GOPATH®
LABORATORIES
Global Pathology Services

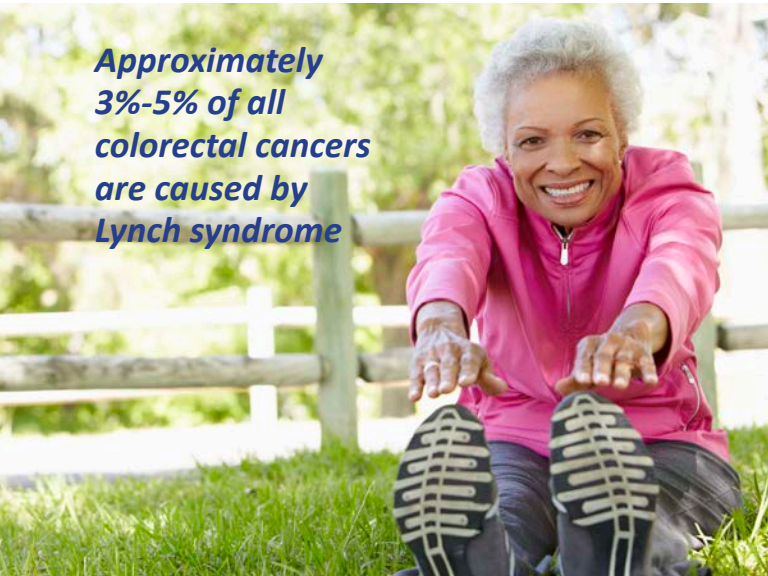
Lynch Syndrome

A Patient's Guide to Genetic Testing for Lynch Syndrome

What is Lynch Syndrome?

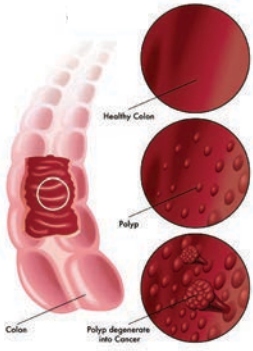
Lynch syndrome is an inherited condition that increases your risk of developing colon cancer and other cancers associated with this syndrome. Lynch syndrome is hereditary, which means it is caused by genetic changes that can be passed from parents to their children. Those with Lynch syndrome are much more likely to develop cancers associated with this syndrome at a younger age (before 50). Also, women with Lynch syndrome are much more likely than the general population to develop endometrial (uterine) cancer.

Lynch syndrome, often called Hereditary Nonpolyposis Colorectal Cancer (HNPCC), affects both men and women. It increases the risk of a number of cancers, particularly cancers of the colon (large intestine) and rectum.

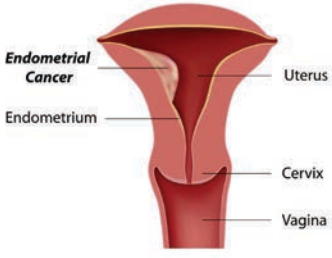


People with Lynch syndrome also have an increased risk of developing cancers of the stomach, small intestine, liver, gallbladder ducts, upper urinary tract, brain, skin and prostate. In female patients, endometrial cancer is particularly linked to Lynch syndrome.

Although Lynch syndrome was not originally linked to the development of colon polyps, people who have the syndrome have been shown to develop noncancerous polyps at an earlier age than the general population. Additionally, while colon polyps do not occur in greater numbers for those with Lynch syndrome than the general population, the polyps are more likely to become cancerous.



