Cleveland Clinic

2024

Colorectal Cancer **Family Registry**

A Message from Cleveland Clinic's Principal Investigator

Dear Study Participant,

Thank you for your participation in the Colorectal Cancer Family Registry (CCFR) study! Your involvement has been invaluable to advancing hereditary colorectal cancer research.

We are pleased to announce that the CCFR study, supported by the National Cancer Institute, has been awarded an additional five years of funding to continue colorectal cancer research through at least 2028.

During the next four years, we will contact you to complete a 10-15 minute follow-up survey. You may choose to complete the survey online or over the phone with our study coordinator.

The purpose of this newsletter is to:

- Review the study and its history
- Answer questions about your participation and the data collected
- Highlight research findings
- Remind you to discuss your family history and cancer screening with your provider

If you have any questions, please contact the study coordinator at 216.444.2693 or by email at coloncfr@ccf.org

Thank you for your continued participation.

Sincerely,

Stephanie Schmit, PhD, MPH
Principal Investigator
Genomic Medicine Institute
Cleveland Clinic

FREQUENTLY ASKED QUESTIONS

What Is the Colon Cancer Family Registry (CCFR)?

Funded by the National Institutes of Health, the CCFR is the largest and oldest single resource for colorectal cancer research worldwide.

Between 1998 through 2012, more than 43,000 study participants were recruited from over 15,000 families across the United States, Canada, Australia, and New Zealand. Participants have contributed blood samples, tumor specimens and health-related information.

Recruitment of new study participants stopped in 2012. However, enrolled participants have been followed up every four to five years to learn if they are getting colorectal cancer screening, and if there has been a change in their family medical history.

The biospecimens and data collected since 1998 have been used for more than 500 research projects and publications to better understand the causes and effects of colorectal cancer. For more information, visit coloncfr.org

What medical centers currently participate in the CCFR?

- University of Melbourne, Australia
- Fred Hutchinson Cancer Research Center
- Sinai Health System, Canada
- University of Hawaii
- Mayo Clinic
- Cleveland Clinic

What are some of the active research themes being studied to advance colorectal cancer creening, diagnosis, and treatment?

Lynch Syndrome. Lynch syndrome, an inherited genetic predisposition to colorectal and some other cancers, varies significantly across patients with the syndrome. For example, colorectal cancer risk may be higher among people with specific genetic mutations and people who drink alcohol, smoke cigarettes, or are overweight. The risk may be lower in people who exercise regularly.

Type X Syndrome. Participants with Type X syndrome have a family history of colorectal cancer but have not tested positive for Lynch Syndrome.

Early Onset Colorectal Cancer. Researchers are studying why colorectal cancer is becoming more common in people under age 50. This will help us provide appropriate recommendations to our study participants and their families.

Risk Prediction: Researchers have used the collected data to improve estimation of an individual's future risk of colorectal cancer, evaluating genetic and environmental factors such as weight, diet, screening, family history of cancer, smoking, alcohol intake and aspirin use. Researchers are studying biomarkers in blood to assess their impact on risk prediction, which could lead to routine blood tests in all patients or those at highest risk of colorectal cancer.

Survivorship: Ongoing research evaluates factors that influence quality of life after a cancer diagnosis: an individual's tumor characteristics, genetic markers, lifestyle choices and behavior. A current project may help us understand whether living in certain regions or neighborhoods impact survivorship.

Immune System: Researchers are studying immune responses for more insight into cancer prevention, treatment, and survival.

REVIEW OF THE STUDY

How it began at Cleveland Clinic

The study began in 1998, and participants were recruited through 2012. They were initially recruited through the Jagelman Inherited Colorectal Cancer Registry, now part of the Weiss Center.

During a clinic visit with a colorectal surgeon or gastroenterologist, the study was introduced if there was a significant family history of colorectal cancer and other cancers and at least one diagnosed before age 50 years.

If interested, individuals met with a study coordinator who provided more information about the study, took a detailed family medical history, including age of diagnosis of colorectal and other cancers, and cause of death.

If the family medical history met the study inclusion criteria, a study coordinator explained the study and what would be involved. The patient then signed a consent form so that biospecimens and data could be collected, for example, to validate family medical history.

How study data was collected

Data was collected at different intervals, and consisted of a study consent form, medical releases, hospital medical records, blood samples, risk factor questionnaires, tumor specimens, follow up surveys, and obituaries or death certificates.

