Virginia Cancer Specialists

# Lynch Syndrome:
# A Guide for Patients and Their Families

Lynch syndrome (LS) is a genetic condition that increases a person's chance of getting colorectal cancer (cancer of the large bowel or rectum), endometrial cancer (cancer of the lining of the uterus), ovarian cancer, and other cancers. LS runs in families, and a genetic test can help determine if your personal and/or family health history of cancer was caused by LS. If you are found to have LS, there are interventions that can help prevent cancer or detect it early. If you are concerned about your personal or family history of cancer, talk to your doctor.

## CAUSES OF LYNCH SYNDROME

LS is caused by mutations (genetic changes) in one of 5 genes: *MLH1, MSH2, MSH6, PMS2*, and *EPCAM*. About 3 out of every 100 colorectal cancers are caused by LS.

## WHY IT IS IMPORTANT TO KNOW ABOUT LYNCH SYNDROME

If you have LS, you are much more likely to get certain cancers, including:

- Up to an 82% risk (about 8 in 10) for colorectal cancer by age 70
- Up to a 60% lifetime risk (6 in 10) for endometrial cancer in women
- Increased risks for cancers of the stomach, ovary, small bowel, hepatobiliary tract (liver, pancreas, gallbladder), urinary tract (kidney, bladder, ureters), brain, and skin

If you are found to have LS, steps can be taken to reduce your cancer risks associated with LS, including:

- Having earlier, more frequent, and/or additional screening for cancer
- Undergoing preventive surgery

## GENETIC COUNSELING AND TESTING FOR LYNCH SYNDROME

An expert panel* recommends that every person with a new diagnosis of colorectal cancer be offered genetic screening for LS. This screen is done on a sample of the colorectal cancer tissue after surgery. If the screen shows that you might have LS, additional genetic counseling and testing will often be needed to find out if you definitely have LS. Genetic counseling and testing for LS is often, but not always, covered by insurance.

## FOR MORE INFORMATION

First, talk with your doctor or other health care provider. You can also find more information on LS at:

Centers for Disease Control and Prevention. Genetic Testing for Lynch Syndrome
https://www.cdc.gov/genomics/disease/colorectal_cancer/index.htm

Genetics Home Reference. National Library of Medicine
https://ghr.nlm.nih.gov/condition/lynch-syndrome

National Society of Genetic Counselors
Find a Genetic Counselor Directory
https://www.nsgc.org/page/find-a-genetic-counselor

**www.virginiacancerspecialists.com/genetic-testing-counseling/**

**Evaluation of Genomic Applications in Practice and Prevention Work Group*

This factsheet is a modified version of the *Patient Information Sheet for Lynch Syndrome* created in 2012 by the Connecticut Department of Public Health's Genomics Office in partnership with the Connecticut Tumor Registry.

In addition, genetic counseling and testing for LS may be appropriate if you meet any of the following criteria:

- You were diagnosed with colorectal cancer in the past
- You have been diagnosed with endometrial cancer (especially before age 50)
- You have several family members with colorectal or other cancers associated with LS
- You have a family member with a known Lynch syndrome mutation

If you are found to have LS, your blood relatives (parents, siblings, children, grandparents, aunts, uncles, nieces, nephews, and more distantly related family members) might also have LS and should consider genetic counseling and testing for the same mutation that you have.

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