

# GIST for Beginners

a guide for patients by patients



**You do not have to be alone!**

**gust**  
support **uk**  
*The GIST cancer charity*

# Gastrointestinal Stromal Tumour

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This is the name of a rare form of cancer which one usually never hears about. This guide is for all GIST patients, their relatives/friends and for others who may be interested. It is a short explanation of GIST cancer and how it is treated.

This booklet was inspired by a booklet produced for the Stichting Contactgroep GIST Nederland-Belgie. It was adapted by Judith Robinson for the first UK edition. This is the third edition (2017) bringing the GIST community up-to-date.

## DISCLAIMER

This booklet has mostly been written by patients except where otherwise stated.

The information is not intended to replace expert medical advice that you may be given. We do our best to ensure that any information we publish is accurate, but any decisions about your treatment should be made after discussion with your consultant (preferably a GIST expert).

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## Introduction

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**Gastrointestinal Stromal Tumour**, or GIST for short, is a very rare cancer, a kind of sarcoma (cancer of the soft/connective tissues, rather than a carcinoma).

So, people who get this diagnosis not only face the shock and fear experienced by all patients who get a cancer diagnosis, but also a feeling of isolation, as no-one (even many medical professionals), will have heard of it.



However, since the year 2000 massive strides have been made in the understanding and treatment of GIST, and the future for GIST patients now looks much brighter than it did back then.

GIST Support UK is a patient support group and charity started and run by patients and their carers, to provide information and mutual support for patients. We also raise awareness amongst patients and medical professionals and raise funds to stimulate GIST research. Much information is now available for GIST patients and their families, provided by various support groups around the world such as our website and the excellent website by GIST Support International ([www.gistsupportuk.com](http://www.gistsupportuk.com)).

This booklet is aimed at newly diagnosed GIST patients and their families and friends in the UK.

Since GIST is rare, the chances of meeting another GIST patient are very small. We hope you will join our community and our Listserve (*private online patient forum*). You are also most welcome to come to our regional patient meetings.

We all remember very well the relief at meeting other patients at our first GIST Support UK meetings. We were no longer so alone, and could talk to others who really understood.

**The Trustees of GIST Support UK**

## What is cancer and what is GIST?

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The human body is made up of countless cells. Each cell contains information which is copied during cell division. The stomach or intestines are made up of special cells which help them to do their job. Most organs remain healthy by getting rid of old cells that no longer work. These are replaced by new cells and this process takes place in the body all of the time.

Cancer occurs when there is a breakdown in the natural genetic process. This process makes a cell grow and divide when it is not supposed to. When this happens it becomes a cancer cell and when a mass of these cells develop it becomes a tumour.

Some tumours are harmless because they lack the capacity to spread to other parts of the body. These are called **benign tumours**. However others can spread and when this happens it is called metastasis. Such tumours can threaten your health and are called **malignant tumours**.

**GIST (Gastrointestinal Stromal Tumour) is a soft tissue sarcoma.** This means that it grows in the gastrointestinal or digestive system. It is classified as a stromal tumour because the cancer starts in the wall of the stomach or intestine, rather than in the cells that line it, which give rise to carcinomas. A GIST can occur in almost any part of the digestive tract but it is most often found in the stomach or small intestine.

GISTs often occur as a single tumour however some of the cancer cells may enter the bloodstream. This can result in new tumours forming in other organs of the body. This is called **metastasis**. If this happens in the liver for example, it is still classified as a GIST as cancers are named by where they first appear and by the kind of cancer cells they are, since this tells you how they are going to behave.

The treatment of sarcomas requires a multidisciplinary team of experienced doctors and other health professionals. Sarcomas

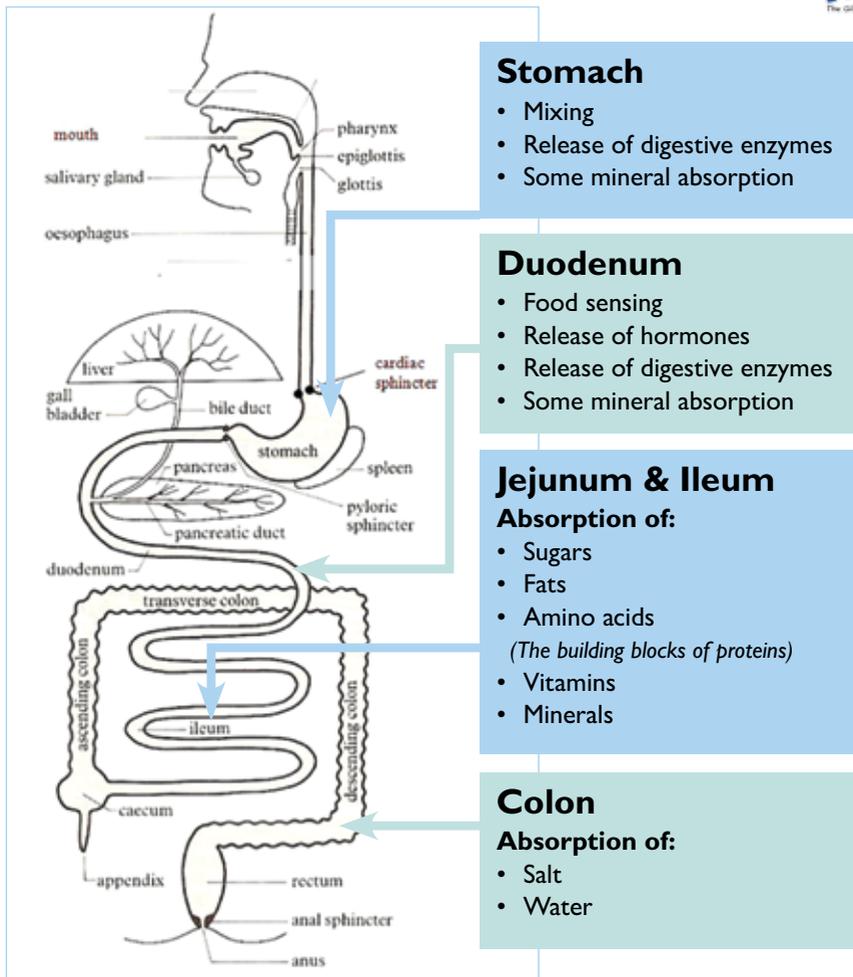
are rare, so there are relatively few doctors who specialise in their treatment. There are a number of hospitals which have a specialist team that manage GIST patients and these are based throughout the UK. The hospital in which you are being treated will have discussed your case at a Multidisciplinary Team (MDT) meeting which is made up of specialists of all medical disciplines related to your treatment and the whole team will agree your treatment.

GISTs can vary greatly in size and in the ease with which they can be treated. They may be very small, 1-2 cm in diameter, or they can be large, up to 20 cm or more in diameter. They may be easily removable, or be wrapped round internal organs. Secondary tumours (metastases), can also develop in a different place from the original primary tumour, either in the liver or elsewhere within the abdominal cavity. This is because blood goes directly from the stomach and intestines to the liver and because cells may have escaped from the outside of the GIST and spread within the abdominal fluid. It is important that the primary GIST is found early and treated, to reduce the risk of it metastasizing, or spreading. Although large fast-growing GISTs are the most likely to return, even small tumours may metastasize eventually.

GIST is most commonly found in the stomach (60%), followed by the small intestine (30%) and the rectum and colon (7%). GIST is also very rarely found in the oesophagus and within the abdomen with no obvious primary site in the bowel.

Occasionally GISTs may be discovered outside the gastrointestinal tract. This can be in the omentum (a large fatty structure covering the intestines inside the abdomen), in the peritoneum (a thin membrane that forms the lining of the abdominal cavity), or in the retroperitoneum (the space in the abdominal cavity behind the peritoneum).

When a GIST is found, metastases may already have grown in other organs. The risk of this increases with increasing tumour size and is



more likely in those GISTs arising in parts of the gut other than the stomach. If the tumour bleeds into the abdomen or ruptures during surgery, cells are likely to spill into the abdominal cavity, giving rise to secondary tumours later. This situation is sometimes treated as if metastasis has already occurred, i.e. with imatinib (see later).

