UT Southwestern
Harold C. Simmons
Comprehensive Cancer Center

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A Comprehensive Cancer Center Designated by the National Cancer Institute

What you should know about Lynch Syndrome (also called Hereditary Non-polyposis Colorectal Cancer or HNPCC)

Lynch syndrome is one of the most common causes of inherited colon cancer, and accounts for 3-5% of all colon cancers. Families with Lynch syndrome often have multiple family members with colon, uterine or other cancers, typically diagnosed before age 50. Lynch syndrome is caused by mutations in one of five different genes, and the specific cancer risks and management recommendations depend on the gene.

The risk for cancer associated with HNPCC

Individuals with Lynch syndrome have up to an 80% risk to develop colon cancer. Women with Lynch syndrome have a 40-60% risk for uterine cancer and a 10-12% risk for ovarian cancer. Men and women with Lynch syndrome also have an increased risk for stomach, small intestine, biliary tract, urinary tract, pancreatic and brain cancers.

The risks to family members

Lynch syndrome is inherited in an autosomal dominant fashion, and is caused by mutations in any one of the following genes: MLH1, MSH2, MSH6, PMS2 and EPCAM. Children, brothers, sisters, and parents of an individual with Lynch syndrome have a 50% risk to have a mutation. Individuals with Lynch syndrome may develop one cancer, more than one cancer, or none at all.

Managing the Risk

For colon cancer:

- Colonoscopy every 1-2 years starting as early as 20-25 (dependent on gene and family history)
- Complete removal of the colon if colon cancer is detected
- Nonsteroidal anti-inflammatory drugs (NSAIDs) , high fiber, low fat diet, multivitamins with folic acid, vitamin D, and calcium may reduce the risk for colon cancer
- 30 minutes of physical activity per day is recommended by the American Cancer Society

For uterine/ovarian cancer:

- Annual surveillance via uterine biopsy can be considered
- CA-125 screening and transvaginal ultrasound can be considered (these tests have limited ability for early detection of ovarian cancer)
- Birth control pills reduce the risk for ovarian cancer
- Removal of ovaries and uterus after child-bearing is complete is an option to reduce the risk

For other cancers:

- Annual physical examination. Annual urinalysis beginning at age 25-30
- Upper endoscopy every 3-5 years, beginning at age 30-35 can be considered (depending on family history and race)
- Dermatological exams every 6 months-1 year for families with a variant of HNPCC known as Muir Torre syndrome

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