



Children's Hospital Colorado
Center for Cancer and Blood Disorders

CANCER PREDISPOSITION CLINIC



Can risks for cancer be inherited?

Approximately one in two men and one in three women will develop some type of cancer in their lifetime; one in 300 during their childhood. At least one in 10 people who develop cancer have an inherited risk factor. In these cases, a person has a mutation, or small change, in their genetic material. Whether new or inherited from a parent, this mutation increases their chances of developing certain types of cancer.

Is the cancer in my family hereditary?

Your doctor or genetic counselor can help you determine if your family history suggests a hereditary risk for cancer. In general, your risk of having an inherited form of cancer is highest in the following situations:

- Multiple family members diagnosed with cancer or tumors
- Cancer or tumors in multiple generations
- More than one cancer or tumor diagnosed in an individual
- Cancer or tumor in an individual who also has two or more congenital anomalies, such as birth defects, abnormal growth or development, or other major medical issues
- Rare or certain types of cancer or tumors, such as:
 - Adrenocortical carcinoma
 - Atypical teratoid and malignant rhabdoid tumor
 - Cardiac myxoma
 - Choroid plexus carcinoma
 - Endolymphatic sac tumor
 - Hemangioblastoma
 - Hepatoblastoma
 - Hypodiploid leukemia
 - Juvenile myelomonocytic leukemia
 - Malignant peripheral nerve sheath tumor
 - Optic pathway tumor
 - Paraganglioma
 - Pheochromocytoma
 - Renal cell carcinoma
 - Retinoblastoma
 - Rhabdomyosarcoma, especially if anaplastic or before age 6
 - Sonic hedgehog medulloblastoma
 - Thyroid cancer, especially medullary
 - Vestibular schwannoma

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

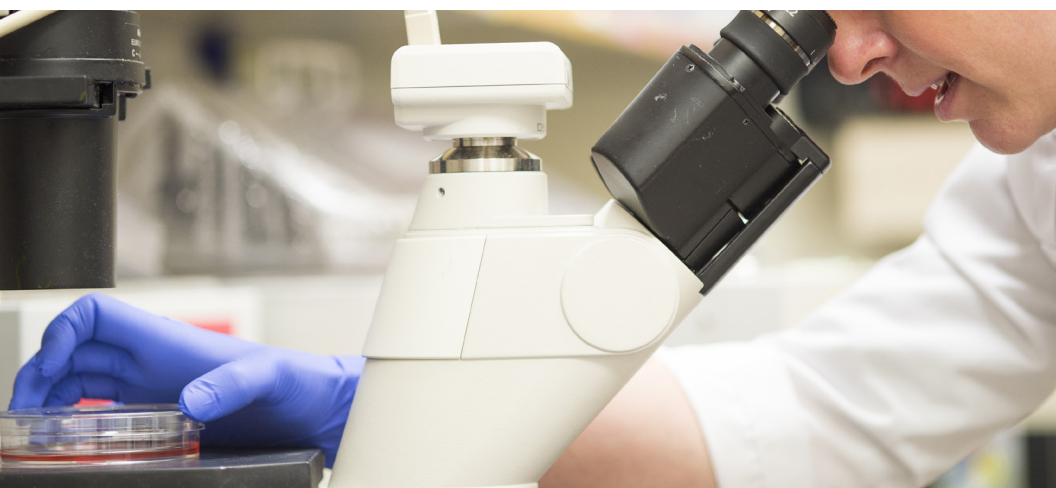
You can investigate the possibility of hereditary cancer in your family with a genetics consultation through the Center for Cancer and Blood Disorders (CCBD). Talking with a genetic counselor can help you learn about inherited cancer and what steps you can take to prevent cancer and/or detect it as early as possible.



What can I expect from genetic counseling?

Your genetic counselor will work with your doctors to make recommendations for you and your family based on your evaluation. This confidential, face-to-face personalized process 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
- Discussion of genetic testing options and exploration of the implications, benefits, and risks of those options
- Information about research studies relating to hereditary cancer specific to you and your family



What is genetic testing and how is it done?

Genetic testing looks at specific genes for mutations or changes associated with hereditary cancer, typically using a blood draw. Your genetic counselor will help you and your physician choose an appropriate genetic test based on the information discussed at your appointment. Whenever possible, it's best to begin testing with a person in the family who has had cancer. If a gene mutation is found in one family member, other relatives can undergo genetic testing to see if they have inherited the same mutation.