GISTs are treated differently from the common cancers of the stomach or bowel and need the attention of surgeons and oncologists who specialise in the treatment of GIST.

## What causes GIST?

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As yet we have not identified any cause such as diet, smoking, occupation or life style that is associated with an increased risk of GIST.

GIST became properly recognised as a disease in its own right in the late 1990's, when it became possible to diagnose it reliably. It arises from the 'interstitial cells of Cajal'. These form a network of cells in the wall of the digestive tract, or bowel and coordinate the movement of the bowel that propels food along it. GISTs can grow from this wall into the abdominal cavity, and sometimes grow very large before causing any problems and being discovered.

Most GISTs are caused by alterations in either the KIT or the PDGFRA gene. These alterations (mutations) can activate cell division and growth and are crucial to the development of the majority of cases. In most cases of GIST, it is the KIT gene that mutates. In about 10%-15% of cases it is the PDGFRA gene that mutates. In a further 10% -15% of cases, neither of these genes has mutated and a different mechanism is responsible. These are called "Wild-type" GISTs (see PAWS-GIST page 37).

Although GIST is diagnosed mainly in people aged between 40 and 60, it can occur in people much younger than this and even (although not often) in children. In younger people it is usually called paediatric GIST and it differs in some ways from the types of GIST found in older people. GIST is hardly ever hereditary, so there is little likelihood of you passing it to your children.

It is estimated that there are about 900 new cases of GIST diagnosed per year in the UK. Accurate data are now being collected. Sometimes in the past, GIST was mistaken for another type of cancer.

## Possible symptoms of GIST

GISTs often show no symptoms for a long time. The first symptoms are often caused by the tumour pressing on some other organ. Sometimes the GIST may bleed into the abdominal cavity or the alimentary canal. This causes anaemia. If the GIST is large, the doctor may be able to feel a swelling in the abdomen. GISTs, particularly in the liver, can also cause night-sweats.

- **GIST in the oesophagus** can cause difficulty with swallowing (dysphagia).
- **GIST in the stomach** can cause pain or discomfort, indigestion, nausea, vomiting, feeling of fullness, bleeding into the gastrointestinal tract causing black coloured stools, or any combination of these.
- **GIST in the intestine** can cause bleeding, constipation, diarrhoea or just vague abdominal discomfort.

All these symptoms can be caused by common problems.

However if they haven't responded to simple treatments, or got better on their own, your GP will then refer you to a gastroenterologist.

Some of the following tests will then be done...



**COULD IT BE GIST? - CANCER**  
<http://www.glistsupportuk.com>

**GIST = Gastro-Intestinal Stromal Tumour**

**How common is GIST?**

- 600-1,000 new cases yearly in the UK
- mostly diagnosed: age group 40 - 60
- 60 - 100 children and younger adults affected each year

**Possible symptoms**

- Abdominal swelling / bloating / lump
- Persistent / Unexplained Indigestion
- Persistent / Unexplained Nausea
- Discomfort or pain in the stomach
- Bleeding from the stomach
- Weight gain / Weight loss
- Fever / Night sweats
- High blood pressure
- Anaemia

**What we do**

- Provide information for patients/doctors
- Improve the treatment of GIST
- Support research
- Represent patients' interests

**GIST is rare, but you are not alone**

[admin@glistsupportuk.com](mailto:admin@glistsupportuk.com)  
 0300 400 0000  
[www.glistsupportuk.com](http://www.glistsupportuk.com)  
[www.facebook.com/GISTsupportuk](https://www.facebook.com/GISTsupportuk)  
[www.twitter.com/GISTsupportuk](https://www.twitter.com/GISTsupportuk)  
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## Diagnostic tests

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### **Endoscopy**

A tube with a tiny camera is passed into the stomach. You may be sedated for this procedure. GISTs growing on the outside of the stomach cannot be seen. Sometimes ultrasound is done from inside the stomach to give a clearer picture than would be possible with ordinary ultra-sound. This is called endoscopic ultrasound (EUS). This will show tumours both inside and outside the stomach. During an endoscopy, small pieces of the tumour can sometimes be removed for examination. This is called an endoscopic biopsy and the samples collected using this method can be used to confirm a GIST diagnosis in the pathology laboratory. If there is fresh blood in the stools you may have a colonoscopy, i.e. the endoscope is passed via the anus into the large bowel (rectum and colon). For small bowel (duodenum, jejunum and ileum) GISTs there isn't any way of getting to the tumour with a tube.

### **CT scan (Computed Tomography)**

This is the commonest diagnostic tool. It uses X-rays to build up a three-dimensional picture of your inside. It is painless. You will usually be asked to drink some water and be given an injection of a contrast medium into a vein. If for some reason you cannot take the contrast medium, you will be given a special liquid to drink before you have the scan.

### **Ultrasound**

This is a painless and harmless procedure using no X-rays. It is used all the time for looking at unborn babies, but is also good for finding tumours.

### **MRI-scan (Magnetic Resonance Imaging)**

This is a technique for measuring the activity of cells and their blood supply by using a magnetic field and radio waves. It uses no radiation, is painless, but noisy, and takes quite a long time.

## **PET scan (Positron Emission Tomography)**

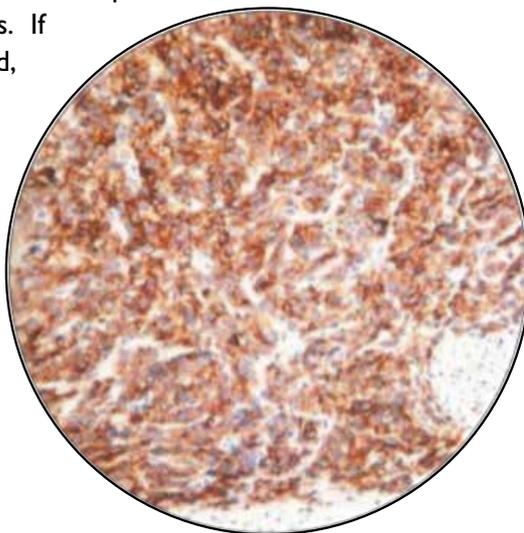
This is rather like a CT scan but you are given an injection containing a kind of glucose containing a small amount of radioactivity. Very actively growing cells will absorb more of this glucose than other cells and are then highlighted on the scan. A PET scan is usually used either before surgery if the doctor thinks there may be more than one tumour, or to see how your tumour(s) is responding to treatment.

## **Blood tests**

Your blood will be tested to see whether you are anaemic, and to check whether your liver and kidneys are working well.

