Genetic Support Foundation

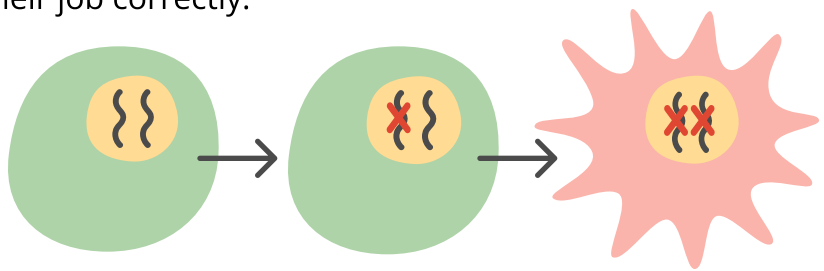
A Patient's Guide to

Hereditary Uterine Cancer

Understanding Hereditary Cancer Risks

What causes cancer?

- **Genes** are the instruction manuals that tell our bodies how to grow and function.
- Certain genes, sometimes called cancer susceptibility genes, help protect against cancer development in specific parts of the body. Cancer occurs when multiple harmful mutations accumulate in these genes and prevent them from doing their job correctly.



A cell that acquires multiple harmful mutations in cancer susceptibility genes can turn into a tumor, which can eventually lead to cancer.

What is sporadic cancer?

The **majority** of cancer cases are *sporadic*, or caused by acquired genetic mutations that occur just **by chance**.

- These acquired mutations cannot be passed on to children.
- Certain environmental and lifestyle factors can increase the risk of sporadic cancer, like tobacco smoke and UV rays.
- Signs of sporadic cancer include a personal/family history of:
  - Cancer diagnosed later in life (e.g., after the age of 50)
  - No family history of cancer or a family history of only a few common cancers diagnosed later in life

What is hereditary cancer?

Less often, cancer is caused by a *hereditary cancer syndrome*, or an **inherited genetic mutation** that increases the risk of developing certain types of cancer over a lifetime.

- When a person has an inherited genetic risk, their parents, siblings, and children each have a 50% chance of inheriting this risk.
- **Genetic counseling and testing** can identify a hereditary cancer syndrome in a family. This can inform an entire family's cancer screening and preventative practices and save lives.
- Signs of a hereditary cancer syndrome include a personal or family history of:
  - Cancer diagnosed at age 50 or younger
  - Multiple types of cancer in one individual
  - Multiple family members with the same type of cancer
  - Rare types of cancer (such as ovarian cancer, pancreatic cancer, or prostate cancer that spreads to other parts of the body)

Signs of a hereditary cancer risk in a family:

*Experienced cancer at a **young age***

*Experienced a **rare** cancer*

*Experienced **multiple** cancers*

Understanding Hereditary Uterine Cancer

When does uterine cancer have a hereditary cause?

- Uterine (or "endometrial") cancer affects approximately 1-in-30 of people assigned female at birth.
- Most often, uterine cancer is *not* hereditary, and instead occurs due to a combination of random chance, body weight, hormonal factors, certain medical conditions, and more.
- **5-10%** of the time, uterine cancer is caused by a hereditary cancer syndrome.

Signs of hereditary uterine cancer in a family:

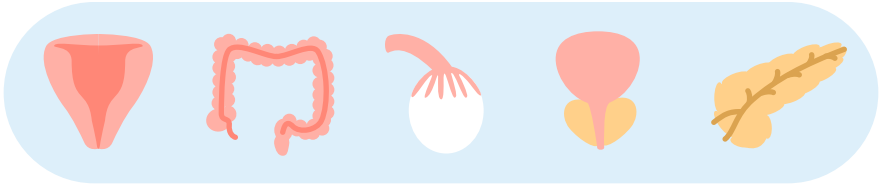
- Uterine cancer diagnosed before age 50
- Uterine cancer at any age and:
  - Colorectal cancer
  - Ovarian cancer
  - Prostate cancer
  - Small bowel cancer
  - Stomach cancer
  - Pancreatic cancer
  - Bladder, renal pelvis, and/or ureter cancer
  - Other cancers

- If you recognize these signs in yourself or your family, **genetic counseling** is recommended to help determine whether there may be a hereditary cancer risk in your family.

*If a hereditary cancer syndrome is suspected, genetic testing can inform an entire family's screening practices and **save lives**.*

What causes hereditary uterine cancer?

- Uterine cancer can be caused by a number of different hereditary cancer syndromes, but the most common cause is **Lynch syndrome**.
- Lynch syndrome is caused by inherited mutations in the *MLH1*, *MSH2*, *MSH6*, *PMS2*, and *EPCAM* genes.
- Lynch syndrome increases the risk of developing **uterine**, **colorectal**, **ovarian**, **prostate**, and less commonly **other** cancers (small bowel, stomach, pancreatic, bladder, renal pelvis and/or ureter, biliary tract, and brain cancer).



- Identifying Lynch syndrome through genetic testing can allow for early cancer screening, early cancer diagnosis, and more effective treatment if cancer develops. Exact cancer risks and screening guidelines depend on which gene is affected, and management recommendations may include:
  - Earlier and more frequent colonoscopies
  - Early upper endoscopies
  - Consideration of surgical removal of the uterus and/or ovaries
  - Family history-specific cancer screening

Meeting with a Genetic Counselor

What can I expect?

- A genetic counselor will ask you questions about your personal and family history and determine whether a hereditary cancer syndrome is suspected.
- If indicated, the genetic counselor will offer you the best genetic testing for your specific circumstances.
- The genetic counselor will talk with you about the potential benefits and limitations of genetic testing, including:

Potential Benefits

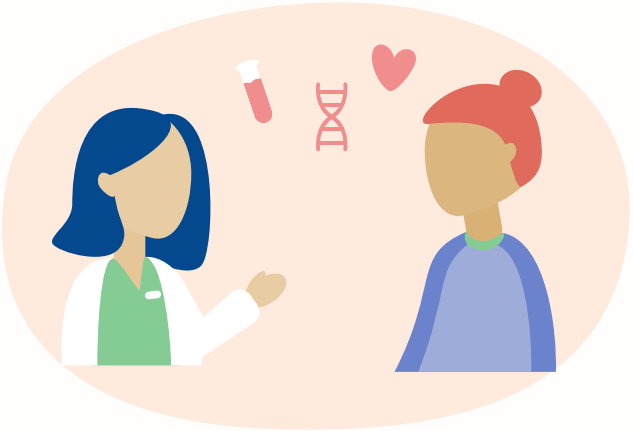
- Results can guide cancer screening and preventative practices.
- Results can impact cancer treatment recommendations.
- Results can inform cancer risk in other family members.

Potential Limitations

- There is no guarantee that genetic testing will identify a hereditary cause of cancer in a family even if one exists.
- Genetic testing may identify genetic mutations that are not well understood.
- Genetic test results may be used by life, long-term care, and disability insurance companies when making policy decisions (but NOT by health insurance companies).

How can I schedule an appointment?

- Your provider can refer you to a certified genetic counselor through Genetic Support Foundation by faxing the relevant medical records and insurance information to 844-813-3892.



- You can also schedule a secure video appointment yourself by visiting geneticsupportfoundation.org/appointments.

Questions?

Talk to a certified genetic counselor by calling:

1-800-364-1641