The study coordinator worked with participants and family members to sign a medical release to obtain copies of medical records. These were needed to confirm colorectal and other cancer details.

The study coordinator communicated with hospitals to obtain a copy of the medical records to validate the reported cancers, age at diagnosis of cancer(s) and cause of death.

Next, the validated family medical history was reviewed to determine which family members would be asked to participate in data collection.

Both unaffected and affected individuals with colorectal cancer and some other cancers were selected.

After study participants were selected, the study coordinator contacted them to explain the study and, if interested, obtain a signed consent form. Arrangements were made for a blood draw at an approved laboratory, and an appointment was scheduled to complete a lifestyle epidemiological survey and diet questionnaire. Tumor specimen samples from study participants with colorectal cancers were obtained from pathology departments where surgery was performed.

How we follow up with study participants

After participants completed the initial survey between 1998 through 2012, they were followed up every four to five years to complete a new survey and provide updates on their family medical history. Medical records for new colorectal cancers and death certificates were collected when relevant and possible.

to do

Update your contact preferences.

Let us know if you have moved in the last five years, if you use only a cell phone, or prefer to stay in touch through email. Call the study coordinator at **216.444.2693** or email coloncfr@ccf.org.

Phuong Hoa

Phuong has been at Cleveland Clinic for 15 years, with 9 of those years spent working in research. Phuong previously served as study coordinator on a breast cancer study called Strive, as well as several clinical trials and investigator-initiated studies for inflammatory bowel disease. In May 2022, Phuong joined our team as the Program Manager for the Cleveland Clinic site of the CCFR. She will be the person reaching out to you in this phase of the study.

CALL TO ACTION

Please take the survey when you're contacted

You will be contacted by the study coordinator during the next four to five years by phone or email to complete a follow up survey. It will take about 15 minutes on the phone, or you can do it online.

We want to know if you are being screened, what has changed, if any family members have developed cancer, or if anyone has passed away.

You can reach the study coordinator at 216.444.2693 or by email at coloncfr@ccf.org.

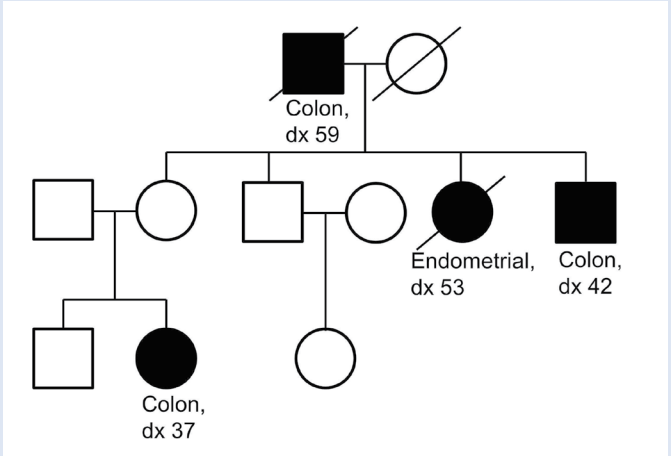
Why you should update your primary care physician if there is a change in family medical history

It is important for you to take an active part in your healthcare and serve as your own advocate! Please be sure your primary care physician and any other medical specialists are aware of any change in your personal and family medical history. This includes a family member who has been diagnosed with colorectal or other cancers, or has died from cancer.

Your individual risk of cancer increases with every new cancer identified in your family, and this affects changes in screening recommendations.

If you have a family history of multiple colorectal cancers and/or other cancers, we recommend you meet with a genetic counselor, or contact the registry coordinator at Cleveland Clinic Weiss Center at 216.444.6470, who can make appropriate screening recommendations for you and your family members.

This is an example of a family tree:



LEARN MORE

Lynch Syndrome

- Lynch syndrome is a genetic condition that increases your risk of developing cancer. People diagnosed with Lynch syndrome are more likely to get cancer before 50 years of age and should undergo appropriate cancer screenings to detect and treat cancer early. Talk to your healthcare provider.
- It is the result of a genetic mutation. Genetic mutations pass from your parents to you during fetal development. Sometimes, genetic mutations occur randomly, without being present in someone's family history.
- It occurs in approximately one in 279 individuals in the United States. An estimated 4,000 cases of colorectal cancer and 1,800 cases of uterine (endometrial) cancer result from Lynch syndrome each year.

