

# GIST for Beginners

a guide for patients by patients



you do not have to be alone!

# Gastrointestinal Stromal Tumour (GIST)

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

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 fourth edition (2020) 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 Cancer UK** (*previously 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 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 and includes our website ([www.gistcancer.org.uk](http://www.gistcancer.org.uk)) and the websites by GIST Support International and The Liferaft Group of America.

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 Cancer UK meetings. We were no longer so alone, and could talk to others who really understood.

**The Trustees of GIST Cancer UK**

## What is cancer and what is GIST cancer?

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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. 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 GI tract (gastrointestinal tract). It is classified as a stromal tumour because the cancer starts in the stroma, which is a type of tissue in the walls 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 GI 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. These are called **metastasis** or secondary tumours. 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 multi-disciplinary team (MDT) of experienced doctors** and other health professionals.

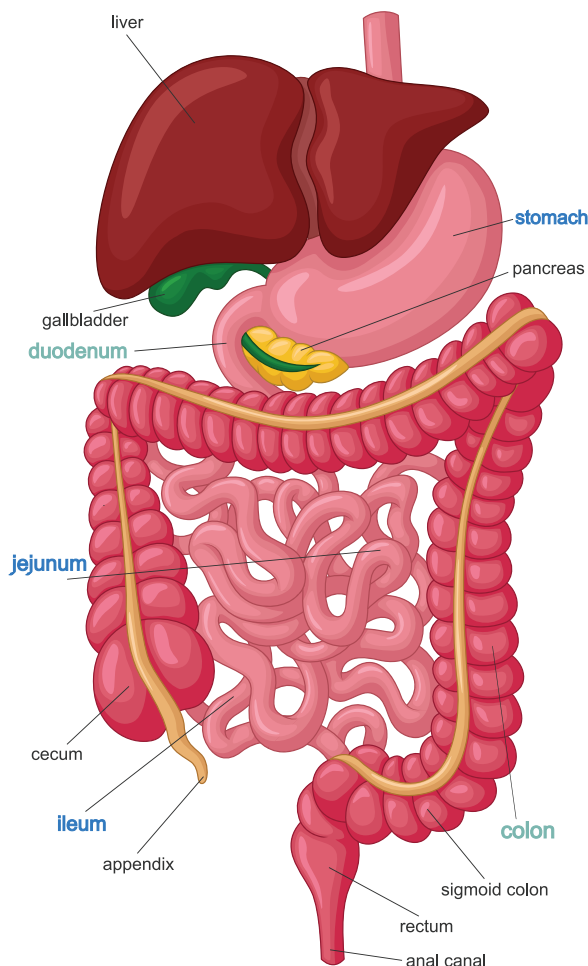
Sarcomas are rare, so there are relatively few doctors who specialise in their treatment. There are a number of hospitals which have a specialist team that manage GIST patients and these are based throughout the UK. The hospital in which you are being treated should discuss your case at a Multi-Disciplinary 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.

GISTs are most commonly found in the stomach (60-65%) followed by small bowel (25-30%), less commonly in the colon and rectum (5%) and rarely in the oesophagus. Very rarely GISTs may arise in the abdomen outside the GI tract, these are called Extra Gastrointestinal GISTs (EGISTs).

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 page number 19).

## Gastrointestinal Tract (GI Tract)



### Stomach

- Mixing
- Release of digestive enzymes
- Some mineral absorption

### Duodenum

- Food sensing
- Release of hormones
- Release of digestive enzymes
- Some mineral absorption

### Jejunum & Ileum

#### Absorption of:

- Sugars
- Fats
- Amino acids (*The building blocks of proteins*)
- Vitamins
- Minerals

### Colon

#### Absorption of:

- Salt
- Water

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 precursors of '**Interstitial cells of Cajal**'. These form a network of cells in the wall of the GI tract and coordinate the movement that propels food along it by a process known as peristalsis. 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 genes present on chromosome 4. 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 pages 16, 37 & 38).

GISTs most commonly occur above the age of 60 years. They are rare under the age of 40 and very rarely occur in adolescents and children. Those GISTs occurring in children, adolescents and young adults behave differently compared with the more common GISTs occurring in adults. Familial GISTs (GISTs occurring in families) are extremely rare so there is very little likelihood of passing the GIST to your children.

