

GIST Cancer UK (GCUK)

GIST Cancer UK is a UK registered charity (no. 1129219) run entirely by volunteer trustees, many of whom are patients or a close relative of a patient. We aim to provide support for GIST cancer patients and their families, whilst furthering medical understanding of GIST and improving the outlook for GIST patients.

We currently hold three meetings each year where patients can meet and hear about the latest developments in the treatment of GIST from leading professionals. We provide day-to-day support via our telephone helpline and a private patient/carer email forum (listserve). Our patient information literature (listed below) provides guidance on coping with treatment for GIST cancer and dealing with side effects.

“GIST for Beginners”

“Eating after GI Surgery for GIST”

“I am a GIST Patient” (a leaflet to carry around in your purse or wallet).

“No Stomach”

GCUK sponsors a specialist Clinic for PAWS-GIST patients held at Addenbrookes Hospital in Cambridge, and works to support an infrastructure that will stimulate GIST research and improve patient care.

How is GCUK funded?

GCUK receives some funds from pharmaceutical companies in the form of unrestricted grants which we use for patient meetings and educational materials. All GCUK research projects rely solely on personal donations and fundraising from our supporters.

To make a donation visit

<https://www.justgiving.com/gistcanceruk>

To donate to our PAWS-GIST initiative visit:

www.virginmoneygiving.com/PAWS-GIST

If you would like to fundraise, please contact fundraising@gistcancer.org.uk for fundraising materials.

This leaflet has been produced by GIST Cancer UK.
Registered Charity No. 1129219
Advice given by GIST Cancer UK is that of patients and carers.
Medical advice should always be sought from those responsible for your treatment.
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For more information visit our website
at www.gistcancer.org.uk
or
call our telephone helpline
on 0300 400 0000

Other useful organisations for information and support:

The Liferaft Group

a GIST patient group based in the US.

www.liferaftgroup.org

GIST Support International

an international patient group based in the US.

www.gistsupport.org

Macmillan Cancer Support

information on all aspects of cancer including information on statutory UK benefits.

www.macmillan.org.uk

Sarcoma UK

UK based charity for Sarcoma patients.

www.sarcoma.org.uk



[@pawsgist](https://www.facebook.com/pawsgist)

[@pawsgist](https://twitter.com/pawsgist)

www.pawsgistclinic.org.uk



You do not have to be alone!

This leaflet will help you if you, or someone close to you, has been diagnosed with a Gastro-Intestinal Stromal Tumour (GIST).

This is a rare cancer, but you do not have to deal with it alone.

The leaflet tells you something about GIST and its treatment, and gives you details of how to find out more and make contact with other GIST patients.

HOW TO CONTACT US

Email: admin@gistcancer.org.uk

Telephone: 0300 400 0000

(Calls are charged at the national rate)

Online:

www.gistcancer.org.uk

[@gistcanceruk](https://www.facebook.com/gistcanceruk)

[@gistcanceruk](https://twitter.com/gistcanceruk)

[@gistcanceruk](https://www.linkedin.com/company/gistcanceruk)

What is GIST?

GIST is a very rare kind of cancer. It can occur anywhere in the oesophagus, stomach and intestines, together known as the Gastrointestinal Tract, hence the name GIST – gastrointestinal stromal tumour. About 50% of GISTs occur in the stomach, 30% in the small intestine. The rest occur in the oesophagus, the large intestine, rectum, or in the various connective tissues associated with the gastrointestinal tract.

It is one of a group of cancers known as sarcomas. These cancers occur in the connective tissues of the body and should not be confused with the much more common kinds of cancer called carcinomas, which can occur in the same parts of the body, but in different types of cell. The distinction is very important, because the treatment of these two kinds of cancer is very different, for example, cytotoxic chemotherapy is not used on GIST.

How rare is GIST?

There are approximately 800 cases of GIST found in the UK each year. GIST usually affects people in their 50s and 60s. However about 15% of GIST patients have **P**aediatric, **A**dolescent, **W**ild-type or **S**yndromic GIST, (PAWS-GIST). The charity GIST Cancer UK has created a specialist initiative focusing on improving treatment and finding a cure for PAWS-GIST. For more information please contact: info@pawsgistclinic.org.uk

How is GIST diagnosed?

GIST is not easy to diagnose. Many GISTs produce few symptoms, or symptoms which might be caused by other things. These include: indigestion, mild abdominal discomfort, night sweats, weight loss or gain. Occasionally there may be bleeding from the tumour, causing blood in the stools or vomit, or just anaemia. Once cells have been removed from the tumour, either after surgery to remove it, or by taking a biopsy, an expert pathologist can give a firm diagnosis.

How is GIST treated?

• Surgery

If possible, the tumour will be removed. **Many patients who have had a GIST removed completely never have any more problems**, (if you are going to have surgery, do look at the details on our website about donating your tumour tissue to our National GIST Tissue Bank). There is a risk of your GIST coming back, the magnitude of this risk depends on many factors such as the position of the first tumour, its size and how fast it was growing. GIST can recur close to the original tumour site, or it may return elsewhere, usually in the liver. Small GISTs in the liver may be removed using Radio Frequency Ablation (RFA).

• Drug treatment after surgery (adjuvant drug treatment)

If there is a high risk of recurrence, you may be offered a drug called imatinib (Glivec™). This is believed to reduce the risk of recurrence, or prevent it. Adjuvant treatment (to try and prevent recurrence) is approved in the UK for three years.

• Drug treatment without surgery

If the GIST is very large or in a difficult position, or there are already several tumours, the normal treatment is with imatinib. This can be a very effective treatment in many patients. Large inoperable GISTs often become small enough to remove. Imatinib does not cure GIST; it controls it. It is important to take the tablets every day as research has shown that GISTs that have almost disappeared may start to grow rapidly again if the imatinib is stopped. Imatinib works by interfering with the signalling system in the tumour cells, stopping them growing.

If imatinib stops controlling the tumour or tumours, another drug is available, called sunitinib (Sutent™), and if sunitinib stops controlling the tumours another drug called regorafenib (Stivarga™) is also available. In many patients these drugs bring the tumour or tumours back under control. Like all drugs, imatinib, sunitinib and regorafenib have side effects.

• Side effects of drugs

Side effects experienced on these drugs should be discussed with your oncologist and/or specialist nurse. There are drugs that can help with side effects, and patients often find ways of managing them. You can join our free patient private email forum (listserv) or come to our meetings to talk with other patient and share advice.

Imatinib affects people in different ways. Most get watery eyes and puffy eyelids. Many people experience nausea, diarrhoea, or swollen ankles. Side effects usually get better after a time.

Sunitinib tends to produce more side effects than imatinib, the most notable being high blood pressure, inactive thyroid, sore hands and feet, fatigue and stomach upset.

Regorafenib tends to produce side effects such as fatigue, sore feet and stomach upset, sore mouth/mouth ulcers and hair loss/curly hair.

• Monitoring

All GIST patients should receive regular scans to see how their disease is responding. Initially scan frequency is every three months. Scan results will show whether you need further surgery or a change of drug.

Research into GIST

The charity GIST Cancer UK funds research to improve our understanding, and treatment of GIST cancers. To find out more please visit our website www.gistcancer.org.uk

What causes GIST?

We do not know why people get GISTs. Several GISTs are caused by genetic mutations, however current research suggests that there are only a few families in the world where there is a genetic link to hereditary GISTs.