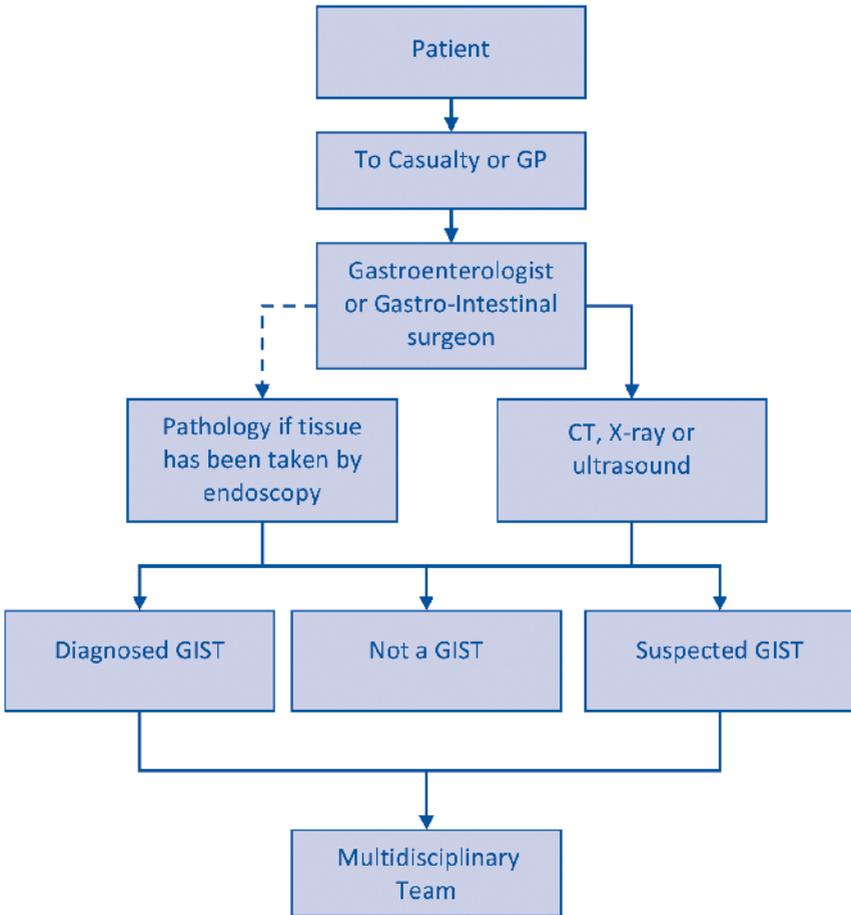
## **Histology**

This means looking at the cells from your tumour under a microscope. If a biopsy is taken before you have any surgery, this biopsy sample will be examined and this will help to confirm the diagnosis. If your tumour is removed, it will be looked at by the pathologist. The diagnosis of GIST can then be confirmed. The edges of the tissues removed will be very carefully examined to make sure that all the tumour has been removed.



**This is what GIST cells look like under the microscope when they have been stained by the pathologist**

This diagram shows the steps that you may have been through before it is suspected that you have a GIST.



N.B You should confirm with your oncologist/surgeon that the MDT (Multidisciplinary Team) working on your case includes or seeks an opinion from an oncologist and surgeon who specialise in GIST.

*I may have been lucky but I have found life on imatinib quite bearable. It has not stopped me from doing anything. And it seems to have been effective in shrinking my tumour. So I am grateful for imatinib and for an NHS which is ready to pay for it.*

**Hugh** GIST patient

## Diagnosis of GIST

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Although the site of a tumour may suggest that it is a GIST, GISTs can only be definitely diagnosed after the pathologist has looked at the cells under the microscope. This may be done before any treatment if a tissue sample has been removed by a biopsy. Otherwise a firm diagnosis will be made after the tumour has been removed

The pathologist will also estimate the rate at which the tumour is growing. This is done by counting the number of cells which are in the process of dividing (undergoing mitosis) in 50 high-power fields of the microscope. This is the “mitotic count per 50 HPF”. The higher this is, the faster the tumour is growing. There are a number of accredited GIST pathology laboratories in the UK – you should request mutational analysis at one of these.

## Risk of recurrence

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The risk of a GIST coming back after surgery depends on three things:

- How big it is
- Its mitotic count (i.e. how fast the tumour cells are multiplying)
- Where it is growing

See the table below detailing of risk of recurrence

Risk category	Tumour size (cms)	Mitotic count per 50HPFs	Place of primary tumour
<b>Very low</b>	Less than 2	5 or less	Anywhere
<b>Low</b>	Between 2 and 5	5 or less	Anywhere
<b>Intermediate</b>	Between 2 and 5	More than 5	Stomach
	More than 5	Between 6 and 10	Anywhere
	Between 5 and 10	More than 5	Stomach
<b>High</b>	Any size	Any	The tumour has ruptured before or during surgery
	More than 10	Any	Anywhere
	Any size	More than 10	Anywhere
	More than 5	More than 5	Anywhere
	Between 2 and 5	More than 5	Not in the stomach
	Between 5 and 10	5 or less	Not in the stomach

Note: This table is proposed by a British group of GIST experts, adapted from a table produced by H Joensuu in 2008.

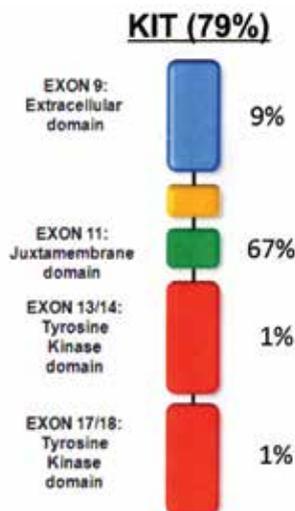
The best GIST to have (apart from none!) is a small one on the stomach, growing very slowly.

## Mutation analysis

Mutation analysis is a key predictor for the course of the disease, and may determine treatment options. If GIST is diagnosed, there is usually a mutation discovered in the KIT or PDGFRA genes. This change takes place at a particular place in the chromosome, called an exon.

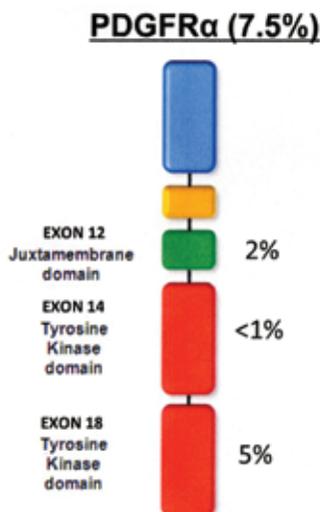
## KIT mutations occur in about 80% of GISTs:

- Exon 9: mostly in tumours in the small intestine
- Exon 11: the commonest mutation, which can occur anywhere in the alimentary canal
- Exon 13: rare
- Exon 17: rare



## PDGFRA mutations occur in about 10% of GISTs:

- Exon 12
- Exon 14 is very rare
- Exon 18 is the most common almost exclusively in the stomach



## Wild-type GIST – where there are no mutations in either KIT or PDGFRA genes occur in c. 10-15% of GISTs:

We recommend that all patients with GIST should ask to have mutational testing performed. Mutational testing is particularly important in the case of tumours in the high risk group and is mandatory before considering adjuvant (i.e. preventive) treatment with imatinib after surgery.

## Special rare types of GIST

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### Wild-type GIST

If none of the normal mutations already described is found, nor any other mutations in KIT or PDGFRA, then the tumour is called “Wild-type”. This can be found in patients of any age but is commonest in younger patients.

### Paediatric GIST

Paediatric/adolescent GISTs occur in patients under the age of 25 years. They are often located in the stomach, can be multifocal and are mostly Wild type i.e. do not have any mutations in KIT or PDGFRA genes.

Some of these can be associated with certain syndromes (see below). It is usual for PAWS-GIST tumours to be slow growing so with specialist management the outlook is generally a positive one. (see PAWS-GIST Alliance on page 37).



### Syndromic GIST

GIST may occur as what is called Carney’s Triad, which is a combination of GIST, lung chondroma and paraganglioma. Two or three of these may occur together. It may also occur in the Carney-Stratakis Dyad Syndrome. Both of these syndromes are extremely rare. GISTs may also occur as part of the neurofibromatosis syndrome (NF1).

### Familial GIST

In an extremely small number of families in the world, there appears to be an inherited form of GIST.

Much more detail about all of these special forms of GIST can be found on the PAWS-GIST clinic website [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk) and more information about the clinic can be found on pages 37 & 38.

## Treatment of GIST

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GIST requires a multidisciplinary approach, which means that a group of experts should be involved, probably including:

- **A surgeon** (with experience of GIST surgery).
- **A gastroenterologist** (a specialist in the gastrointestinal tract)
- **An oncologist** (a doctor who specialises in diagnosing and treating cancers)
- **A pathologist** (a doctor who specialises in cell biology & imaging).
- **A radiologist** (a doctor who specialises in diagnosing and treating cancers using medical imaging techniques).
- **A specialist nurse** (often referred to as a CNS – Clinical Nurse Specialist).

They form the **Multidisciplinary Team, (MDT)**, and decide together on the best treatment for each patient.

It is really important that a relationship of trust is established between you and your doctors. If for any reason you feel uncomfortable about the way you are being treated, **do ask for a second opinion**. This is particularly important if you are facing major surgery. Your GP can arrange for a second opinion, and you may be able to find suitable GIST experts from our website or from the lists on our website [www.gistsupportuk.com](http://www.gistsupportuk.com).”