There are about 600-900 new GIST cases per year in UK. In the past GIST could have been classified as, or mistaken for another 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 GI tract. 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 GI 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 which can mask or delay a diagnosis.

However, if the symptoms persist and 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?**

[www.glistcancer.org.uk](http://www.glistcancer.org.uk)

**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**

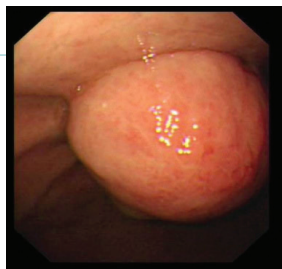
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**glist canceruk**

## Diagnostic tests

### 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.



**Endoscopic picture of a stomach GIST**

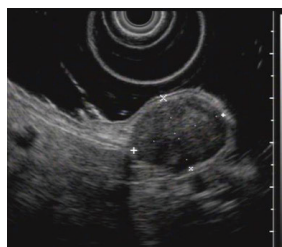
During an endoscopy, small pieces of the tumour can sometimes be removed for examination. This is called an endoscopic biopsy and the samples collected using this method can be used to confirm a GIST diagnosis in the pathology laboratory. If there is fresh blood in the stools you may have a colonoscopy, i.e. the endoscope is passed via the anus into the large bowel (rectum and colon). For GISTs in the small bowel (jejunum and ileum) biopsies using endoscopic tube may not be possible.

### 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)

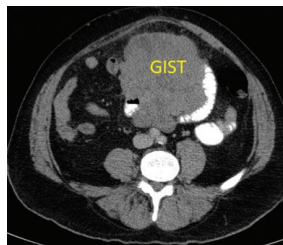
This is a technique for measuring the activity of cells and their blood supply by using a magnetic field and radio waves. It uses no radiation, is painless, but noisy, and takes quite a long time.



**Endoscopic Ultrasound appearance of a stomach GIST in the stomach wall underneath the internal layer**

## CT scan (Computed Tomography)

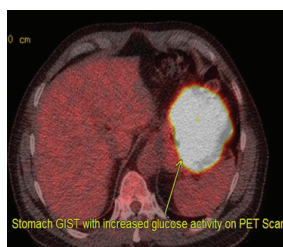
This is the most common diagnostic tool. It uses X-rays to build up a three-dimensional picture of your inside. It is painless and uses a small amount of radiation. You will usually be asked to drink some water and be given an injection of a contrast medium into a vein. If for some reason you cannot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



**CT scan appearance of a small bowel GIST**

## PET scan (Positron Emission Tomography)

This is rather like a CT scan but you are given an injection of 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.



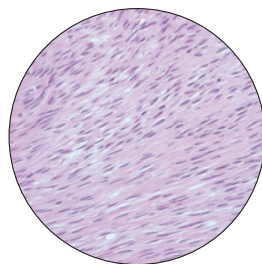
**PET CT appearances of a stomach GIST**

