

Gastrointestinal Stromal Tumor (GIST)

Gastrointestinal stromal tumors (GIST) are rare, soft tissue sarcomas that occur between the muscle layers of the GI tract. About 5,000 new cases of GIST occur in the U.S. each year. This is 0.2% of all GI cancers.

Common Sites of GIST

- Stomach (40% - 70%)
- Small intestine (20% - 40%)
- Colon and rectum (5% - 15%)
- Esophagus (less than 5%)

What is GIST?

GIST begins when a **kit** gene in the center (nucleus) of a cell has a defect (mutation). The **kit** gene makes a protein, called KIT. This protein is found on the surface of the cell. The KIT protein is part of a system that makes a cell divide and grow. When the **kit** gene mutates, the KIT protein becomes too active. It signals the cell to grow and divide without stopping and with no turn off. The cell divides out of control forming a tumor. Mutations in **kit** are found in 90 – 95% of GISTs. GIST may grow slowly and remain stable for years. Or, it may progress quickly, spreading (**metastasizing**) to other organs. GISTs are typed as low, intermediate, or high risk. The typing is based on their size, the rate at which they divide, and the site.

GIST occurs most often in adults between the ages of 40 and 80. The average age at first diagnosis is 63. It occurs slightly more often in men than women. There are no known risk factors. There is a small increase in risk if someone in your family has had the disease.

Symptoms

Small GISTs are often found when the patient has a routine test or procedure for some other problem. There may be no warning symptoms. Larger tumors may

cause pain, nausea, vomiting, loss of appetite, weight loss, bloating, early feelings of fullness, fatigue, or bleeding.

Prognosis

The best ways to predict chance of recovery are the size of the tumor and rate at which the cell divides.

Diagnosis and Staging

Tests and procedures are used to diagnose GIST. They can also help decide the stage of disease or extent of the cancer. The stage of the disease is a key part in making a treatment plan.

- **Physical exam** and complete health history.
- **Blood tests** – Looking for anemia and liver or kidney functions.
- **CT scan** (CAT scan) – A detailed picture of the inside of the body. This is taken by a special x-ray machine that is attached to a computer.
- **MRI** (magnetic resonance imaging) – An x-ray exam that uses a magnet, radio waves, and a computer to make detailed pictures of the inside of the body.
- **PET scan** (positron emission tomography) – Tumor cells use a lot of energy. PET scans show sites of high energy. They are often used to find cancer that has spread to other parts of the body.
- **Endoscopy** – A procedure performed by a doctor who specializes in GI tract diseases. A small, lighted tube (scope) is passed through the mouth, esophagus, and into the stomach. Tissue samples (biopsy) can be taken. They are looked at under the microscope to check for cancer.

- **Biopsy** – Cells or tissues are removed. They are looked at under the microscope to check for cancer. Tissue can be removed during an endoscopy or surgery, or CT with ultrasound guidance. Special stains are needed to detect KIT, which is present in 90-95% of all GIST patients.

Stages of GIST

Staging is a way to describe a cancer in terms of size, location, and whether it has spread to other tissues or organs.

Very Low Risk

- Smaller than 2 cm, less than 5/50 HPF (high-powered field)

Low Risk

- 2 cm to 5 cm, less than 5/50 HPF

Intermediate Risk

- Larger than 5 cm, 6 to 10/50 HPF
- 5 cm to 10 cm, less than 5/50 HPF

High Risk

- More than 5 cm, more than 5/50 HPF
- More than 10 cm, any mitotic rate
- Any size, more than 10/50 HPF

Treatment

Surgery

Surgery is the main treatment for GIST tumors that have not spread. GISTs rarely spread to lymph nodes. Lymph nodes do not need to be removed. Surgery may also be used after treatment with a targeted therapy. Therapy shrinks the tumor, making surgery possible.

Radiation

GIST tumors tend not to respond to radiation treatments. Sometimes, radiation may be used to treat symptoms of a lesion which has spread.

Chemotherapy

Usual chemotherapy treatment has little effect on GISTs. Targeted therapies called **selective tyrosine kinase inhibitors** have been used to disrupt the abnormally active KIT protein.

Clinical Trials

Clinical trials may be offered at our Cancer Center. Ask your doctor how you can take part in these trials. They help find new and better treatments for people with GIST.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 9/2018 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6737