## What are the options?

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**I. Surgery** If the tumour is small and easy to get at, and has not spread, surgery is the usual treatment. This may be possible laparoscopically, (by key-hole surgery), but open surgery may be needed. If this is happening you may find a copy of our booklet, **“Eating after GI Surgery for GIST”** useful.

## **2. Adjuvant treatment with imatinib (Glivec®) after surgery**

If the tumour has a high risk of recurrence, trial data shows that taking imatinib after surgery statistically increases the time to recurrence. It also increases overall survival, and more data is being collected to confirm these findings. Imatinib has now been approved in the UK as a standard treatment for 3 years following surgery in high risk patients.

## **3. Treatment with imatinib before surgery, or for advanced disease**

If the tumour is too difficult to remove surgically and there is a possibility that it might shrink with imatinib, making surgery possible, then imatinib is likely to be the initial treatment. Imatinib usually stops the tumour or tumours growing. It may also cause a tumour to shrink, sometimes making it possible for it to be removed surgically. Apart from inoperable tumours there are two situations where primary treatment with imatinib should be considered – either a large tumour in the stomach where immediate surgery would involve removing the whole stomach (total gastrectomy), and a tumour in the rectum, where it has been shown that initial treatment with imatinib usually makes surgery easier and it may be possible to avoid having a permanent colostomy (bag on the abdominal wall).

If the disease has spread, either to the liver or to other places within the abdomen, then initial treatment will always be with imatinib. Imatinib does not have the same side effects as cytotoxic chemotherapy, used for many other cancers. Normal chemotherapy affects all growing cells, and causes healthy cells to be destroyed. This leads to a number of difficult side effects such as low blood cell counts, infection risk and hair loss. Imatinib works differently and is one of a group of drugs called targeted agents (see page 21). These act mainly on the GIST cells, so they cause far fewer side effects than the usual drugs used to treat cancer. Targeted drugs are taken every day as a pill.

However, imatinib does cause a number of side effects such as tiredness, nausea, diarrhoea, puffy eyes (and sometimes ankles), skin rash and other problems. Some of these, such as the tiredness

and diarrhoea, may get easier after the first 6 months of treatment. Occasionally it is necessary to decrease the dose to reduce the severity of side effects, but problems like diarrhoea and nausea can be ameliorated by giving drugs such as loperamide and metoclopramide. Imatinib is given with food, usually the main meal of the day, and some patients find the tiredness and fatigue less troublesome if they take it at night.

While you are taking imatinib you should have regular blood tests to make sure that you are not anaemic and that your liver and kidneys are working well. You should also have CT or MRI scans every three months, at least in the first few years.

## What if imatinib does not work or stops working?

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### **I. Change to sunitinib (Sutent®)**

To deal with the problem of resistance, other drugs are available to use when imatinib stops working or does not work. The drug usually prescribed after imatinib is sunitinib (Sutent). Sunitinib binds differently to the KIT or PDGRA protein, sometimes overcoming resistance to imatinib, and it also helps to stop new blood vessels from growing. This may contribute to the antitumour effect on the GIST, although this is unclear, but because it is a general effect, rather than just affecting the GIST cells, sunitinib can produce more side effects than imatinib, such as worse fatigue, hoarse voice, severe diarrhoea, and high blood pressure.

Before you are given sunitinib, you should be given the patient booklet published by Pfizer. This gives you hints about how to prepare, how to take the pills and what to do about any side effects you may have. If the normal regimen doesn't suit you it may be possible to change the dose or the pattern of the way you take the drug. Talk to your doctor if you want to change the way you take sunitinib, or the dose you take.

## **2. Increase the dose of imatinib to 800 mgs a day**

Funding for this is not generally available under the NHS, but some NHS CCG (Clinical Commissioning Groups) areas will fund it from the Cancer Drug Fund. If you know you have an exon 9 mutation, this would probably be the best course to take if you can get the drug, since it has been proved to work better than 400 mg for exon 9 mutant GISTs.

## **3 Regorafenib (Stivarga)**

This drug has now been approved for GIST in the European Union and is available for oncologists to prescribe after patients have progressed or are intolerant to imatinib and/or sunitinib. At the time of writing regorafenib is the standard third line treatment for GIST patients in Scotland and Wales and is available to patients in England via the Cancer Drug Fund. If you live in Northern Ireland your doctor can apply to your local Health and Social Care (HSC) Trusts through the Individual Funding Requests (IFR) process.

## **4. Enter a clinical trial**

There are sometimes new drugs becoming available which are currently under trial. Ask your oncologist about whether you might be eligible for entry into a trial. Trials usually have very strict entry criteria which depend on what treatments you have already had, so eligibility will not be a foregone conclusion.

## **5. Have more surgery**

This could be open or laparoscopic..

## **6. Less common treatments**

- **Radio Frequency Ablation**, where the tumour is effectively cooked by focused microwaves. This may be appropriate for a limited number of tumours in the liver.
- **Radiotherapy**. It had been thought that radiotherapy does not work for GIST. However there has recently been some experimental use of radiotherapy on GIST patients who have no other treatment left to try. It has been found to be quite successful in shrinking the

tumours, so more work needs to be done to see how radiation can best be used for GIST patients.

The Cyberknife can irradiate the tumour from many directions by highly focused X-rays. Currently there are very few Cyberknife installations in the world, and the treatment is still experimental.

- **Embolisation**, where the blood supply to the tumour is choked off, so that the tumour dies.

If you like diagrams, the chart on the next page shows the possible steps in your treatment. This has been adapted from a chart in “Suggested Guidelines for the Management of GIST 2011.

There is now a National GIST Tissue Bank for GIST cancer samples, where fresh tumour or wax blocks of tissue can be stored along with blood samples.

Please confirm with your surgeon if you wish to consent for your tissue samples to be sent to the National GIST Tissue Bank at the Royal Marsden Hospital in London. You can access the consent form and further information via [www.givemysample.org](http://www.givemysample.org) where the National GIST Tissue Bank is registered. Please see page 42 for more information.

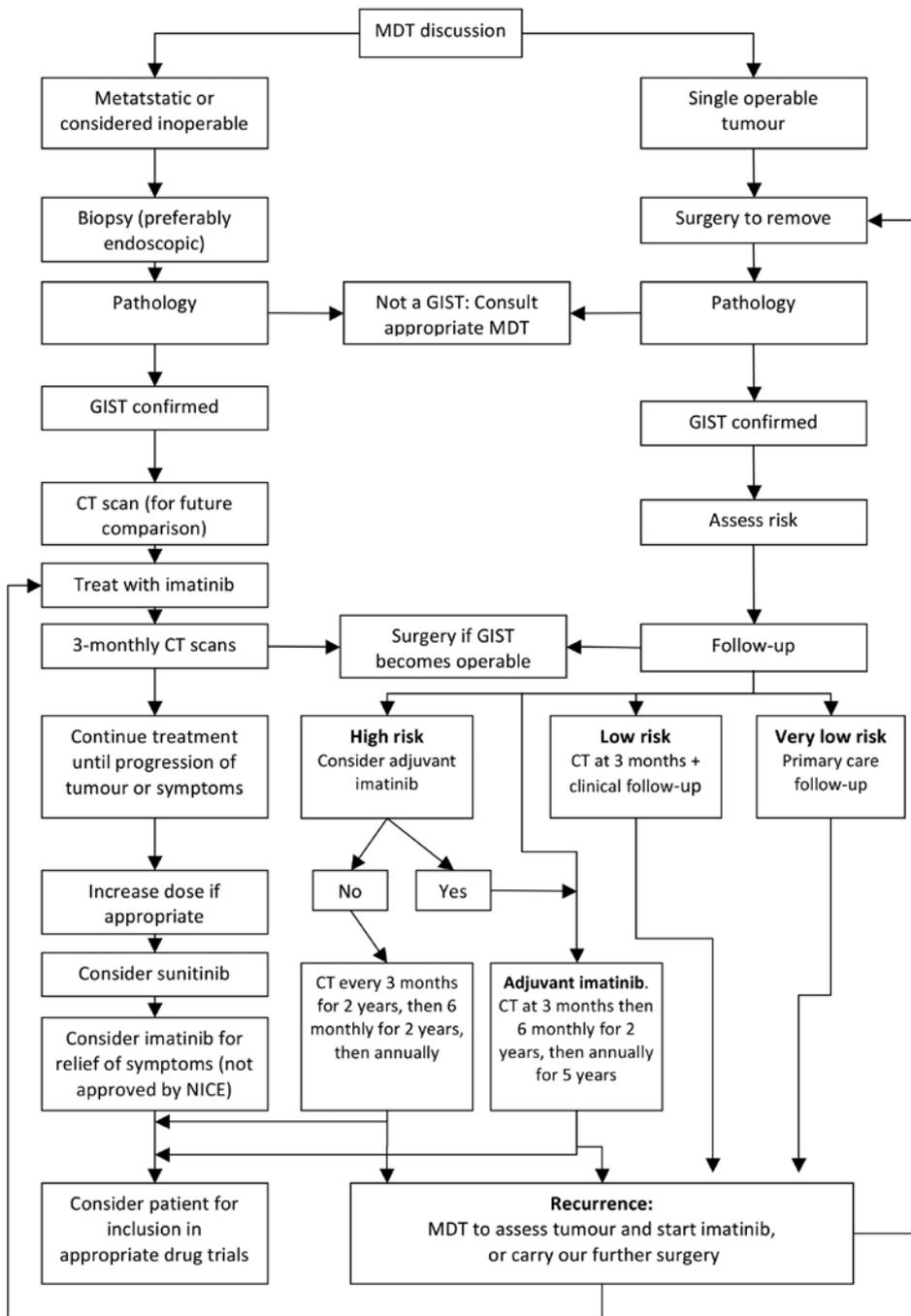
This should be organised and agreed well in advance of surgery.