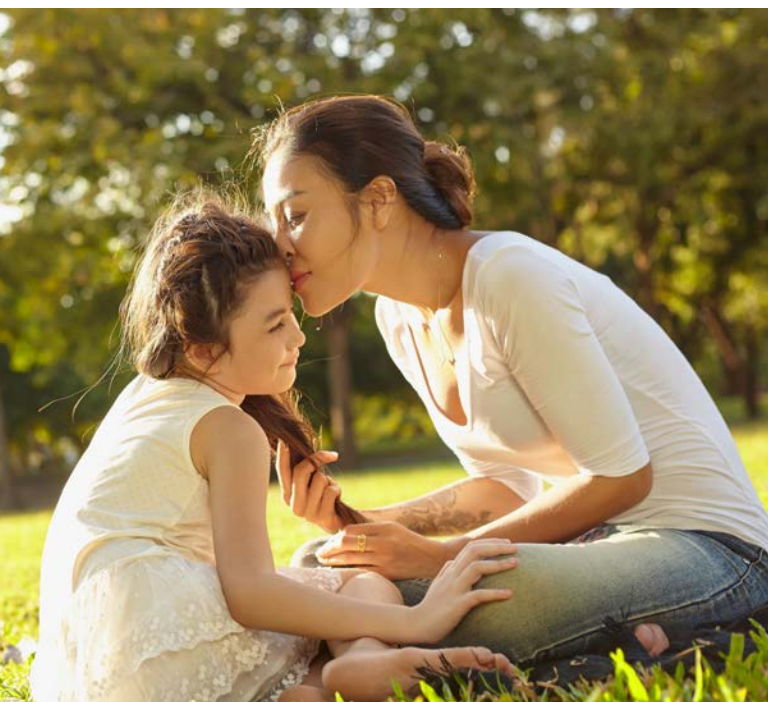
Colon Cancer



Endometrial Cancer

Families who have Lynch syndrome usually have more cases of colon cancer than would typically be expected. Those with Lynch syndrome have a 50%-80% higher than normal chance of developing colorectal cancer during his or her lifetime. Endometrial cancer, ovarian cancer, stomach cancer and other various types of aggressive cancers are also more likely to occur, often at a younger age.

If you are diagnosed with Lynch syndrome, be sure to let your family members know. Your parents, children, sisters, and brothers would have a 50% (1 in 2) chance of having this condition too. Other close relatives are also at increased risk of having Lynch syndrome. If you test negative for Lynch syndrome, that means you do not carry your family's Lynch syndrome genetic mutation. If you do not carry the mutation, you cannot pass on Lynch syndrome to your children.



GoPath Laboratories offers genetic testing to determine if you have a genetic mutation that causes Lynch syndrome. If you are identified as being at an increased risk for Lynch syndrome, genetic testing can help assess your risk for developing cancer.

If the test does find a mutation, there are options you have to reduce your risk of developing cancer.

Your physician and a genetic counselor can help you decide whether or not genetic testing is right for you.

What genetic testing for Lynch syndrome may reveal:

This test can tell you if you have a mutation that causes Lynch syndrome. Although Lynch syndrome indicates a higher risk for cancer, not everyone with the mutation will develop cancer. Therefore, this test will not tell you whether or not you will develop cancer.

Also, this test cannot determine whether or not your family members (parents, siblings, and children) will also have Lynch syndrome. However, it is possible that if you have the mutation, close family members may also have it. It is important to share this information with your family.

Lynch Syndrome:
Increased Cancer Risk

If you are found to have Lynch syndrome, you are at a greater risk for developing cancers associated with this syndrome. This increased risk is due to inherited genetic mutations that interfere with your DNA's ability to repair itself (often referred to as DNA mismatch repair or MMR). That means if something goes wrong with a cell--such as cancer forms--your body might not have the tools it needs to fix the problem.

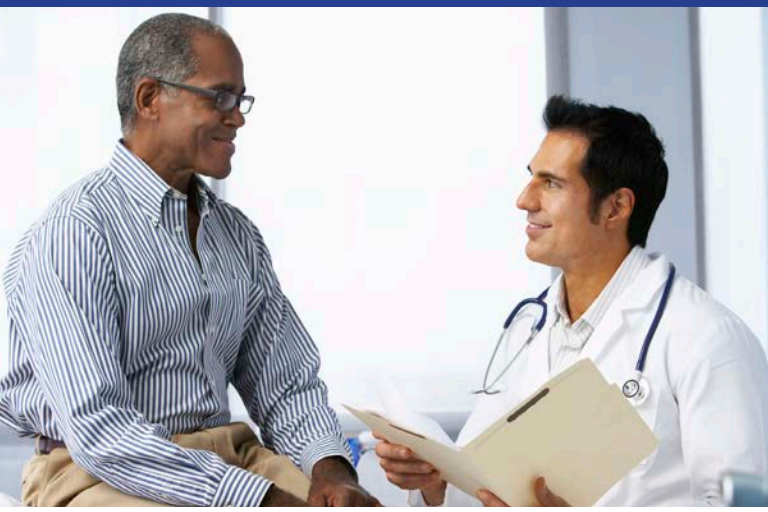
Estimated Cancer Risks and Screening Suggestions Associated with Lynch Syndrome