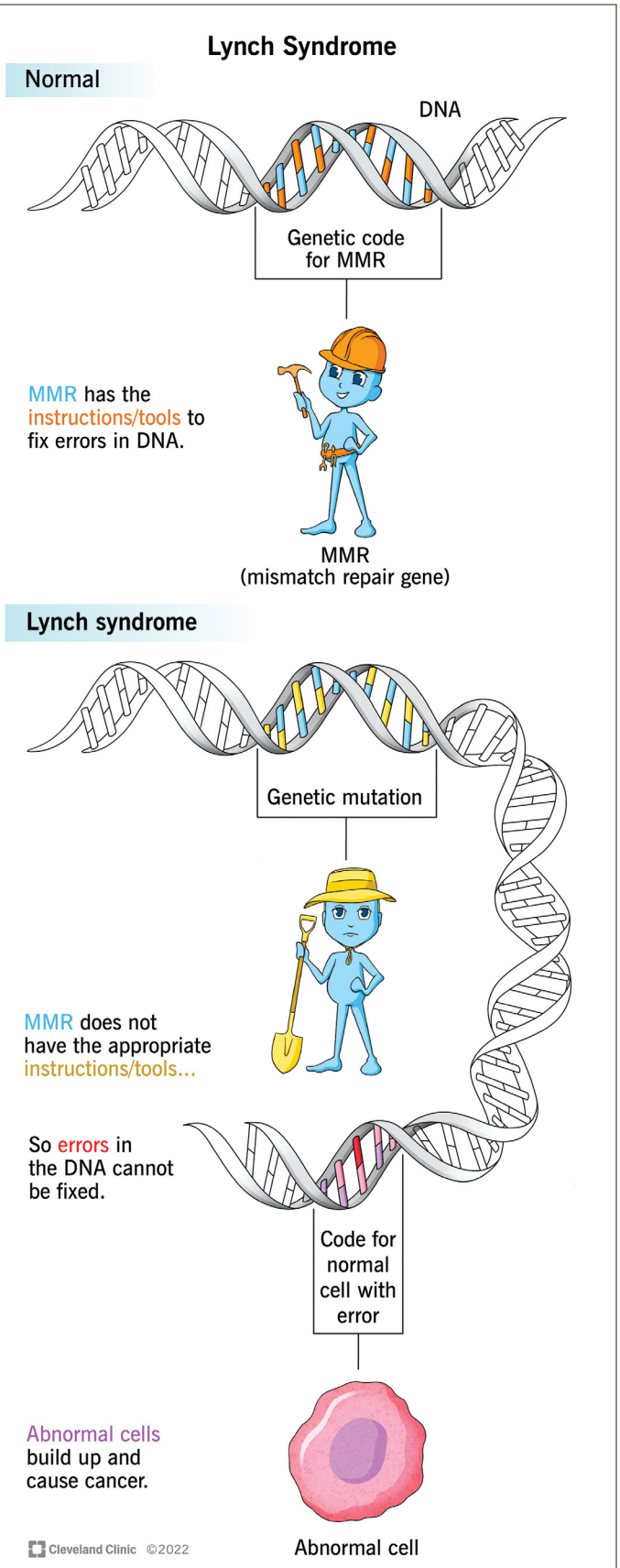
Check out the Cleveland Clinic link below to answer your questions about Lynch Syndrome. What are the symptoms? How is it diagnosed? What are the associated cancers? What is the best medical management and prevention?

my.clevelandclinic.org/health/diseases/17195-lynch-syndrome-and-hnpcc

to do

My To Do List

- **Talk to your healthcare provider about cancer screening.** You should discuss what screening is right for you, including screening for colorectal (colon), uterine (endometrial), and other cancers other related cancers. You may need screenings more often and starting at an earlier age than most people.
- **Tell your family members if you have been diagnosed with Lynch syndrome.** Talking to family members can help them better understand their risk for cancer and make better informed decisions regarding their health. Family members who get genetic testing should be tested for the same genetic change that you have.



This graphic shows how in normal DNA the mismatch repair (MMR) gene has instructions/tools to fix errors in DNA, but if you have Lynch syndrome, The MMR gene does not have appropriate instructions/tools. Therefore, Lynch syndrome puts you at a high risk of developing cancer.