## How targeted drugs work.

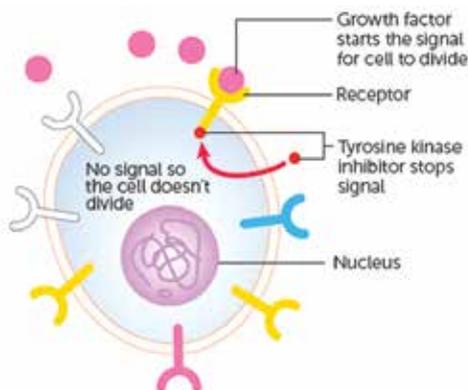
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The first, second and third line targeted drugs available in the UK are imatinib (Glivec®), sunitinib (Sutent®) and regorafenib (Stivarga®). Clinical trials are being performed across the world investigating other new targeted drugs.

Tumours form when a cell starts to grow in an uncontrolled way. It does this because there has been a change in the genes in the cell. We do not know why this happens in GIST. The genetic change means that



the very complex system, which should tell the cell when to grow and when not to grow, stops working. The cell just goes on dividing, and a tumour grows. What the targeted drugs do is to block one of the essential steps in the growth-signalling system in these particular cancer cells, without affecting the normal cells of the body.



Imatinib was the first targeted drug used to successfully treat GIST, and it is still the first choice because it is usually easy for patients to take and gives relatively few side effects. At the moment we don't have a specific treatment to deal with the loss of the enzyme succinate dehydrogenase, which is found in most Wild-type GISTs, although this does result in some responsiveness to sunitinib and regorafenib, both of which inhibit the blood vessel growth (angiogenesis) pathway. The PAWS-GIST initiative has been started both to support patients and help foster research in this area. (see page 37 & [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk)).

Unfortunately, we now know that GIST cells quite often mutate again, and find a way round the block in the signalling pathway. This means that the tumour can start to grow again. In some patients this happens in a few months, but we know of some patients who have been taking imatinib for 10 + years, and it is still working. The average time is two to three years. Why there is this difference is a question we cannot yet answer. Another question we don't know all of the answers to, is why there is a small percentage of patients who do not respond to imatinib at all. We know that Wild-type and paediatric GISTs respond less well than other GISTs to imatinib, but there is much more we need to know about this. This is why the PAWS-GIST initiative has been started.

The most common side effects of imatinib noticed by patients are	Patients' suggestions for dealing with them
Puffy eyelids	Put up with it: we all have this!
Swollen ankles	Put your feet up when you can
Indigestion or feeling sick	Take your pills with your main meal and with a large glass of water. Try peppermints, or if they don't work try Gaviscon.
Being sick	Ask your GP for help. There are various medicines which can help
Diarrhoea or abdominal pain	Ask your GP for help.
Rash	Ask your GP for help
Cramp, particularly at night.	Make sure your blood chemistry is fine. If it is, some patients find that quinine helps. Tonic water contains small amounts of quinine, but if this is not enough, ask your GP.
Tiredness	The only answer is to get more rest.

## Side effects

If you read the leaflet which is enclosed with the pills of imatinib, sunitinib or regorafenib, you could start feeling ill – before you have even taken a single pill! However, remember that the company which makes the pills has to mention every side effect ever known, and most of them are very rare. Some are fairly common, but most of these, at

least for imatinib, are quite easy to cope with (see table on page 24). With all drugs, some patients have virtually no side effects, and many people find that the side effects they have at first become less of a problem after time. You should always discuss any side effects that you are experiencing with your consultant.

## Nutrition

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Taking targeted medicines may cause a temporary loss of taste. Food and drink suddenly taste different. This does usually get better in time. In the meantime, try to keep up a healthy weight by eating all kinds of good food, and try to avoid eating a high-fat diet or too much sugar. Eat plenty of fresh fruit and vegetables.

If you feel sick, it may be helpful to eat small amounts of food and keep the fluids up well. If this doesn't help, your doctor may prescribe you a medicine to tackle the nausea. If you experience significant weight loss please ask your GP or oncologist to refer you to a consultant nutritionist who will help you to create a strategy to gain and stabilise your weight.

**Note:** Grapefruit (juice) in combination with imatinib (Glivec®), sunitinib (Sutent®) and regorafenib (Stivarga®), is strongly discouraged, as grapefruit will interfere with the way the liver eliminates the drugs from the body leading to much more severe side effects. There are other side effects that may show up when you have your blood tests at your hospital checks, and the hospital doctors will advise you about these. You will also have regular CT scans, usually every three months, to check that the treatment is working.

There are a few very rare and possibly serious side effects. These include, chest pain, sudden bleeding in the stomach or intestine producing black stools, sudden high fever or very sore throat, rapid swelling and weight gain, and sudden shortness of breath. If you have any of these, go to your nearest A&E department, and make sure the doctors there know that you are a GIST patient and taking imatinib,

sunitinib or regorafenib.

If you are one of the very few unlucky people for whom the side effects become intolerable, and nothing seems to help, it may be possible to lower the dose. **This is something you must talk to your GIST specialist about.** (We do know of a patient who remained stable on only 100mg imatinib per day.) It is your life, and only you can decide when something is too bad to live with.



There are some drugs which interact with imatinib, and should not be taken. Always inform your doctor if you are taking any other medication.

GIST Support UK publishes a little pocket booklet called “**I am a GIST Patient**”, which lists the drugs you need to avoid, and in which you can record the details of your own treatment.

If you need medicines for something other than GIST, you can always show your pocket booklet to your GP or to the hospital where you are being treated. Always carry the booklet with you. You should also remember that you must avoid some foods, and over-the-counter remedies, like grapefruit and St John’s Wort. It is a good idea to keep a list of everything you are taking, even vitamins, and show it to your hospital doctor.

## Guidelines for treating GIST

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Teams of doctors have prepared guidelines for the best way of treating GIST. They have looked at all the known evidence from clinical trials. For example, there are the European ESMO guidelines, which are brought up to date as new evidence becomes available. There is also a version of this for use in the UK called the “UK clinical practice guidelines for the management of GIST, which form part of the National Sarcoma guidelines and which takes into account the UK

health system and the treatments permitted by NICE.\*

[www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Sarcoma-and-GIST](http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Sarcoma-and-GIST)

These Guidelines also recommend the best follow-up regimen for patients with different risks of recurrence.

