genetic testing typically requires a blood draw or a sample of tumor tissue and analyzes specific genes to determine if there are gene mutations associated with hereditary cancer. Whenever possible, it is best to begin genetic testing with a person in the family who has had cancer. If a gene mutation is found in one family member, then genetic testing can be made available to other relatives to determine if they have inherited the same gene change.

Genetic testing may help you and your family to more accurately plan healthcare strategies. It may provide some peace of mind, discovering that your chances of developing cancer are not as great as you believed. Genetic testing can also determine if you have an increased chance of developing certain types of cancer and allow you and your relatives to take more proactive steps to detect cancer earlier or to prevent cancer.

What are my options if genetic testing shows that I have a gene mutation?

If a gene mutation is found, this means you have a hereditary risk to develop cancer. Although no form of cancer screening or prevention is perfect, options may include increased cancer surveillance (such as beginning mammograms or colonoscopies at earlier ages or having ultrasounds or MRIs performed), taking certain medications that can reduce the chances of developing cancer, and/or having surgery to remove at-risk tissue before cancer develops.

If a gene mutation is found, what should my relatives do?

Your genetic counselor and your physician will help determine which of your relatives are also at risk to have a gene mutation. You would be strongly encouraged to inform your relatives of your test results if a mutation were detected so that they can have the option of talking to their physicians about genetic counseling, genetic testing and appropriate cancer screening.

What if genetic testing does not find a gene mutation?

If you are the first person in a family to have genetic testing, then this test result has several possible meanings. Your genetic counselor will explain all of the potential reasons that genetic testing did not find a gene mutation. If you have a relative with a known gene mutation and your test results show that you do not have the gene change previously found in your family, then your chances of developing cancer are probably no higher than anyone else's in the general population.

What else should I consider before making a decision about genetic testing?

There are many things to consider when deciding whether or not to have genetic testing including:

- Would the knowledge and information gained from genetic testing help you to make healthcare decisions?
- If you knew you had an inherited risk for cancer, would you feel comfortable continuing your current cancer detection program?
- How would you feel if you learned that you had a hereditary risk for cancer?
- When is an appropriate time for your minor child to be tested for a hereditary risk for cancer?

Your genetic counselor is trained to help you explore your feelings and opinions about genetic testing. The results of genetic testing affect the whole family, not just the individual being tested. It is unlikely that genetic test results will affect an individual's ability to obtain or keep health insurance. Your genetic counselor will review with you the laws in place protecting genetic health information.

About the genetic counseling services:

Children's Hospital Colorado established the first genetic counseling program for the evaluation of hereditary cancers in children in Colorado. The clinic's genetic counselor, Kami Wolfe Schneider, MS, CGC, obtained a master's degree in medical genetics and psychosocial counseling training from a training program accredited by the American Board of Genetic Counselors (ABGC), achieved board certification from the ABGC, and is actively involved as a member of the National Society of Genetic Counselors.