

FACT SHEET

Hereditary Colon Cancer

What do we know about heredity and colon cancer?

Colon cancer, a malignant tumor of the large intestine, affects both men and women. It affects 2-6% of all men and women in their lifetime. The vast majority of colon cancer cases are not hereditary. However, approximately 5 percent of individuals with colon cancer have a hereditary form. In those families, the chance of developing colon cancer is significantly higher than in the average person. Identifying those individuals and families that might be at-risk for hereditary colon and associated cancers can dramatically reduce the number of cancer diagnoses in these families.

Scientists have discovered several genes contributing to a susceptibility to two types of colon cancer:

- **FAP (familial adenomatous polyposis)**
Individuals with this syndrome develop many polyps in their colon (often over 100). People who inherit mutations in this gene have a nearly 100 percent chance of developing colon cancer by age 40.
 - If a patient has more than 10 adenomatous polyps in their lifetime a cancer risk assessment is appropriate.

- **HNPCC (hereditary nonpolyposis colorectal cancer)**
Individuals with an HNPCC gene mutation have an estimated 80 percent lifetime risk of developing colon or rectal cancer. There is also a 40-60 percent chance for endometrial cancer. Other cancer risks are increased as well. Patients with the following characteristics should be referred for a cancer risk assessment.
 - Patient diagnosed with colon cancer younger than age 50 years
 - Patient has multiple colon cancers or more than one HNPCC related cancer*
 - Patient has colon cancer and one relative with an HNPCC related tumor* under age 50 years.
 - Patient has colon cancer and two or more first or second degree (parents, siblings, aunts, uncles, grandparents) relatives with HNPCC related* cancers at any age.

*colon, endometrial, ovarian, stomach, small bowel, biliary tract or transitional cell of the renal pelvis

Is there a test for hereditary colon cancer?

Gene testing can identify some individuals who carry genes for FAP and some HNPCC cases of colon cancer. However, the tests are not perfect at this point in time. So, some families may have alterations in the FAP or HNPCC gene that can not be detected.

What Recommendations might be given to a patient with FAP or HNPCC in the family?

FAP is a childhood onset condition. **Screening for polyps begins between ages 10-12 years.** Some physicians even recommend screening for a liver cancer starting at birth. Therefore genetic risk assessment is usually done in childhood. This might differ in HNPCC. **Patients with HNPCC or strongly suspected HNPCC need to have colonoscopy exams starting at age 20-25 years and this needs to be repeated every 1-2 years.** Also, screening for endometrial cancer is recommended and includes transvaginal ultrasound and endometrial biopsy. This is usually begun between the ages of 25-35 and repeated every year. Some patients pursue surgery to reduce their cancer risks. Careful screening in HNPCC families has been shown to reduce the cancer diagnoses by over 50%. These cancers usually start young so screening must start before age 50 years. Although some of these options may reduce the risk for developing colon cancer, no option totally eliminates this risk.

Cancer Risk Assessment in Ohio

Akron

- Hereditary Cancer Program at the Genetics Center at Akron Children's Hospital: 330-543-8792

Dayton

- Regional Genetics Center at Children's Medical Center: 937-641-3800

Canton

- Hereditary Cancer Program, Aultman Hospital: 330-363-4163

Cincinnati

- Cincinnati Children's Hospital Medical Center, Hereditary Cancer Program: 513-636-4760

Cleveland

- Center for Personalized Genetic Healthcare, Cleveland Clinic: 216-445-5686
- Hillcrest Hospital Cancer Program: 440-312-5634
- MetroHealth Medical Center, Hereditary Cancer Clinic: 216-778-4323
- University Hospital Center for Human Genetics, Cancer Genetics Clinic: 216-844-3936

Columbus

- Mount Carmel Cancer Risk Program: 614-546-4330
- OhioHealth Cancer Genetics Program: 614-566-4321 or 1-800-752-9119
- Clinical Cancer Genetics Program, The Ohio State University James Cancer Hospital & Solove Research Institute: 614-293-6694

Dayton

- Children's Medical Center, Regional Genetics Center: 937-641-3800

Gallipolis

- Holzer Cancer Program: 740-446-5474

Toledo

- MUO Cancer Institute, Hereditary Cancer Program: 419-383-3727

Youngstown

- The Genetics Center, Forum Health: 330-884-3106

Additional Information Available at: NCI Genetics of Colon Cancer PDQ

<http://www.cancer.gov/cancertopics/pdq/genetics/colorectal/healthprofessional>