

The Lynch Syndrome Center Registry

The Lynch Syndrome Center Registry is enrolling patients with known or suspected Lynch syndrome in a research study that collects clinical information and samples to help researchers learn more about Lynch syndrome with the goal of developing strategies that can improve prevention, early detection and treatment of cancer.

Eligibility Criteria

Individuals 18 years or older, plus any of the following would be eligible to enroll in the registry:

- Individuals with a positive genetic mutation for Lynch syndrome
- Individuals diagnosed with a cancer with mismatch repair deficiency or microsatellite instability AND a variant of uncertain significance in a Lynch syndrome gene with a family history suggestive of Lynch Syndrome

Length of study commitment

You will be in the research study for an indefinite amount of time but, active participation will be limited to an annual questionnaire completion and sample collections in some individuals.

Study requirements

The below may be required of individuals who join the registry:

- Complete an initial survey to collect information on your diet and lifestyle, as well as your family and personal history
- Complete an annual follow-up survey to collect information regarding any changes to your diet and lifestyle, or your family or personal history
- Donate blood samples annually (no more than 2 and $\frac{3}{4}$ tablespoons per year)
- Donate any of the following samples, if applicable:
 - Urine samples either in clinic or at home with a urine collection kit
 - Stool samples using a home collection kit and mail to the study team
 - Biopsy samples from screening procedures
 - Tissues samples from screening procedures (such as colonoscopies or endoscopies) or surgery

This study may or may not provide direct benefit, but we hope it can benefit those in the future. Whether or not you decide to join the study, your current clinical care will not be affected.

Registry Clinical Research Coordinator

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