## Blood tests

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

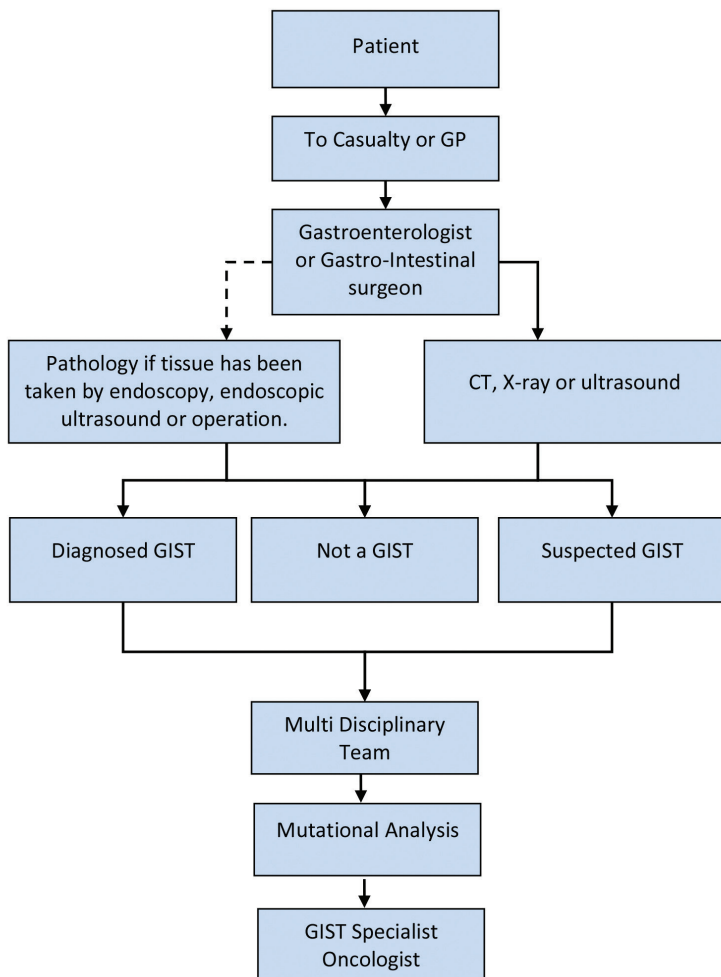
## Histology

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 spindle cells from a stomach GIST look like under the microscope.**

This diagram shows the steps that you may have been through before it is suspected that you have a GIST and the path you should follow once you have been diagnosed with 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 a 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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The pathologist will 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 a 5 square millimeter area of the tumour. This is called the mitotic count/5mm<sup>2</sup>. GISTs with a higher mitotic count tend to have a more aggressive behaviour. However, this does not apply to the wild type GISTs seen in children and adolescents.

Once the GIST diagnosis is confirmed, the next step is to understand what the mutational status is. Mutational analysis of your GIST is done in specialist accredited laboratories. Knowing the mutational status of your GIST is important for its management. You should discuss mutational testing with your oncologist and request for the test to happen if it has not already been done.

## Risk of recurrence

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

1. How big the tumour is (i.e. tumour size in centimeters).
2. What the mitotic count is
3. Where the tumour started from (stomach, duodenum, small bowel, rectum)

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 recommended by a British group of GIST experts, adapted from a table produced by H Joensuu in 2008. Dr Joensuu has also published another way of predicting risk of recurrence using prognostic contour maps (ref: Joensuu 2012)

## Mutation analysis

Mutation analysis is probably a key predictor for the course of the disease, and will determine treatment options after the primary GIST has been removed or a biopsy has been taken. Most GISTs have mutations in either KIT or PDGFRA genes in parts of the gene called exons (similar to a compartment in a train).

We strongly 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. It is mandatory before considering adjuvant (i.e. preventive) treatment with imatinib after surgery and in patients where the GIST has spread to other parts of the body.

Mutational analysis helps in defining the dose of imatinib and whether newer tablets are more likely to be beneficial. (For example, PDGFRA D842V mutant GISTs do not benefit from imatinib, therefore, it is not appropriate to prescribe imatinib for a patient with PDGFRA D842V GIST). Newer drugs in the pipeline will be available for this type of GIST via clinical trials or from compassionate use programs.

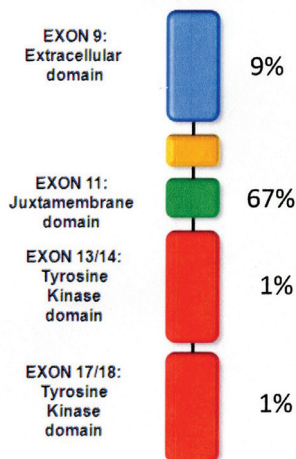
### **KIT mutations occur in about 80% of GISTs:**

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

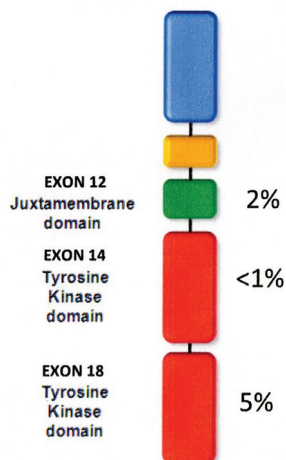
### **PDGFRA mutations occur in about 10% of GISTs:**

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

#### **KIT (79%)**



#### **PDGFRA (7.5%)**



## **Familial / Inherited KIT mutated GIST**

These are inherited forms of GIST where KIT mutations are present in every cell of the body and are genetically inherited in the families. These are extremely rare and only a small number of families have been identified worldwide.

