

Judy's Story



When I got genetic testing, many people asked, "Why do you want to do that?" I replied, "Why *wouldn't* I want to do that?"

I already had cancer once. Knowing I have Lynch syndrome, the odds are not in my favor that I'll go through life and not get cancer again. For me, it's a matter of when I will get cancer again and trying to catch it early. With Lynch syndrome, I am eligible for more preventive care. The annual colonoscopies that I have are important because in a person with Lynch syndrome the tumors grow much more quickly than in a person without Lynch syndrome.

Lynch Syndrome Cancers

A person who has a Lynch syndrome mutation is at risk to get one or more of these cancers or may not get cancer at all:

- Colorectal
- Uterine (women)
- Ovarian (women)
- Stomach
- Small intestine
- Brain
- Kidney
- Skin

Genetic Information Privacy

A law passed in 2008, the Genetic Information Nondiscrimination Act (GINA), protects people from discrimination by employers and health insurers based on genetic information, including family health history. But not all types of insurance are covered, and there are some exemptions for small employers. The Patient Protection and Affordable Care Act (ACA) offers more protections from discrimination.


For More Information

Lynch Syndrome International
www.lynchcancers.com

Genes in Life
www.genesinlife.org

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Genetic Testing & Cancer Prevention for **Lynch Syndrome**



Family Diagnosis and Lynch Syndrome

Lynch syndrome is the most common hereditary cause of colorectal and endometrial cancer. This means people are born with a gene mutation that places them at increased risk for certain cancers. This mutation can be passed through families: from grandparent to parent to child.

People with Lynch syndrome tend to get diagnosed with cancer at a younger age than the general population, but older people with cancer still might have Lynch syndrome. If multiple cancers are present in your family, you should tell your healthcare provider, regardless of the ages.

Sharing your diagnosis can help you and your family members:

- Identify risks due to shared genes
- Talk to each other about health
- Seek genetic counseling and testing
- Summarize health information to give to healthcare providers
- Catch cancer(s) at the earliest, most treatable stage and even prevent it



HELPFUL HINT



Schedule your annual screenings around your birthday or a holiday. Have a big celebration, then get your screening, and don't worry about it for another year.

Cancer Prevention

People who have a Lynch syndrome mutation have a 50-85 percent risk of getting colorectal cancer in their lifetime. If you have already had colorectal cancer, you have a higher risk of getting it again. But, with your diagnosis of Lynch syndrome, you have options for cancer prevention and early detection. **Regular screening can help find cancers at the earliest possible stage, or even in the precancerous stage.** Yearly colonoscopies are important to remove pre-cancerous polyps. Women with Lynch syndrome should also have yearly pelvic exams to screen for uterine cancer.

Another option is to have surgery to remove at-risk body parts before cancer develops. This is called risk-reducing surgery, and can include colectomy (removal of the colon), hysterectomy (removal of the uterus), and oophorectomy (removal of the ovaries).

Living a healthy lifestyle is also key for Lynch syndrome management. It is important to eat a healthy diet, exercise, and get regular screenings. **With screening, you can stop cancer before it starts.**

Genetic Testing & Working with Your Healthcare Provider

Genetic testing is the best way to diagnose Lynch syndrome. Talk to your doctor about your family health history of cancer. He or she can order genetic testing or refer you to a genetics provider.

Genetic counseling can help you understand genetic testing and your diagnosis. Your genetics provider will:

- Explain the testing process.
- Explain your results.
- Help you understand your family tree to figure out who is at risk and who may need genetic testing in the future.

If you already have cancer, there are tests called tumor screening that are done directly on your tumor. There are two types of tumor screening for Lynch syndrome: microsatellite instability (MSI) testing and immunohistochemistry (IHC) testing. They look for gene changes or proteins that may be linked to Lynch syndrome.

Tumor screening gives clues, but the best way to diagnose Lynch syndrome is to get genetic testing on a blood sample. If a mutation is found in a Lynch syndrome gene, a laboratory can look for the same mutation in other family members to see if they also have Lynch syndrome.

Tumor screening and genetic testing are not the same as screening for polyps with a colonoscopy. If you have Lynch syndrome, you should continue to get regular colonoscopies to prevent and detect cancer.