

Recurrence and Metastasis

Like most cancers, GIST can *metastasize* – it can spread from the original (primary) site to other locations in the body, especially the liver and the peritoneum (the membrane that lines the abdomen). These secondary tumors are GIST *metastases* ("mets"). (Note that when GIST spreads to the liver, these secondary tumors are GIST tumors, *not* liver cancers). Metastases to the lymph nodes or lungs are rare, but do occur. GIST cancers do not always metastasize. The risk of metastasis of a primary GIST can be estimated by a pathologist based on tumor size and mitotic rate (a measure of the rate at which the tumor cells are dividing). Recurrence and metastasis are common in GIST and continuing medical observation is essential.

Can Children Get GIST?

Most cases of GIST occur in adults but it does



Pediatric GIST patient Leah Knopp and LRG Staffer Tricia McAleer

sometimes occur in children. Pediatric GIST seems to have significant differences from the adult disease, but much more research is needed. The Life Raft Group publishes a separate pamphlet on Pediatric GIST.

Looking Toward the Future

GIST and Gleevec are considered by many to be a model for innovative targeted cancer therapies. With high patient participation in clinical trials, and great interest in targeted cancer therapy by many drug companies, progress continues to be made in treating GIST. For patients with Gleevec-resistant GIST, the second-line drug, Sutent, is available. In addition, there are many clinical trial options, so it is important for GIST patients to remain informed. The Life Raft Group is a major source of current information.



Life Raft Group Resistance Research

The Life Raft Group has created a strategic resistance research plan that will enable us to direct grant funds to those research priorities with the greatest prospect of giving us new information and treatments as quickly as possible. We have created a supportive grant infrastructure that holds each researcher accountable for specific results, redirects resources when a project is exhausted and supplements new research when need arises. We have also created two separate tissue banks (one for pediatric GIST and one for adult GIST) to provide researchers with the tools that they need to perform their work.

The Life Raft Group

The LRG is an international patient support organization for people with GIST and their family members. The mission of the Life Raft Group is to ensure the survival of GIST patients while maintaining the quality of their lives. To accomplish this mission the Life Raft Group devotes its efforts to: Information & Support, Treatment Surveillance, Research, Patient Consultation & Assistance, and Advocacy.

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G astro
I ntestinal
S tromal
T umors

**Ensuring that no one
has to face GIST alone**

This pamphlet will tell you the basics about GIST and its treatment. It is intended to answer some of your questions about the disease, but is not a substitute for your physician's guidance and care.

What you need to know right away...

What is GIST?

GIST is the short name for Gastrointestinal Stromal Tumor, a type of sarcoma. Sarcomas are cancers of connective tissue, muscle, or bones. GIST is uncommon and many doctors may never have seen a patient with GIST before. GIST was only recognized as a distinct disease a few years ago. Until then, GISTs were often incorrectly classified.



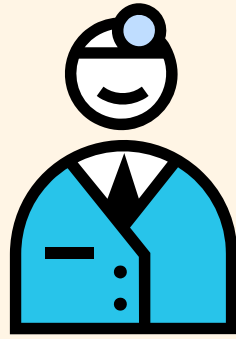
*GIST Patient
Norma Christian*

Am I going to die from this disease?

GIST is a life threatening disease, but many patients are cured by surgery. And, thanks to recent medical breakthroughs, even patients with metastatic GIST are living for many years and with a good quality of life. GIST may soon become a chronic condition that can be managed successfully by most patients.

Why did I get GIST?

We don't understand why most people get GIST. GIST strikes young and old, rich and poor. Sometimes GIST runs in families, but most cases do not. There are no known environmental, occupational, or lifestyle causes of GIST. GIST results when mutations occur in certain genes and in certain cells, but we do not know why these mutations happen.



Managing Treatment

In addition to your general practitioner, you may be treated by specialists such as surgeons and medical oncologists. Radiologists may help with diagnosis and determination of whether the treatment is working. Your doctor may wish to refer you to a specialized cancer center for further consultations. Many patients find that a strong personal support network of family and friends helps them to manage their conditions.

Will I need surgery?

Surgery is often required for removal of the primary GIST tumor. The goal is to remove the tumor and to achieve clear margins. The nature of the surgery will depend on the size and location of the GIST tumor. Surgery is sometimes used later in the course of the disease.

Can GIST be treated with drugs?

The most important advance in GIST treatment has been the development of Gleevec, the first drug approved (in 2002) specifically for this disease. Several other new drugs for GIST are under development or in clinical trials. We expect that the options for GIST treatment will expand significantly in the next few years.



ABOUT Gleevec®

Gleevec (also known as Glivec, Imatinib, or STI571) is a tablet taken by mouth. Gleevec is a targeted therapy for GIST. It is normally used to treat GIST if the tumor cannot be removed by surgery or has metastasized. Gleevec generally does not cause the more serious side effects such as hair loss that are commonly associated with cancer chemotherapy. Side effects may include fatigue, stomach upset, fluid retention, and muscle cramps. These can usually be managed with the help of your doctor. You may wish to discuss the appropriate Gleevec dose with your doctor. Sometimes the starting dose will need to be adjusted, depending on individual response to treatment or side effects. If you do not have insurance or cannot afford to pay for Gleevec, it may be possible to obtain financial assistance.



Monitoring Your Condition

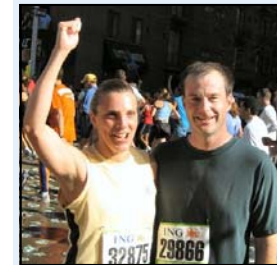
Since many patients' tumors become resistant to Gleevec, regular follow-up examination of GIST patients is very important. This monitoring is done by physical examination and by medical imaging techniques such as CT and PET scanning. Typically, follow-up CT scans are performed every three months. Blood tests are also needed to monitor the general health status of patients receiving Gleevec or other drugs, although they do not directly measure tumor response.

Is GIST the same thing as "stomach cancer"?

No. GIST tumors can start in any part of the digestive tract, including the esophagus, stomach, colon, and rectum. It most commonly starts in the stomach, but it is different than the type of tumor most physicians are referring to when they talk about classic stomach cancer, which arises in glandular cells and not connective tissue. GIST is very different from the more common breast, lung, stomach, and colon cancers (carcinomas). Often, more than one tumor will be found either initially or at a later date.

How is GIST diagnosed?

Usually, a doctor first suspects GIST on the basis of a patient's symptoms, such as anemia or abdominal pain. GISTs may also be discovered during emergency surgery for perforations that cause infections or internal bleeding. Another possibility is that the GISTs may ulcerate and cause blood in the stool, vomiting of blood or anemia. GIST is not diagnosed by a blood test. Specialized tests allow the pathologist to identify GIST cells in a sample of tumor tissue. (A pathologist is a doctor who diagnoses diseases by laboratory tests, such as examination of cells under a microscope.) Pathology is always critical for making the diagnosis of GIST. Almost all GISTs are positive in the "KIT" test (an immunohistochemistry test, also called "brown staining", for identifying KIT protein over-expression). This test determines whether the cancer cells produce a protein called KIT.



Patient Michael Byrne ran the NYC marathon to raise money for the Life Raft in 2004. Michael had a football size GIST removed in 1996.