## **E-GIST**

On very rare occasions GISTs are found outside of the GI tract. These types usually carry mutations that are found in the more common GISTs. These E-GISTs are treated in the same way as the other more common GISTs.

## **Special rare types of GIST**

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### **Wild-type GIST**

Where there are no mutations in either KIT or PDGFRA genes - this occurs in about 10-15% of GISTs.

Collectively patients who do not have KIT or PDGFRA mutations have been grouped together as PAWS-GIST (see PAWS-GIST on pages 37 and 38 for more information).

### **Paediatric/Adolescent/Wildtype/Syndromic GIST (PAWS- GIST)**

PAWS-GIST is the collective name given to different subgroups of GISTs which do not have the KIT and PDGFRA mutations. Some of these can be associated with certain syndromes (see below).



### **Succinate Dehydrogenase Deficient (SDH Def) GISTs**

The majority of PAWS-GISTs maybe related to a deficiency of the Krebs cycle enzyme called SDH (succinate dehydrogenase). These are called SDH deficient GISTs and they occur either due to a mutation in the SDH gene or through silencing of the gene through other mechanisms.



Some types of SDH deficient GIST can be associated with other tumours such as paraganglioma and pulmonary chondroma as part of certain syndromes. e.g. SDH deficient GIST may occur as what is called **Carney's Triad**, which is a combination of GIST and two other types of tumours, lung chondroma and paraganglioma. GISTs in this syndrome are due to mutations in the SDH gene in the tumour and are not due to an inherited mutation in the germline.

### **Inherited syndromes**

SDH deficient GISTs can also occur as part of **Carney-Stratakis Dyad Syndrome**. In this group of patients there is an inherited mutation in the SDH gene which causes the GIST and other tumours such as paragangliomas.

### **Neurofibromatosis 1 and GISTs**

**NF1** is a rare genetic condition characterised by multiple neurofibromas (a tumour formed on a nerve cell sheath), café au lait pigmentation and some NF1 patients may also develop GIST tumours, most commonly in the small bowel and less frequently in the stomach and large bowel.

### **Extremely rare GIST subtypes**

There are some extremely rare GIST subtypes that can be found using the latest genomic sequencing techniques. These include **BRAF mutated GIST** (<1%) and **NTRK fusion GIST** (0.5%).

### **Quadruple Wild-type GIST**

These types of GIST have been given this name as they lack mutations/ abnormalities in the four genes **KIT**, **PDGFRA**, **SDH** or **BRAF**. Some of these may have NTRK gene mutations. At present we do not know much about these GISTs and more research is needed to characterise these rare subtypes of GIST.

Further information about PAWS-GIST can be found on the PAWS-GIST clinic website [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk) and more information can be found on pages 37 & 38 in this booklet.

## Treatment of GIST

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GIST should be managed by a multidisciplinary team who have experience of treating GIST patients. GIST is not the same as more common cancers. The multidisciplinary team (MDT) should include:

- **A surgeon** (with experience of GIST surgery).
- **A gastroenterologist** (a specialist in the GI tract)
- **An oncologist** (a doctor who specialises in diagnosing and treating GIST 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 with a GIST specialist who may be found at one of the NHS designated Sarcoma centres listed in the National Sarcoma Service Specification or at one of the hospitals designated as an extension to the Sarcoma centre MDT.

A link to the National Sarcoma Service specification can be found on our website **[www.gistcancer.org.uk](http://www.gistcancer.org.uk)**

## What are the options?

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**1. Surgery – resection of the primary tumour.** If the GIST is localized (restricted to a particular place) and easy to resect, surgery is the preferred treatment option for primary, localized GISTs. The surgeon may use laparoscopic (keyhole surgery) method or open laparotomy. This depends upon the size and location of the GIST, any previous abdominal operations and the local expertise. Open surgery may lead to longer recovery time. (You may find our booklet 'Eating after GI Surgery for GIST' useful).

