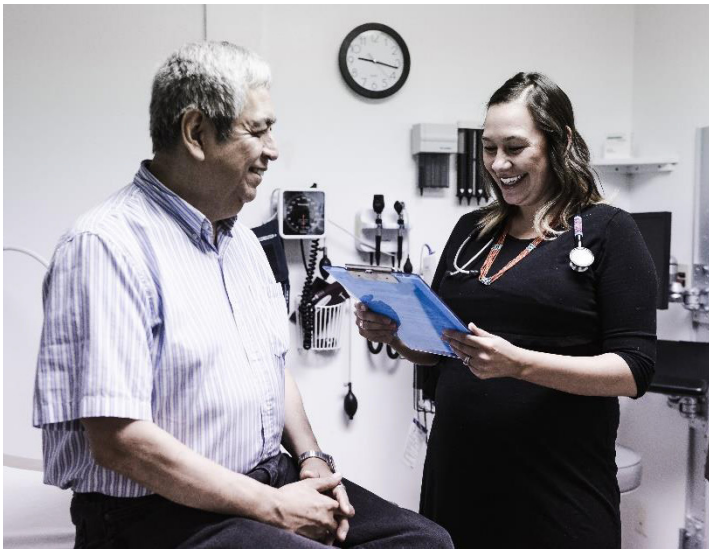
LYNCH SYNDROME | A SURVIVOR'S STORY

Making the decision to be proactive about Lynch Syndrome



What is Lynch Syndrome? (CDC)

- Lynch Syndrome, also known as hereditary nonpolyposis colorectal cancer (HNPCC), is the most common cause of hereditary colon cancer.
- Lynch syndrome is due to inherited mutations in genes that affect DNA mismatch repair, a process that fixes mistakes when DNA is copied.
- These genes normally protect you from getting certain cancers, but some mutations in these genes prevent them from working properly.

Quick Facts About Lynch Syndrome

- Lynch syndrome affects men and women of all races and ethnicities
- People with Lynch syndrome are at a higher risk for many cancers, including colorectal, endometrial/uterine, ovarian, stomach, small intestine, brain, skin, kidney, pancreatic, and bladder cancers.
- If you have a Lynch syndrome gene mutation, each of your children has a 50% chance of inheriting it.
- People with Lynch Syndrome have a risk of getting colorectal cancer in their lifetime and about a 60% risk of getting endometrial cancer.
- About 1 in 35 cases of colorectal and endometrial cancer are caused by Lynch syndrome. These cancers can be prevented and/or caught early, when they are most treatable.

A SURVIVOR TALKS ABOUT THEIR EXPERIENCE WITH LYNCH SYNDROME

I keep up with all the screenings recommended by my doctor, and I pay close attention to my diet. I made the decision that I, not Lynch Syndrome, had to be the one in control.

> "I got genetic testing for Lynch Syndrome because I wanted to be the one making the decisions..."

After I received my results, one of the first things I came to realize was the lack of awareness surrounding Lynch Syndrome. I knew then that I had to be proactive in advocating for testing to those around me.

While some members of my family were receptive to my pleas, others remained hesitant. Due to generations of trauma inflicted upon Indigenous peoples, it can be hard for us to trust hospitals and doctors' offices. However, I knew I had to face this trauma in order to protect my tribe and honor the example of my ancestors.

Why is it important to let my family know I have Lynch Syndrome?

If you or someone in your family has Lynch Syndrome, other family members, adults, or children, may also have Lynch syndrome and not know it. Sharing your health information will help you:

- Make informed decisions about your health and healthcare.
- Know if you need to yourself and your immediate family genetically tested for Lynch Syndrome.
- Know if you need to get regular screenings to detect and prevent cancer.
- Think about riskreducing surgeries to remove your colon, uterus, and/or ovaries.

References

1. CDC. About Lynch Syndrome. Hereditary Colorectal (Colon) Cancer. April 14, 2026. Accessed June 8, 2026. https://www.cdc.gov/colorectal-cancer-hereditary/about/lynch-syndrome.html
2. In: StatPearls. StatPearls Publishing; 2026. Accessed June 8, 2026. http://www.ncbi.nlm.nih.gov/books/NBK564511/
3. Talking to Your Family About Your Lynch Syndrome Diagnosis. Hereditary Colorectal (Colon) Cancer. April 14, 2026. Accessed June 8, 2026. https://www.cdc.gov/colorectal-cancer-hereditary/conversation-tips/index.html

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