

## **Lynch Syndrome: Additional Resources for Patients and Providers**

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*Please click the blue links to open the web-based resource*

### ***For Patients:***

#### **Collecting a Family History:**

##### **[My Family Health Portrait](#)**

'My Family Health Portrait' is a web-based tool from the U.S. Surgeon General that helps individuals collect and organize their family history information.

##### **[Kintalk](#)**

Kintalk is a platform to help people easily and securely share important genetic health information with at-risk family members and learn about hereditary cancer syndromes.

##### **[Family Gathering Health History E-Card](#)**

The Center for Disease Control and Prevention (CDC) Office of Public Health Genomics has developed a tool to assist families with starting the conversation about family health history. This e-card can be e-mailed to family members as a reminder to schedule a discussion.

##### **[Does it Run in the Family?](#)**

A partnership between Genetic Alliance, a non-profit health advocacy group, and diverse stakeholders created tailored family health history tools to promote conversations about health among family members. These tools translate knowledge of family health history into healthy choices.

#### **Information and Support Connections:**

##### **[A Patient Guide: Understanding Lynch Syndrome](#)**

The American Gastroenterological Association created a patient guide for individuals with Lynch syndrome to help patients understand their diagnosis. This guide contains tools that help patients with Lynch syndrome understand their risk and guidelines for preventing cancer.

##### **[Fight Colorectal Cancer](#)**

The leading patient advocacy group in colorectal cancer provides information, networking, and advocacy opportunities to ensure victory over colon and rectal cancers.

##### **[Alive And Kickn](#)**

A patient advocacy group for families affected with Lynch syndrome connects individuals with resources, research, networking, education, and screening support.

#### **Information about Genetic Counseling and Testing:**

##### **[Making Sense of Your Genes: A Guide to Genetic Counseling](#)**

Genetic Alliance has produced a public-friendly introduction to genetic counseling and its applications that may be helpful for patients.

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### ***For Providers:***

#### More Information on Lynch syndrome:

##### [Cancer.net: Lynch Syndrome](#)

Cancer.net includes compiled and concise information for physicians and patients to utilize to learn more about Lynch syndrome, its causes, and related cancer risks.

##### [Lynch Syndrome Screening Network](#)

This network promotes universal Lynch syndrome tumor screening. It also includes facts, evidence-based arguments, and recommendations on Lynch syndrome management.

##### [GeneReviews Lynch syndrome](#)

GeneReviews contains a thorough and concise report about the clinical characteristics, diagnosis, testing, management, and counseling concerning Lynch syndrome. This resource is useful for guiding providers through the diagnosis and testing process.

##### [National Cancer Institute Physician Database Query – Genetics of Colorectal Cancer](#)

The Genetics of Colorectal Cancer PDQ – Health Professional Version includes a detailed description of Lynch syndrome including diagnostic criteria, molecular/ genetic testing, cancer risks, screening, and interventions that may help providers manage patients with Lynch syndrome.

#### Diagnosis and Screening Resources:

##### [American Gastroenterological Association Institute Guideline for the Diagnosis and Management of Lynch Syndrome](#)

The official recommendations of the AGA Institute on the diagnosis and management of Lynch syndrome focusing on identifying cases of Lynch syndrome and risk management of colorectal cancer can be found here.

##### [Colorectal Cancer Risk Calculator](#)

The National Cancer Institute has created a tool that can be used to help estimate a person's risk of developing colorectal cancer by considering certain variables.

#### What providers need to know about Genetic Counseling:

##### [National Society of Genetic Counselors – Healthcare Providers](#)

The NSGC has created suggestions about what providers can expect when they include genetic counseling as part of a healthcare team approach to patient management. This resource includes information about who should be referred to genetic counseling and how genetic counseling adds a unique perspective to the management and care of patients.