Sometimes, there is no clear answer as to how you should be treated in a particular situation. The way forward should then be a matter for you and your close family to discuss with the oncologist and surgeon looking after you. You have the right to be referred elsewhere if you are unsure or unhappy with your current physician or treatment. The UK Guidelines for Gastrointestinal Stromal Tumour can be found on the British Sarcoma Group website [www.britishsarcomagroup.org.uk](http://www.britishsarcomagroup.org.uk).

\* NICE: National Institute for Health Clinical Excellence. This is the government body responsible for deciding which treatments can and cannot be paid for under the NHS in England, Wales and Northern Ireland. In Scotland the Scottish Medical Consortium has this role.

## Compliance

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This just means doing what your doctor has told you to do! In other words, take the pills. It is important for your care that you do your very best to remember to take them. If you don't then the tumour cells have a chance to start growing again. If you happen to miss a dose or two, do tell your doctor. Your care is a joint venture and you do need to have a doctor you trust, and he can only do his best for you if you are honest with him.

## Preparing for your next visit to the oncologist

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Make a list of all the medications you use, whether regularly or once in a while. Talk about any drugs and vitamins you take, both from the chemist and from the supermarket. The best thing is to ask your oncologist or your family doctor what you are allowed to use.

Make written notes of all the questions you want to ask. It is very easy to forget something until you are on the way home. The time with

*I am a patient and a GP, and even with all the knowledge and resources that come with the profession, nothing came close to the help, information, advice and reassurances I received from the group. The group helped me ask the right questions at the right time, and so helped me steer my management in a positive and beneficial way. I am so grateful to everyone and yourselves for this invaluable group.*



**AMNA** GP and GIST patient

your consultant goes very quickly, but s/he will be happy to answer your questions.

It's a very good idea to take a family member or a friend with you. They will often remember things from the discussion that you don't.

### **Questions you might like to ask your oncologist about your treatment:**

- 1 Where is the primary tumour?
- 2 Are there any metastases (secondary tumours)?
- 3 Do you know the mutation (Kit exon, PDGFRA exon, Wild-type?) If not, please can I have mutational analysis?)
- 4 What treatment are you proposing?
- 5 What are the possible side-effects and risks?
- 6 What is the chance that the tumour will come back and that there will be metastases?

- 7 Can I participate in a trial, or are there any new approaches to treatment available?
- 8 How many GIST patients do you treat?
- 9 If you are preparing for or have had surgery: I would like my tissue to be stored in the National GIST Tissue Bank. Are you able to organise this for me?

## Life with GIST

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Hearing the news that you have a rare cancer, and having to face up to all the treatments and hospital appointments can put a huge strain on the life of a GIST patient. Feelings of panic and fear are almost inevitable. Your family and friends will be scared too. There may well be times when you feel depressed, and this is very understandable. Since it often takes years before a GIST is finally discovered, you may have experienced a long period of unexplained symptoms and the lonely feeling of not being understood.

Talking about your feelings helps. You may find it helpful to tell your story to the hospital oncology nurse, who may refer you to a specialist for counselling.

Or you can go to your GP and ask him for support. In any case, do not keep these feelings to yourself, but get help somehow.

GIST Support UK has an online community of GIST patients from all over the UK and further afield. GIST patients and their relatives/carers who sign into our Listserve (online email group) often find other patients who live near to them and form useful friendships, sharing experience and supporting one another. Some meet up regularly for coffee etc.

There are other more general cancer support groups available locally. Some towns have Sarcoma groups, and GIST is a sarcoma, so these groups would be open to you. There may be Macmillan cancer

support facilities near you, or a Maggie's Centre. These provide general information about living with cancer, eating well, and offer complementary therapies which may make you feel better. They also offer a good cup of tea and understanding friendship.

## Finding other GIST patients

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Because GIST is so rare, you are very unlikely to find another GIST patient by chance.

You can find out more about GIST by going to our web site **[www.gistsupportuk.com](http://www.gistsupportuk.com)**, and if you want to, you can make contact with this patient group by emailing us at [admin@gistsupportuk.com](mailto:admin@gistsupportuk.com)

Then you will be invited to the regular patient support meetings. You will also be invited to join our Listserve email group. This group is only for patients and their carers. You may just want to read the postings from others, or you may want to contribute with your story, or to ask questions about other patients' experiences or your own treatment. How you use the group is up to you.

Many patients get huge support from this new group of friends, who really do understand what you are talking about.

## Specialist GIST centres in the UK

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There are a number of hospitals in the UK with specialist clinics and physicians for GIST patients. It can be useful to be aware of these facilities and we will happily share details of your nearest specialist hospital, on request.

This does not mean that your treatment at other hospitals is not good. However, the specialist hospitals see many more GIST patients than smaller ones so they may have more up-to-date information. They are also the hospitals where clinical trials take place.

## Speakers at GIST Support UK patient meetings

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### **Oncologists:**

Dr Charlotte Benson Consultant Medical Oncologist, The Royal Marsden Hospital

Dr Ramesh Bulusu Consultant Clinical Oncologist, Addenbrookes Hospital, Cambs

Dr Palma Dileo Consultant Medical Oncologist, UCH, London

Dr Stephen Falk Consultant Clinical Oncologist, Bristol Royal Infirmary

Dr Ian Geh Consultant Clinical Oncologist, Queen Elizabeth Hospital, Birmingham

Prof Bass Hassan Professor of Medical Oncology, University of Oxford

Dr Ivo Hennig Consultant Medical Oncologist, Nottingham University Hospital

Dr Robin Jones Consultant Medical Oncologist, The Royal Marsden Hospital

Prof Ian Judson Professor of Cancer Pharmacology, The Royal Marsden Hospital

Dr Mike Leahy Consultant Medical Oncologist, Christie Hospital, Manchester

Dr Maria Marples Consultant Medical Oncologist, St James, Leeds

Dr Carys Morgan

Dr David Peake Consultant Clinical Oncologist, University Hospitals, Birmingham

Dr Michelle Scurr Consultant Oncologist, The Royal Marsden (Now living in Australia)

Dr Beatrice Seddon Consultant Clinical Oncologist, UCH, London

Dr Peter Simmonds Consultant Oncologist, Southampton University Hospital

Dr Mark Verrill Consultant Medical Oncologist, Northern Centre for Cancer Care,  
Newcastle

Dr Geoff White Consultant Medical Oncologist, Beeston, Cancer Centre, Glasgow

Prof Penella Woll Sarcoma Specialist Medical Oncologist, Weston Park Hospital, Sheffield

Dr Mark Lynch Consultant Medical Oncologist, The Royal Marsden Hospital

### **Surgeons:**

Mr Evangelos Efthimiou Consultant Surgeon, The Royal Marsden

Mr Long R Jiao Consultant Surgeon, Hammersmith Hospital

Mr Satvinder Mudan Consultant Surgeon, The Royal Marsden

Mr Simon Wood Consultant Surgeon, Royal Gwent Hospital

Mr Simon Toh Consultant Surgeon Portsmouth

## **Other experts:**

**Dr Zahir Amin** Consultant Radiologist, University College Hospital

**Ms Jane Ballantyne** Macmillan Benefits Advisor

**Dr Dominic Bray** Clinical Psychologist, Southport & Aintree Hospitals

**Mr Nick Duncan** Principal Pharmacist, Queen Elizabeth Hospital Birmingham

**Jennie Dyer** Clinical Lead, Complimentary Therapies, The Royal Marsden

**Professor Claire Foster** Professor of Psychosocial Oncology, University of Southampton

**Prof Andy Hall Director**, Northern Institute for Cancer Research, Founder of the National GIST Tissue Bank

**Dr David Hughes** Consultant Histopathologist, Sheffield Teaching Hospitals

**Dr Bill Newman** Consultant Clinical Geneticist, Manchester University

**Ms Sarah Newton** Senior Dietician, The Royal Marsden

**Mrs Cerys Propert-Lewis** Clinical Nurse Specialist, The Royal Marsden

**Janine Salter** National GIST Tissue Bank Manager – The Royal Marsden, London

**Dr Peter Stephens** Clinical Research Associate, Newcastle Cancer Centre

**Dr Phillippe Taniere** Consultant Histopathologist, Queen Elizabeth Hospital, Birmingham

**Dr Newton Wong** Consultant Histopathologist, Bristol Royal Infirmary

**Mr Roger Wilson** CBE Founder of Sarcoma UK and expert patient advocate

**Sara Welby** Clinical Nurse Specialist, The Christie Manchester

## About GIST Support UK

GIST Support UK has been a registered charity since 2008 and is run by a team of volunteer trustees, many of whom are also GIST cancer patients or carers. **Our primary aim is to offer many kinds of support.**



**The GIST cancer charity**    Registered Charity No: 1129219

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**Who we are:**



We are a network of patients and carers, all of whom are affected by GIST.  
We are here to help GIST patients, their families and friends.

