

GIST Support UK (GSUK)

GSUK is a Charitable Trust. The Trust is run for the benefit of GIST patients and carers in the UK by a small group of Trustees, who are themselves patients and carers. Currently there are two meetings for patients and carers each year, run in different parts of the country where patients can meet and hear about the latest developments in the treatment of GIST from leading professionals.

We provide day-to-day support by email or phone, and host a private email discussion group that patients and carers can join. We also have facebook and twitter communities. We can supply the following booklets which cover a range of useful GIST topics:

“GIST for Beginners”

“Eating after GI Surgery for GIST”

“I am a GIST Patient”

(a leaflet to carry around in your purse or wallet).

GSUK 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 GSUK is funded

GSUK receives Unrestricted Educational Grants from Novartis and Pfizer. We also receive personal donations and legacies. Please visit our website to learn more. Or to support us by making a donation online, please visit

www.justgiving.co.uk/gistsupportuk

To donate to our PAWS-GIST fund please visit:

www.justgiving.com/PAWS-GIST

contact fundraising@gistsupportuk.com for fundraising materials.

This leaflet has been produced by:

GIST Support UK

Reg Charity No. 1129219

Advice given by GIST Support UK is that of patients and carers. Medical advice should always be sought from those responsible for your treatment

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**Other useful organisations
for information and support:**

GIST Support International
is an independent patient group based in the US
www.gistsupport.org

The Liferaft Group
is a GIST patient group based in the US, and
supported by Novartis
www.liferaftgroup.org

Macmillan Cancer Support
Tel: 0808 808 2020
Macmillan has many information leaflets on
all aspects of cancer including information on
statutory UK benefits.
www.macmillan.org.uk

Sarcoma UK
is a UK charity for Sarcoma patients and carers
www.sarcoma.org.uk



www.twitter.com/pawsgist
www.facebook.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@gistsupportuk.com

Telephone: 0300 400 0000

(Calls are charged at the national rate)

Online:

www.gistsupportuk.com
www.facebook.com/gistsupportuk
www.twitter.com/gistsupportuk

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 or gullet, the large intestine, rectum, or in the various connective tissues associated with the gut.

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, ordinary chemotherapy is not used on GIST.

How rare is GIST?

There are fewer than 1000 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 Paediatric, Adolescent, Wild-type or Syndromic GIST, (PAWS-GIST) There is a recently formed group of doctors and patients in the UK who are focusing on improving treatment and finding a cure for PAWS-GIST. For more information please contact:
info@pawsgist.co.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 the web site about giving your tumour to our Tumour Bank.)

The doctor may think that there is a risk of your GIST coming back. It may come back close to the original tumour site or it may return somewhere else, usually in the liver. Whether this happens will depend on where the first tumour was, how big it was and how fast it was growing. Small progressing 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 increase the time before recurrence, or prevent it. Adjuvant treatment (to try and prevent recurrence) is approved in the UK for three years, and some clinicians will keep you on treatment for five years depending on how they assess the risk.

• 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 is a very effective treatment in most patients. Large inoperable GISTs often become small enough to remove. Imatinib does not cure GIST: it controls it. It is important to take the pills 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™). In many patients this brings the tumour or tumours back under control. Like all drugs, imatinib and sunitinib have side effects.

Side effects of drugs

Imatinib affects different people in different ways. Most get watery eyes with slight swelling of the eyelids. Many people have nausea or diarrhoea, or swollen ankles. There are other drugs which can help with these symptoms, and the side effects usually get better after a time. Discuss any problems you may have with your oncologist or specialist nurse.

Sunitinib tends to produce more side effects than imatinib, the most notable difference being with high blood pressure and sore hands and feet. Discuss any problems you have with your oncologist or specialist nurse.

• Regorafenib

This drug may be prescribed if imatinib or sunitinib are not working. It is currently approved for use in Scotland and will hopefully be added to the prescribing list for the rest of the UK soon.

• Monitoring

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

Research into GIST

There are groups of researchers looking at new treatments for GIST in UK, Europe and USA.

What causes GIST?

We do not know why people get GISTs. Current research suggests that there are only a few families in the world where there is a genetic link.