



Lynch Syndrome

Lynch syndrome is a genetic disease that dramatically increases the risk of cancer, especially colon and uterine cancers. Knowing about Lynch syndrome is important for patients and their family members to prevent future cancers. Our efforts are focused on educating individuals and health care providers about Lynch syndrome. Through education we can increase the awareness of Lynch syndrome, identify affected individuals, and either diagnose cancers at their earliest possible stage. Our efforts can significantly improve the life and longevity of individuals with Lynch syndrome or prevent cancer altogether.

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COLON CANCER ALLIANCE FOR RESEARCH AND EDUCATION FOR LYNCH SYNDROME (CCARE—LS)

Our mission is to educate the public and health care professionals about Lynch syndrome and to help fund research to cure this disease.

CCARE-LS was founded by Drs. Neil and Sharon Perlman in memory of their family members affected with Lynch Syndrome. CCARE-LS is an approved 501(c)(3) non-profit organization.

Donations are always appreciated to help us accomplish this mission. Please visit www.fightlynch.org.



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www.fightlynch.org

LYNCH SYNDROME

COLON CANCER

In both men and women, colorectal cancer is the third most diagnosed cancer in the United States. 150,000 people are diagnosed each year, and for over 50,000 it will be fatal. 25% have a family history of colon cancer and 1 in every 35 have Lynch syndrome. Since Lynch syndrome is an autosomal dominant DNA mutation, there is a 50% chance that brothers, sisters, and children of an affected individual have Lynch syndrome. While the average age of colon cancer is 71, for individuals affected with Lynch syndrome it is only 44. For this reason, screening is more aggressive.

Colonoscopies are recommended to start between the ages of 20-25 and should be repeated every 1-2 years. While colon cancer only affects 5% of the general population, for those affected with Lynch syndrome, the lifetime risk of getting cancer is up to 74% in men and 52% in women.

Less frequently, the lifetime risk of developing other gastrointestinal cancers is increased in Lynch syndrome including: stomach, small intestine, hepatobiliary, and pancreas. Individualized screening procedures should be discussed with your physician.

WOMEN WITH LYNCH SYNDROME

The second most common cancer associated with Lynch syndrome is uterine (endometrial) cancer. Women with Lynch syndrome have up to a 71% lifetime risk of developing this disease, compared to 3% for woman without Lynch. Also, the lifetime risk of ovarian cancer is increased up to 12% for Lynch, compared 2% without Lynch. To prevent problems, it is essential that all women with Lynch syndrome discuss this with their physician. Starting at the age of 20, yearly pelvic examinations with PAP smears are recommended. A screening program may also include pelvic ultrasounds, endometrial biopsies, and CA125 blood tests. Once a woman decides that childbirth is completed, removing the uterus and ovaries should be considered to reduce the risk of cancer.

OTHER CANCERS

Lynch syndrome has also been associated with a slight increased risk of cancers from the brain, kidney, bladder, and a rare skin tumor called sebaceous gland neoplasms.

GENETIC TESTING

Lynch Syndrome is an autosomal dominant inherited DNA mutation of a mismatch repair gene. These genes help repair the DNA if a replication error occurs when new cells are

made. There are 5 genes known to cause Lynch syndrome including MLH1, MSH2, MSH6, PMS2 and EPCAM. Testing for all these genes can cost up to \$5,000. However, a genetic counselor can help focus the testing to keep costs down. Also, once a specific abnormality is identified, testing family members costs between \$200 - \$500.

INSURANCE ISSUES

The Genetic Information Nondiscrimination Act of 2007 (GINA) prohibits insurers from using genetic diseases in determining insurability. However, once a person develops cancer, their rate can go up unrelated to whether they have Lynch syndrome. As of September 2010, the new United States National Health Care Act prevents insurance companies from excluding children with preexisting conditions, including cancer, from their family policy. However this did not occur for adults until January 1, 2014. GINA does not apply to disability, life, or long term care insurance. For this reason, if you are concerned you may have Lynch syndrome, you should obtain the necessary insurance before any testing is started.