**2. Adjuvant Imatinib – taking imatinib tablets following primary GIST resection.** Imatinib for a total period of three years has been licensed and approved by NICE for those GIST patients who have had their primary GIST resected and who are at significant risk of tumour recurring. The aim is to minimize the risk of tumour recurrence. The Scandinavian/German research study has shown that taking imatinib tablets for three years after surgery decreases the risk of recurrence and also improves overall survival.

Presently, 3 years of adjuvant imatinib is the standard of care in UK for patients with high risk resected GISTs with an imatinib sensitive mutation. You should discuss this with your oncologist before you start on the 3 year imatinib programme.

**N.B. Mutational analysis is mandatory before starting adjuvant imatinib.**

**3. Treatment with Imatinib before Surgery (called Neo adjuvant or pre-operative Imatinib).** In patients with big/bulky tumours and in patients who may require complex surgery to remove the GIST, the multidisciplinary team may recommend starting imatinib tablets before the operation in order to shrink the tumour and facilitate a more conservative operation with the hope to preserve organ function.

Here are two examples of where pre-operative imatinib could be considered:

- i) In patients with large stomach GISTs which may require a total gastrectomy
- ii) In patients with rectal GIST where imatinib may help to shrink the tumour and facilitate an easier operation and avoid the need for a permanent colostomy (a bag in the abdominal wall).

The typical duration of imatinib treatment is 3-9 months occasionally up to 12 months. Regular scans during this period will help the team to make the decision regarding the timing of the operation.

**It is mandatory that mutational analysis is done and the imatinib sensitive mutational status of the GIST is confirmed before starting pre-operative imatinib.**

**4. Advanced Disease (where the GIST has spread to other organs).** If the disease has spread, either to the liver or to other places within the abdomen, then initial treatment is 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 24). 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 plenty of water. 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 will be having regular CT/MRI scans every 3-4 months and then every 6-12 months for the first 5 years.

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

### 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) which is referred to as a second line drug treatment. This drug 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, high blood pressure and hand/foot syndrome in some people.

Sunitinib can also have an adverse effect on the heart function. Your oncologist will advise on regular monitoring of heart function with special scans to assess the pumping function of the heart.

Before you start sunitinib, you will be given an information booklet/ leaflets on how to take the tablets, how to monitor the side effects and how to manage the side effects. Please do not hesitate to phone your nurse specialist if the side effects become troublesome. If the standard dose and schedule of sunitinib does not suit you, it may be possible to

change the dose and the schedule so that you can tolerate it better and stay on the drug longer without compromising your quality of life.

## **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 is available for oncologists to prescribe after patients have progressed or are intolerant to imatinib and/or sunitinib. Regorafenib is the standard third line treatment for GIST patients in England, Scotland and Wales. 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.

Side effects with regorafenib can be similar to sunitinib and the dose and schedule should be tailored to how you tolerate the drug. Different patients can be given different doses and schedules based upon how they tolerate the tablets.

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

Sometimes new drugs become available under a clinical trial. Trials are generally run at Specialist GIST centres rather than local hospitals. We maintain a list of clinical trials for GIST in the UK on our website. Please ask your oncologist about whether you might be eligible for entry into a trial. Trials usually have 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 needs to be discussed and agreed with your GIST MDT. It may not be appropriate for every patient.

## 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 it has been found to be quite successful in shrinking some 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.

For rare NTRK gene fusion GISTs the drug Larotrectinib is now available to patients via the cancer drug fund.

The **National GIST Guidelines** can be found on our website ([www.gistcancer.org.uk](http://www.gistcancer.org.uk)).

The **National GIST Tissue Bank** was opened in 2014 and is a central location for GIST cancer samples, where fresh tumour or wax blocks of tissue and blood samples are stored.

Please advise 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. This consent is separate from the standard consent that you will be asked to sign at your hospital. You can access the consent form and further information via [www.gistcancer.org.uk/national-gist-tissue-bank/](http://www.gistcancer.org.uk/national-gist-tissue-bank/). Please see pages 42 to 43 for more information for more information. This should be organised and agreed with the National GIST tissue bank well in advance of your surgery in order to make the necessary arrangements.