Genetic testing and counseling may help you and your family to plan your healthcare approach. It may offer some peace of mind to discover your chances of developing cancer are not as great as they had seemed. It can also determine if you have an increased risk of developing certain types of cancer, allowing you and your relatives to take more proactive steps toward earlier detection or prevention.

What if genetic testing finds I have a gene mutation?

If genetic testing finds a gene mutation, it means you have a hereditary risk to develop cancer. No form of cancer screening or prevention is perfect, but options may include increased cancer surveillance (such as ultrasounds or MRIs, or mammograms or colonoscopies beginning at an earlier age). Other options may include taking medications that can reduce the chances of developing cancer, and/or surgery to remove at-risk tissue before cancer develops.

What should my relatives do?

Your genetic counselor and physician will help determine which of your relatives have an increased risk for having a gene mutation. We would strongly encourage you to inform relatives of your test results if a mutation were detected so that they can talk to their physicians about genetic counseling, genetic testing, and appropriate cancer screenings.

What if genetic testing does not find a gene mutation?

If you are the first person in the family to have genetic testing, then this test result has several possible meanings. Your genetic counselor will explain all the potential reasons your test 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 mutation previously found in your family, then your chances of developing cancer are probably no higher than anyone else's.

What else should I consider?

Genetic testing impacts the whole family. Your genetic counselor is trained to help you explore your feelings and opinions about genetic testing and the potential results. It is unlikely that that genetic test results would impact an individual's ability to obtain or keep health insurance, but your genetic counselor will help you understand the laws in place protecting genetic health information. Additionally, you may want to consider the following with the help of your genetic counselor:

- Would the knowledge and information gained from genetic testing help you 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 child to be tested for hereditary cancer risk?

What if I have already had genetic counseling?

Follow up contact with a genetic counselor is important, especially in the context of childhood cancer. Cancer genetics is a rapidly changing area of medicine which consistently produces new understanding about diagnosis, management and recurrence risk. Additionally, family medical history information may change over time, and different information learned from genetic counseling is relevant at different stages of a child's development. It is important that you periodically seek updated genetic information, especially before any reproductive decisions are made or if any new diagnoses of cancers or tumors occur in the family.

The CCBD genetic counseling program recommends at least annual contact with a genetic counselor.

ABOUT GENETIC COUNSELING

Children's Colorado established the first genetic counseling program in Colorado specifically for the evaluation of hereditary cancers in children. The clinic's genetic counselors obtained master's degrees from training programs accredited by the American Board of Genetic Counselors (ABGC)/Accreditation Council for Genetic Counseling (ACGC), are actively involved as members of the National Society of Genetic Counselors, and are ABGC board certified.



**CENTER FOR CANCER
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CONTACT US

If you are concerned about your family history of cancer or would like more information about genetic counseling, ask your CCBD medical care team or primary care provider about making a referral for genetic counseling. You can also contact one of the genetic counselors directly: Kami Wolfe Schneider, MS, CGC at 720-777-2627 or Alexandra Suttman, MS, CGC at 720-777-2265 or visit us online at childrenscolorado.org/geneticcounseling.

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If you need these services, contact the Medical Interpreters Department at 720.777.9800.

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You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 1-800-368-1019, 800-537-7697 (TDD) Complaint forms are available at www.hhs.gov/ocr/office/file/index.html.

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ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-720-777-9800.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-720-777-9800.

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注意: 如果您使用繁體中文, 您可以免費獲得語言援助服務。請致電1-720-777-9800。

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-720-777-9800.

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رقم 720-777-9800-1 ملحوظة: إذا كنت تتحدث لغة أخرى، فإن خدمات المساعدة اللغوية متوفرة لك بالمجان. اتصل برقم 720-777-9800.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-720-777-9800.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-720-777-9800.

ध्यान दें: होसल्लासने नेपाली बोलचालमा भने सहायता निशुल्क मात्रा सहजता सवाहू न-अल्क रूमा उपलब्ध छ । फोन गर्नु हेरनु 1-720-777-9800 ।

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-720-777-9800.

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Ni: O buri na asu lbo, asuy aka oasu n'efu, defu, aka. Call 1-720-777-9800.