GIST Support International

Our Mission

- To help GIST patients become their own best advocates
- To educate about the latest advances in research & care
- To share emotional support

GIST Support International is an ***all-volunteer*** nonprofit organization. We are an internet-based community of over 1500 patients, family members, friends, and health care professionals in 25+ countries. We provide education and support worldwide to people facing gastrointestinal stromal tumor (GIST) through …

Our website at www.gistsupport.org

- Featuring up-to-date medical information about GIST and its treatment
- Showing experts' answers to patients' questions
- Sharing stories and essays by people affected by GIST
- Guiding patients to the latest effective therapies and clinical trials
- Suggesting sources of financial assistance

Our e-mail listserv for patients, family, and anyone interested in GIST

- Offering a safe place where individuals can ask questions
- Sharing practical advice and emotional support
- Forming an online community of friends who face GIST together

Our e-mail listserv for pediatric and wildtype GIST

- Serving the special needs of rare young patients with GIST
- Offering a community for all wildtype GIST patients and their families

Our wiki at http://gistsupport.medshelf.org/Main_Page

- Listing practical strategies for coping with GIST
- Summarizing ways to alleviate symptoms and treatment side effects
- Collecting tips about a variety of topics that concern GIST patients

Our telephone help line at (215) 340-9374

Our Phone Pals: phone friends for those who prefer talking to typing

Contact us if we can help you!
gsi@gistsupport.org (215) 340-9374

Questions for your doctor …

General questions …

- How many GIST patients have you treated?
- Do you follow the NCCN guidelines for GIST treatment?

Pre-surgery questions …

- Where is my tumor?
- Do I need an expert sarcoma surgeon?
- What surgery is needed?
- Should I take drug therapy before surgery?
- Is a biopsy needed?
- What baseline imaging studies are needed?

Post-surgery questions …

- Explain my pathology report.
- Was the tumor removed with clear margins?
- What is my risk for spread of the disease?
- Do I need mutation testing on my tumor?
- Should I take drug therapy?
- Should I consider clinical trials?
- Do I need special nutrition following surgery?
- What future monitoring will I need?

Understanding GIST: Gastrointestinal Stromal Tumor

GIST Support International

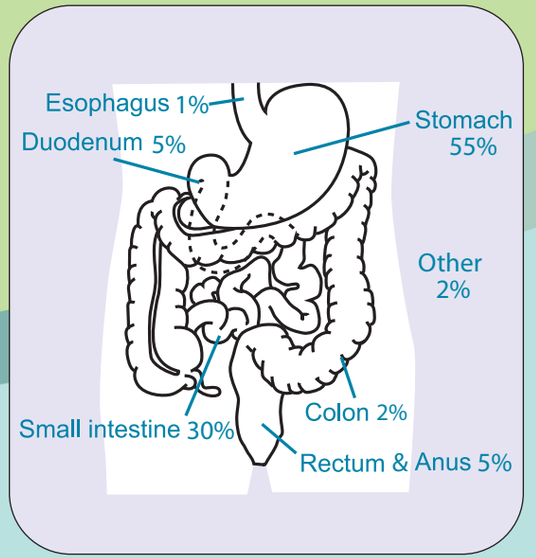
Education and support for people facing gastrointestinal stromal tumor

Visit our website at www.gistsupport.org

email: gsi@gistsupport.org
Phone: 215.340.9374

What is GIST?

Gastrointestinal stromal tumor (GIST) is a type of sarcoma (cancer of connective tissue). Most GISTs originate from within the wall of the digestive tract and usually grow *outward*, pushing against other organs. GISTs behave differently than common gastric or intestinal cancers that arise inside the digestive tract from its lining.



GIST can occur anywhere along the digestive tract but it arises most frequently from the stomach or small intestine. Uncommon locations include supporting membranes of the abdominal organs, liver, pancreas, ovaries, uterus, and prostate. The liver is the most frequent site of GIST spread (metastasis), followed by the abdominal membranes. Spread to bone, lung, or non-abdominal sites is rare.

Who gets GIST?

GISTs are diagnosed at a yearly rate of 15 cases per million people. Most GIST patients are over age 50, but some are young adults; a few are children. Symptoms may be vague (abdominal fullness, digestive discomfort, palpable mass) or alarming (bleeding, vomiting, diarrhea, anemia).

What causes GIST?

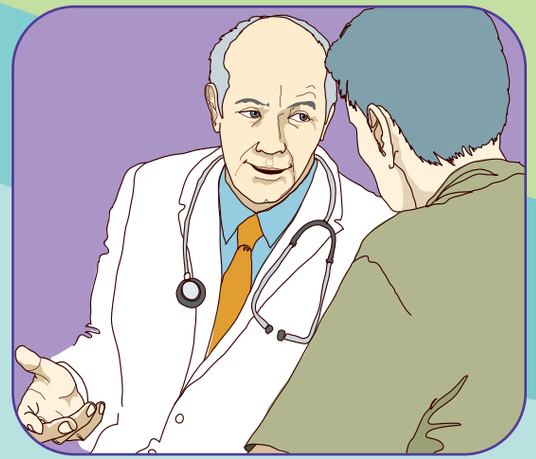
Mutations in the genes for growth factor receptors (KIT or PDGFRA) cause uncontrolled tumor growth in most adult GISTs. A few GISTs have a mutation in the BRAF gene. GIST lacking identified mutations is called *wildtype*, more often found in young patients. Genetic and epigenetic factors in wildtype GIST are under investigation. Most GISTs are sporadic, with no preventable risk factors. Neurofibromatosis 1 and rare familial genetic syndromes increase the risk for GIST.

How is GIST diagnosed?

A pathologist examines biopsy samples or the surgically removed tumor. Most GISTs test positive for KIT protein (CD117) and DOG1. Mutation testing is advised to help diagnose CD117-negative GISTs. The pathologist evaluates cell division rate (mitotic rate) and tumor size to estimate the risk of recurrence or metastasis.

How is GIST treated?

Surgery, the mainstay of treatment, is potentially curative for smaller primary tumors. Surgical oncologists specializing in sarcomas are most skilled at removing GIST. Sometimes drugs are used before surgery to reduce the scope of the operation. Radio frequency ablation and hepatic artery embolization are used for selected liver tumors.



Monitoring with radiologic scans (CT or MRI) continues post-surgery to identify possible progression. After complete surgical resection, if the GIST has a high risk of progressive disease, the oncologist may recommend taking a drug to prevent recurrence (adjuvant therapy).

Molecularly targeted therapies are oral drugs that are effective for most GISTs. These drugs have fewer side effects than traditional chemotherapies, which are ineffective against GIST. Imatinib (Gleevec), the first-line therapy, may shrink inoperable GISTs or achieve stable disease. Sunitinib (Sutent) is second-line therapy for imatinib-resistant tumors and patients who cannot tolerate imatinib. Targeted therapies are not curative; therefore, the drugs are taken indefinitely by patients with metastatic disease. Optimum duration of adjuvant therapy has not yet been identified.

Because patient response to targeted therapies depends upon the particular gene abnormalities in their GISTs, mutation testing (genotyping) may aid treatment decisions for high-risk tumors, non-gastric tumors, and those that might be wildtype. Your physician can order this testing.

Many patients develop resistance to imatinib after about 2 years, usually due to the appearance of secondary mutations. If sunitinib also fails to maintain tumor control, patients may consider clinical trials or other drugs with potential effectiveness. Numerous new drugs are in development for GIST.

For further details please see:

www.gistsupport.org

Also see the GIST Task Force Reports and Soft Tissue Sarcoma Guidelines at

www.nccn.org