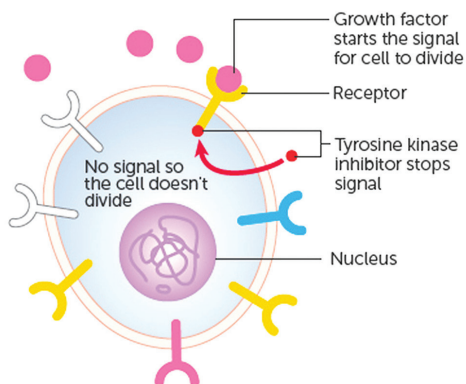
## How targeted drugs work

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 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 a large proportion of Wild-type GIST's, although this does result in some responsiveness to sunitinib and regorafenib, both of which inhibit the blood vessel growth (angiogenesis) pathway.





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 was started.

## Side effects and management suggestions

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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 26). 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.

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.

The most common side effects of imatinib noticed by patients are	Patients' suggestions for dealing with them
Puffy eyelids	Diuretic tablets Better not to drink alcohol or coffee
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. Take the pills just before bed so you sleep through the side effects
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.

**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 Cancer 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.

<http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Sarcoma-and-GIST>

There is also a version of this for use in the UK called The National GIST Guidelines which forms part of the National Sarcoma Service Specification and which takes into account the UK health system and the treatments permitted by NICE\*.

\* 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.

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).

<https://clinicalsarcomaresearch.biomedcentral.com/articles/10.1186/s13569-017-0072-8>

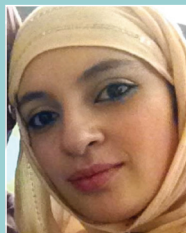
These Guidelines also recommend the best follow-up regimen for patients with different risks of recurrence. They are referenced in the NHS England National Sarcoma Service specification:

<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2019/07/Sarcoma-Service-Specification.pdf>

Sometimes, there is no clear answer about 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.

*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

## 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 s/he can only do their best for you if you are honest with them.

## 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 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 for support. In any case, do not keep these feelings to yourself, but get help somehow.

GIST Cancer 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.gistcancer.org.uk](http://www.gistcancer.org.uk)** and if you want to, you can make contact with this patient group by emailing us at **[admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk)** requesting to be registered.

Once registered you will be invited to the regular patient support meetings. You will also be invited to join our private patient and carer Listserve email group. 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 Cancer 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 Adam Dangoor Consultant Medical Oncologist, Bristol Cancer Institute, Bristol

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

Dr Spyridon Gennatas Locum Consultant in Medical Oncology, The Royal Marsden Hospital

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 Mark Lynch Consultant Medical Oncologist, (ex The Royal Marsden Hospital)

Dr Maria Marples Consultant Medical Oncologist. St James, Leeds



Dr Carys Morgan Consultant Clinical Oncologist, Velindre NHS Trust, Wales  
 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 Robin Young Consultant Medical Oncologist, Weston Park Hospital, Sheffield

### **Surgeons:**

Mr Adam Barlow Consultant Surgeon, Leeds  
 Mr Evangelos Efthimiou Consultant Surgeon, The Royal Marsden  
 Mr Samuel J. Ford General & Sarcoma Surgeon University Hospitals Birmingham NHS Foundation Trust  
 Mr Jeremy Hayden - Consultant Surgeon, Leeds  
 Mr Long R Jiao Consultant Surgeon, Hammersmith Hospital  
 Mr Satvinder Mudan Consultant Surgeon, (ex The Royal Marsden Hospital), now at The London Clinic.  
 Mr Myles Smith Consultant Surgical oncologist & General surgeon, Royal Marsden Hospital  
 Mr Simon Toh Consultant Surgeon Portsmouth  
 Mr Simon Wood Consultant Surgeon, Royal Gwent Hospital