**What we offer:**



**A Help line 0300 4000000**  
for GIST patients and their carers.

**Meetings** where GIST patients & carers can share experiences & hear about the latest developments in the treatment of GIST from leading professionals.





A private online patient & carer discussion/question & answer group.

Facebook & Twitter communities





**Booklets and information** for patients/carers/hospitals covering a range of useful topics such as: Treatment options, Eating after surgery...



**PAWS-GIST** - a specialist branch of GIST Support UK that focuses on Children, Younger people and all with Wild-Type GIST. [www.pawsgistclinic.org](http://www.pawsgistclinic.org)

**What we do:**

**Raise awareness of GIST**

**Represent GIST patient interests at:**

- NICE appraisals of new treatments
- National & International meetings

Work to create an infrastructure that supports research and improves GIST patient care.  
e.g. National GIST Tissue Bank

Lobby for the rights of GIST Cancer Patients

Work with the pharmaceutical industry to support research and good patient information about their drugs.

Keep abreast of developments in the treatment of GIST by maintaining contact with:

- pharmaceutical companies
- specialist doctors and research groups
- patient support groups all over the World.

Fundraising to support our work and GIST Research.

***Gastrointestinal Stromal Tumours are rare, but you are not alone!***

If you would like to find our more please visit our website [www.gistsupportuk.com](http://www.gistsupportuk.com) and write to us at [admin@gistsupportuk.com](mailto:admin@gistsupportuk.com) or call our helpline 0300 4000000

## We provide:

- web sites: [www.gistsupportuk.com](http://www.gistsupportuk.com) and [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk) packed with useful information and contacts
- a telephone help line **0300 4000000** for patients and carers
- a private online GIST patient and carer discussion /question and answer group (Listserve)
- 2-3 annual UK regional patients and carer conferences, where you can meet each other and hear about the latest research and developments from the GIST specialists
- Facebook & Twitter communities. Giving you the most up to date information on GIST cancer developments and what GIST Support UK is doing to improve services for GIST patients

## We can give you:

- This booklet **“GIST for Beginners”**, for you and your family. This booklet is also for hospitals to give to newly diagnosed patients
- A pocket sized booklet for patients to keep on their person **“I am a GIST Patient”**
- Information on **“Eating after GI Surgery for GIST”**
- **“No Stomach?”** Help and tips for patients after removal of the stomach/total gastrectomy”
- GIST ribbons so that patients can recognize each other (e.g. at a hospital clinic)
- Awareness posters highlighting symptoms for your hospital or GP to display
- More copies of this booklet for your GP or family



- Advice on the specialist services available to GIST patients and where to obtain specialist second opinions
- Information and help with sending any GIST tumour samples to the **National GIST Tissue Bank** – if you have had or are about to have surgery, please let us know. – This element of our work is vital to assist with GIST research in the UK

### **We also:**

- Keep informed about results of research being undertaken across the world
- Represent GIST patient interests at NICE appraisals of new drugs and other treatments
- Represent GIST patient interests at a National and International level re GIST cancer
- Work to improve/create an infrastructure that is supportive of research to improve treatments and find a cure for GIST.  
E.g. the National GIST Tissue Bank
- Lobby for the rights of rare GIST cancer patients
- Work with the pharmaceutical industry to support research and good patient information about their drugs
- Encourage and support clinical trials and other research
- Try to keep informed about results of research being done across the world
- Represent patients interests at NICE appraisals of new drugs and other treatments
- We lobby for the rights of rare GIST cancer patients



The GIST cancer charity

Registered Charity No: 1129219

**Help Line**

0300 4000000



**Website**

[www.gistsupportuk.com](http://www.gistsupportuk.com)

**Email us**

[admin@gistsupportuk.com](mailto:admin@gistsupportuk.com)

**Facebook**

<https://www.facebook.com/GISTSUPPORTUK>



**Twitter**

<https://twitter.com/gistsupportuk>



**Donate**

<https://justgiving.com/gistsupportuk>



[www.pawsgistclinic.org](http://www.pawsgistclinic.org)

**Facebook**

<https://www.facebook.com/GISTSUPPORTUK>



**Twitter**

<https://twitter.com/pawsgist>



**Donate**

<https://justgiving.com/paws-gist>

**Gastrointestinal Stromal Tumours are rare, but you are not alone!**

If you would like to find our more please visit our website [www.gistsupportuk.com](http://www.gistsupportuk.com) and write to us at [admin@gistsupportuk.com](mailto:admin@gistsupportuk.com) or call our helpline 0300 4000000

## PAWS-GIST (a GIST Support UK initiative)

When my 15 year old daughter was diagnosed with the Paediatric Wild-type form of GIST it was undoubtedly the worst news our family had ever received. Very little was known or available to patients with this diagnosis.



Encouraged by the Trustees of GIST Support UK, with fundraising from our supporters and the knowledge, skills and dedication of **Dr Ramesh Bulusu**, we have opened a specialist clinic for **Paediatric Adolescent Wild-type and Syndromic GIST (PAWS-GIST)**. Our work is aiming to improve treatment, provide highly specialised care plans and find a cure for this rare form of cancer. Our team will work with you to make life as normal as possible for you.

In the longer term we believe that seeing more Wild-type, syndromic and paediatric GIST patients will help us to improve our understanding of this disease and identify specific and effective treatments.

### Jayne Bressington

GIST Patient Carer, Patient Director PAWS-GIST  
Vice Chair and Trustee GIST Support UK



Dr Bulusu (centre left)  
First PAWS-GIST clinic (2014)



## PAWS-GIST

GSUK has promoted an alliance of specialist doctors and patients called “PAWS-GIST”

This group concentrates on **Paediatric, Adolescent, Wild-type & Syndromic GIST (PAWS-GIST)**, raising awareness, raising funds and being a catalyst for research to improve PAWS-GIST treatments.



Working with our clinical lead Dr Ramesh Bulusu we have established the “PAWS-GIST clinic” at Addenbrookes hospital in Cambridge, UK to complement the work being undertaken in America.

If you are a PAWS-GIST patient, please register to attend one of the PAWS-GIST clinics or [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk) rather than the GSUK website address.

Here you will receive world-class advice, a personalised treatment plan and by attending you will be contributing towards research for a cure.

GIST Support UK provides assistance with travel and accommodation for each patient and a carer who attends the PAWS-GIST clinic.

Please contact Jayne Bressington [jayne@pawsgistclinic.org.uk](mailto:jayne@pawsgistclinic.org.uk) for more information.

 [www.facebook.com/pawsgist](http://www.facebook.com/pawsgist),

 [twitter.com/PAWSGIST](https://twitter.com/PAWSGIST)

Or via our website [www.gistsupportuk.com](http://www.gistsupportuk.com)



## Funding and fundraising

GSUK are very grateful to receive grants from Novartis and Bayer. We use these grants to finance our patient meetings and produce information and materials to help patients.

The majority of our funding comes from the general public, patients, their family, friends and other supporters. As we are all volunteers and have no paid staff every penny raised is used to support patients and further our aim of finding alternative treatments and a cure for GIST cancer.

Fundraising is a vital element for the future of our charity and continuing the work that we can undertake on behalf of GIST cancer patients.

In addition to supporting our core operation, it has helped us to undertake further work such as opening the **PAWS-GIST clinic**, **The National GIST Tissue Bank** and financing vital **new GIST research projects**.