Cancer Type	Estimated Risk*	Possible Screening Suggestions Based on Family History or Other Risk Factors
Colorectal**	Up to 80%	Colonoscopy every one to two years, starting at ages 20-25
Endometrial	20% to 60%	Endometrial biopsy, annually starting ages 30 to 35
Stomach	11% to 19%	Upper endoscopy every 2 to 4 years starting at ages 30 to 35 years; testing and treatment for H. pylori
Ovarian	9% to 12%	Yearly pelvic examination and ultrasound, endometrial biopsy, starting ages 30 to 35
Hepatobiliary (Liver, bile duct, gallbladder)	2% to 7%	AFP blood test and/or Ultrasound
Urinary Tract	1 to 4%	Possible urinalysis or urine cytology annually starting at ages 30 to 35 years

* Estimates compiled by the American Society of Clinical Oncology (ASCO)
** The estimated lifetime risk of colorectal cancer for those with Lynch syndrome has a wide range, with 80% being the upper limit of that range. Estimates are for those with Lynch syndrome who are not having regular colonoscopy screenings. Regular screenings with colonoscopy significantly reduces this risk.

Screening does not prevent cancer and cannot always find cancers when they are too small to be treated successfully.

Lynch Syndrome Screening:
What to Expect, Step-by-Step

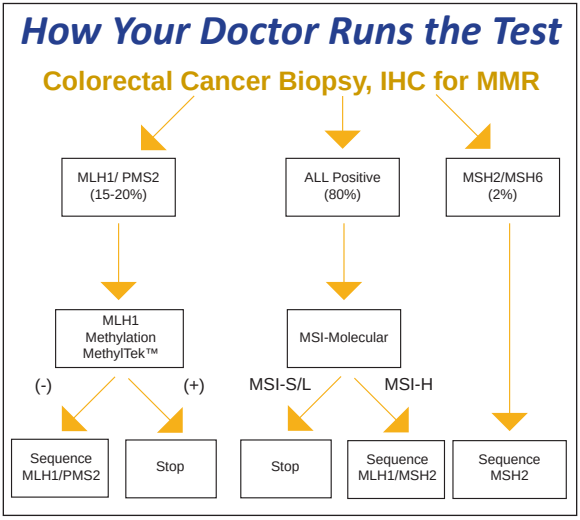


1). Review of your health history
The first step in determining whether or not to proceed with genetic testing is to discuss your family health history with your doctor or a genetic counselor. If your physician or counselor determines that you may be a good fit for testing, your physician can order the test for you. If you need help finding a genetic counselor, please call GoPath Laboratories at **855-GOPATH9** to speak with someone who can help.

2). Consult with your insurance provider
Coverage of Lynch syndrome testing depends on your insurance provider. Your doctor's office may be able to help by contacting your provider for you or by giving you information about your test including testing codes that will help your insurance provider determine whether or not the test is covered. *(GoPath Labortories accepts insurance from most major carriers. If your insurance does not cover genetic testing, contact us for additional payment options.)*

