

GIST Support UK (GSUK)

GSUK is a Charitable Trust, (number 1129219). There are seven Trustees who are patients and carers, and who run the Trust for the benefit of all GIST patients and their carers in the UK. Currently there are two meetings for patients and carers each year, one in London and one in the North. The Trust provides day-to-day support by email or phone, and there is also a private Maitalk group that patients and carers can join. GSUK also has contact worldwide with other organisations concerned with GIST.

How GSUK is funded

GSUK receives Unrestricted Educational Grants from Novartis and Pfizer. We also receive some personal donations and legacies.

How to contact GIST Support UK

Email addresses can be found on the website:

www.gistsupportuk.com

Or you can phone on

0300 400 0000

(Calls are charged at the national rate.)

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:

Macmillan Cancer Support

www.macmillan.org.uk

Tel: 0808 808 2020

Macmillan and Cancer Backup have now merged and have many information leaflets on all aspects of cancer including information on statutory UK benefits.

GIST Support International

is an independent patient group based in the USA

www.gistsupport.org

The Liferaft Group

is a patient group based in the USA, and supported by Novartis

www.liferaftgroup.org

Sarcoma UK

is a UK group for Sarcoma patients and carers.

We work closely with them.

www.sarcoma-uk.org



You have been given this leaflet because you have been diagnosed with a Gastro-Intestinal Stromal Tumour (GIST). This is a rare cancer, but you do not have to be 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.



www.gistsupportuk.com

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 different kinds of cancer is very different.

How rare is GIST?

There are about 850 cases of GIST found in the UK each year. Most people affected are in late middle age, but it can occur in young people too, although this is extremely rare. GIST in children and young adults is called paediatric GIST, and seems to behave rather differently from GIST in older people. Paediatric GISTs tend to grow more slowly and respond differently to drugs.

(For more information, go to the Liferaft web-site.)

What causes GIST?

We do not know why people get GISTs. There are a few families worldwide where there appears to be a genetic link.

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.

However, the doctor may think that you have a high 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.

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. There is only limited evidence so far on whether this helps the patient in the long term. This is not yet funded automatically by the NHS, but your doctor may decide to apply to your Primary Care Trust (PCT) for exceptional treatment.

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 imatinib

These affect different people in different ways. Most get watery eyes with slight swelling of the eyelids. Many people have nausea or diarrhoea, or swelling ankles. There are other drugs which can help with these symptoms, and the side effects usually get better after a time. Do read the information sheet carefully, and discuss any problems you have with your oncologist or specialist nurse.

Side effects of sunitinib

Sunitinib tends to produce more side effects than imatinib. Again, read the information sheet carefully and discuss any problems you have with your oncologist or specialist nurse.

Further surgery

It may be possible to remove small stable GISTs by further surgery or by using a technology called Radio Frequency Ablation (RFA).

Research into GIST

There are groups of researchers and pharmacists looking at new treatments for GIST.

Clinical trials are carried out at the major Sarcoma Centres in the UK as well as in other countries. This is one reason why it is recommended that most patients with GIST should be treated in these specialist centres.