

Lynch Syndrome (Hereditary Nonpolyposis Colorectal Cancer or HNPCC) Information for Consumers

What is Lynch syndrome?

Lynch syndrome is an inherited genetic condition that significantly raises a person's risk of developing cancer. The cancer is most frequently in the colon, but it could also be in the stomach, small intestine, liver, gallbladder ducts, urinary tract, brain, skin, and prostate. Women have higher risk of endometrial (lining of the uterus) or ovarian cancer.

A person with Lynch syndrome is at greater risk of developing cancer at a younger age, usually before they are 45 years old. If one parent carries the gene mutation related to Lynch syndrome, there's a 50 percent chance the mutation will be passed on to each child that person has.

Not everyone who carries these mutations develops cancer. For people with a family history of cancer, knowing if you or a person in your family has Lynch syndrome is important so the affected individuals take the steps to prevent illness.

What causes Lynch syndrome?

Lynch syndrome is caused by a mutation, or change, in a type of gene that helps repair DNA. Humans have several of these kinds of genes that help repair DNA, and if one of them stops working because of a mutation, this could cause cancer.

When should you see a doctor or genetic counselor about Lynch syndrome?

- You or someone in your family developed colon cancer before 50 years of age
- Your family has a history of endometrial cancer
- You have multiple relatives with tumors of the colon, ovaries, stomach, small intestine, kidney, brain, or liver
- More than one generation of your family is affected by a particular type of cancer

How is a person diagnosed with Lynch syndrome? What kinds of test are done?

Talking to a doctor or genetic counselor about a family health history is the first step. If particular types of cancer are found in your family, and/or family members develop cancer at ages below 45, then testing may be necessary.

A person may undergo several types of tests, depending on whether or not they or another person in their family developed cancer. Genetic testing can be done to confirm if a person has a mutation, but it is not always useful to test everyone in the family for Lynch syndrome. Speaking to a genetic counselor is important to see which tests should be done.

If a Lynch-syndrome mutation is found, what are the risks for developing cancer?

How much your risk is increased depends on which gene is present in your family and whether you undergo cancer screening to reduce your risk of cancer. However, it is estimated that among those with Lynch syndrome, 30 percent to 74 percent develop colorectal cancer; 28 percent to 60 percent of women develop endometrial cancer; 5 percent to 8 percent develop stomach cancer; and 4 percent to 11 percent of women develop ovarian cancer. The risk for other Lynch syndrome-related cancers is lower, though substantially increased over general population rates.

If Lynch syndrome runs in the family, how can cancer be prevented?

The only proven ways to reduce cancer risk is frequent cancer screenings and preventative surgery when appropriate. Screening helps detect cancer in its earliest stages when it is easiest to treat. Depending on the family, screenings should start between ages 20 and 25 or 10 years before the

earliest age of a cancer diagnosis in the family. If you have Lynch syndrome but have not been diagnosed with cancer, your doctor will create a cancer-screening plan appropriate for you.

What are some organizations that provide more information and support for people affected by Lynch syndrome?

CCARE Lynch Syndrome

<http://www.fightlynch.org/>

Colon Cancer Alliance

<http://www.ccalliance.org/>

Fight Colorectal Cancer

<http://fightcolorectalcaner.org/>