We are very grateful to patients and other supporters who organise and participate in fundraising events for us. We have tee-shirts, banners and other items for use at fund-raising events both for GIST Support UK and for PAWS-GIST. More information and fundraising packs can be obtained by:

**email:** [fundraising@gistsupportuk.com](mailto:fundraising@gistsupportuk.com)  
[fundraising@pawsgistclinic.org.uk](mailto:fundraising@pawsgistclinic.org.uk)

**website:** [www.gistsupportuk.com/fundraising.htm](http://www.gistsupportuk.com/fundraising.htm)  
[www.pawsgistclinic.org.uk/donate.htm](http://www.pawsgistclinic.org.uk/donate.htm)



**Donations can be sent to:**

The Treasurer GSUK,  
28 Main Street, Wymondham, Leicester, LE14 2AG

**Cheques for:**

**GSUK funds** to be made out to **GIST Support UK**

**PAWS-GIST funds** to be made out to **GSUK (PAWS-GIST)**

**You can donate online** using **Just Giving** or **Virgin Giving**

**You can donate on a mobile phone by texting:**

GSUK01 £amount to 70070

PAWS01 £amount to 70070

**1000 hours:**

Our '**1000 Hours for GIST**' project is to encourage 1000 busy people who wish to help, to sign up and donate one hour (or equivalent) of their wages each month.

Every penny raised enables us to continue to support patients, raise awareness and fund GIST cancer research. You can help and donate by...

**Setting up a standing order with your bank.**

GIST Support UK banks with HSBC and the bank details are:

**Account name:** GIST Support UK

**Account number:** 00078670

**Sort code:** 40-41-57

*Please quote either 'GSUK 1000 Hours' or 'PAWS-GIST 1000 hours' as a reference.*

Sign up with Charities Trust:

[www.charitiestrust.org.uk](http://www.charitiestrust.org.uk) and select GIST Support UK as your charity of choice.

If you are a tax payer please complete a gift-aid form which can be found on our website and post it to our treasurer above.



## Useful links

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**Sarcoma UK** An organisation dedicated to support and research on all kinds of sarcoma [www.sarcoma-uk.org](http://www.sarcoma-uk.org)

**UK Clinical Trials** The NHS site giving details of UK trials [www.nhs.uk/Conditions/Clinicaltrials/Pages/Introduction.aspx](http://www.nhs.uk/Conditions/Clinicaltrials/Pages/Introduction.aspx)

**Macmillan Cancer Support** Macmillan has many leaflets on all aspects of cancer including information on statutory UK benefits [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Pediatric & Wild-type GIST Clinic USA** [www.pediatricgist.org](http://www.pediatricgist.org)

**Maggie's Centres** These provide emotional and practical support for all cancer patients [www.maggiescentres.org](http://www.maggiescentres.org)

**GIST Support International** An independent international US-based patient group. They have a Listserve group and have produced an excellent leaflet on understanding your pathology results. [www.gistsupport.org](http://www.gistsupport.org)

**SPAEN (Sarcoma PAtients EuroNet)** European organisation for support and advocacy on behalf of sarcoma patients and their carers. GSUK is a member. [www.sarcoma-patients.eu/index.php](http://www.sarcoma-patients.eu/index.php)

**Life Raft Group U.S.A.** A US patient group supported by Novartis [www.liferaftgroup.org](http://www.liferaftgroup.org)

**Twitter:** [GISTSupportUK](https://twitter.com/GISTSupportUK)

**Facebook:** [www.facebook.com/GISTSupportUK](http://www.facebook.com/GISTSupportUK)

# National GIST Tissue Bank

The National Tissue Bank for GIST cancer samples is at The Royal Marsden centre for Molecular Pathology in London, UK.

Here fresh or wax blocks of tumour tissue and blood samples can be stored and are available to researchers.



If you are preparing to have a GIST operation please contact:

**Janine Salter** the Tissue Bank Manager to make arrangements for a sample to be sent to the National GIST Tissue Bank.

**NATIONAL GIST TISSUE BANK**  
INFORMATION FOR CLINICAL STAFF

**FREQUENTLY ASKED QUESTIONS...**

**What clinical approval have you obtained for this bank?**

The National GIST Tissue Bank is a GIST Support Unit. It is a GIST Support Unit which provides a service to GIST patients and their families. It is a GIST Support Unit which provides a service to GIST patients and their families.

**How long will it take to obtain a sample?**

The time to obtain a sample will depend on the type of sample you require. It may take up to 24 hours to obtain a sample. It may take up to 24 hours to obtain a sample.

**What level of samples do you accept?**

We accept the following types of samples:

- fresh tumour tissue
- a small GIST wax block
- a small GIST wax block
- a small GIST wax block

**What should we do if we are hospital already?**

Please contact us if you are hospital already. Please contact us if you are hospital already.

**How can we contact you?**

Professor Rudy Hall, GIST Support Unit, Royal Marsden Centre for Molecular Pathology, 200 Chelsea Road, London SW3 6JJ, UK. Tel: 020 7352 8200. Email: rudy.hall@tmd.ac.uk

**gist**  
The Tissue Bank

**NBODY WANTS GIST TUMOURS WE DO...**  
**NATIONAL GIST TISSUE BANK**

**THE NATIONAL GIST TISSUE BANK LAUNCHED BY NOW - INDIVISIBLE**

More than 1000 patients are registered with the bank. More than 1000 patients are registered with the bank.

**What does this mean for you?**

- The bank is a valuable resource that will support GIST research locally, nationally and internationally.
- It will provide researchers with a diverse selection of high quality GIST tumour specimens for research. It will provide researchers with a diverse selection of high quality GIST tumour specimens for research.
- Research investigators need to have a good supply of GIST tissue specimens to run their research. Research investigators need to have a good supply of GIST tissue specimens to run their research.

**How will the Tissue Bank Operate?**

Operating within the NHS in Newcastle, the GIST Tissue Bank will continue the collection, storage and distribution of a variety of specimens used in GIST research including fresh, frozen and paraffin blocks in addition to small tumour and blood tissue samples. Operating within the NHS in Newcastle, the GIST Tissue Bank will continue the collection, storage and distribution of a variety of specimens used in GIST research including fresh, frozen and paraffin blocks in addition to small tumour and blood tissue samples.

**HOW YOU CAN HELP THE GIST TISSUE BANK...**

If you are a GIST patient or have had or are about to have a GIST tumour removed, please contact the bank of your tumour. Please contact the bank of your tumour.

**CONTACT INFORMATION**

Location: 200 Chelsea Road, London SW3 6JJ, UK. Tel: 020 7352 8200. Email: rudy.hall@tmd.ac.uk

**gist**  
The Tissue Bank

N.B Your local hospital may not be aware of how to organise this so please go to [www.givemysample.org/gist](http://www.givemysample.org/gist) and also alert our **Trustee Jayne Bressington** on [admin@gistsupportuk.com](mailto:admin@gistsupportuk.com). Jayne is very experienced in assisting patients who wish to donate their tissue for research

Letter template to request that tissue samples are sent to the National GIST Tissue Bank.

Dear Dr .....

**Re transfer / registration of my GIST tumour samples with the National GIST Tissue Bank (NGTB) at the Royal Marsden Hospital in London.**

In advance of/further to (*\*please delete as appropriate*) my operation to remove my Gastro Intestinal Stromal Tumour, I am writing to request that my tumour sample, is transferred to/or registered with\* (*\*please delete as appropriate*) the **National GIST Tissue Bank at the Royal Marsden Centre for Molecular Pathology in London.**

**The National GIST Tissue Bank** is collecting, fresh, frozen and paraffin embedded tumour tissue and serum samples from GIST patients throughout the UK who have undergone or who are about to undergo surgery where GIST is diagnosed.

The National GIST Tissue Bank has REC approval and an HTA research licence to make these materials available to researchers in academia or industry for projects concerned with GIST cancer research.

I am very keen to support this work and therefore request that my samples are transferred to or at least registered with the bank.

I have enclosed a copy of my signed consent form and more information about the bank can be found on

[www.givemysample.org](http://www.givemysample.org)

Please can you confirm when the transfer has taken place.

Yours sincerely



[www.gistsupportuk.com](http://www.gistsupportuk.com)

This booklet is published by GIST Support UK  
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