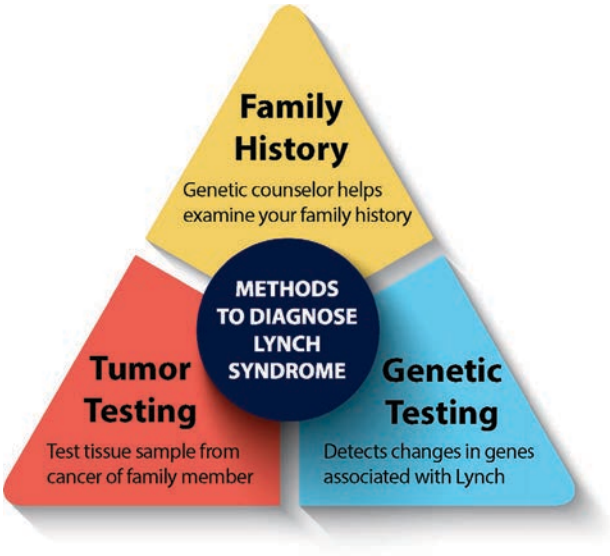
3). Taking the Test

If you and your doctor decide that Lynch syndrome testing would be beneficial for you, and you are comfortable with your insurance and/or payment options, then your doctor will order the test. GoPath has created a series of tests that not only can detect the five basic genetic mutations most commonly associated with Lynch syndrome (called MLH1, MSH2, MSH6, PMS2 and EPCAM), but also can detect other genes identified as being linked to the syndrome. If you have not been diagnosed with cancer, the test can often be done through a simple blood draw. If you have been diagnosed with a Lynch syndrome-related cancer, your physician may take the following steps:



4). Discuss the results with your doctor

We know the testing process can be a stressful one, which is why we strive to provide you with results as quickly as possible, most often within 10-14 days. Once you receive your results, you can discuss them with your doctor and decide what course of action needs to be taken to reduce your risk of developing cancer.



Interpreting the Results:

What do your results mean?

A positive result does not necessarily mean you will develop cancer. A positive result simply means that you carry a mutation that puts you at a higher-than-average risk for developing certain cancers. If you do have a mutation, your doctor will discuss with you what your options are for lowering your risk for developing cancer. Common options may include:

- Increased cancer screenings (such as more frequent colonoscopies or starting them at an earlier age)
- Lifestyle changes (quitting smoking, cutting back on alcohol, etc.)
- Preventive Surgery
- Medications

Test Result Definitions:

Positive

Your test detected a Lynch syndrome mutation. This means you are at an increased risk for developing cancers associated with Lynch Syndrome and at an earlier age. Discuss your options with your healthcare provider on how you can be proactive in reducing your cancer risk.

Negative

Your test did not detect a Lynch syndrome mutation. It's possible that another gene or factor is responsible for the cancer in your family. Your healthcare provider can help you understand what your revised risk is, as well as how to proceed with managing your healthcare such as when and how often to have cancer screenings based on your personal and/or family history of cancer.

Variant of Unknown Significance

Your test results may include a term called "Variant of Unknown Significance" or VUS. This means that we have found a genetic mutation that we do not yet know much about. This alteration may not have been previously reported or may have been reported but we have inadequate or conflicting evidence regarding its impact on gene function. Your healthcare provider can help guide you on how to best manage your healthcare and when to have cancer screenings based on your personal and/or family history of cancer.

Who should consider having genetic testing for Lynch syndrome?

Families with Lynch syndrome often have multiple members who have had cancer. Consider speaking with your physician or genetic counselor if you have experienced any of the following:

- You have had colon or uterine cancer before age 50
- You have a relative who has tested positive for Lynch syndrome
- You have had two or more of the following cancers at any age: colon, uterine, ovarian, or stomach cancer
- You have a family history of colon, uterine, ovarian, or stomach cancers
- You have experienced abnormal tumor test results, either for colorectal or endometrial tumors

Is testing for Lynch syndrome right for you?

To discover whether or not you are a candidate for Lynch syndrome genetic testing, consult both your physician and a genetic counselor.

If you need help finding a counselor, contact GoPath Laboratories at **855.GOPATH9.**

Here are some additional online resources to help you learn more about Lynch syndrome and cancer:

GoPathGenetics.com

Cancer.net

MySupport360.com

ShareCancerSupport.org

OncoLink.org

CCAlliance.org

IHaveLynchSyndrome.org

CancerCare.org

LynchCancers.com

CancerSupportCommunity.org

ColonCancerFoundation.org

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