### **Other experts:**

Dr Zahir Amin Consultant Radiologist, University College Hospital, London  
 Ms Jane Balantyne CMacmillan Benefits Advisor  
 Dr Dominic Bray Clinical Psychologist, Southport & Aintree Hospitals  
 Dr Elena Cogocar — Clinical Research fellow, Royal Marsden, London  
 Mr Nick Duncan Principal Pharmacist, Queen Elizabeth Hospital Birmingham  
 Jennie Dyer Clinical Lead, Complimentary Therapies, The Royal Marsden  
 Dr Malee Fernando Consultant Histopathologist, Sheffield Teaching Hospitals  
 Professor Claire Foster Professor of Psychosocial Oncology, University of Southampton  
 Emeritus Professor Andy Hall, Newcastle University, Founder of the National GIST Tissue Bank  
 Dr David Hughes Consultant Histopathologist, Sheffield Teaching Hospitals  
 Dr Christine Ingram Consultant Radiologist, Western Park Hospital, Sheffield  
 Dr Fiona McDonald National Cancer Registration Service (NCRAS)  
 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 Karen Sisley Dept of Oncology and metabolism University of Sheffield Medical School  
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 Cancer UK

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GIST Cancer UK has been a registered charity since 2009 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 to patients and their carers.

### We provide:

- web sites: **www.gistcancer.org.uk** and **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
- **2-3 PAWS-GIST clinics** where PAWS-GIST patients and their carers meet with world-class experts who provide highly specialised care plans while patients contribute to research by attending the clinic and participating in translational research projects.

- **Facebook, Twitter & Instagram communities.** Giving you the most up to date information on GIST cancer developments and what GIST Cancer UK is doing to improve services for GIST patients



Registered Charity No: 1129219

**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 400 0000 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.uk](http://www.pawsgistclinic.org.uk)

**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 out more please visit our website [www.gistcancer.org.uk](http://www.gistcancer.org.uk) and write to us at [admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk) or call our helpline 0300 400 0000



Registered Charity No: 1129219

**Help Line** 0300 400 0000

**Website** [www.gistcancer.org.uk](http://www.gistcancer.org.uk)

**Email us** [admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk)

**Facebook** @GISTCancerUK

**Twitter** @GISTCancerUK

**Donate** [www.justgiving.com/gistcanceruk](http://www.justgiving.com/gistcanceruk) [www.virginmoneygiving.com/gistcanceruk](http://www.virginmoneygiving.com/gistcanceruk)

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

**Facebook** @PAWSGIST

**Twitter** @PAWSGIST

**Donate** [www.virginmoneygiving.com/PAWSGIST](http://www.virginmoneygiving.com/PAWSGIST)

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

If you would like to find out more please visit our website [www.gistcancer.org.uk](http://www.gistcancer.org.uk) and write to us at [admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk) or call our helpline 0300 400 0000

## 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 Cancer UK badges** 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 GIST tissue 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 the 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 both 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 undertaken across the world

## PAWS-GIST (a GIST Cancer 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 Cancer 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 Cancer UK



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



## PAWS-GIST

GIST Cancer UK (GCUK) has encouraged an alliance of specialist doctors and patients called “PAWS-GIST”

This group concentrates on **P**aediatric, **A**dolescent, **W**ild-type & **S**yndromic 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 GCUK 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 Cancer 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](https://www.facebook.com/pawsgist)

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

or via our websites [www.gistcancer.org.uk](http://www.gistcancer.org.uk) or [www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk)



## Funding and fundraising

GCUK are very grateful to receive grants from Pharmaceutical companies to help fund our patient meetings and produce information and materials to help educate patients.

The majority of our funding comes from the general public, patients, their families, 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 by our supporters is a vital element for the future of our charity to help us continue 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, their families, friends and other supporters who organise and participate in fundraising events for us. We have tee-shirts, banners and other items for use at fundraising events both for GIST Cancer UK and for PAWS-GIST. More information and fundraising packs can be obtained by:

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

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



## Donations can be sent to:

The Treasurer GCUK, c/o 5 Monks Way, West Kirby, Wirral, CH48 7ER

## Cheques for:

**GCUK funds** to be made out to **GIST Cancer UK**

**PAWS-GIST funds** to be made out to **PAWS-GIST**

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

## 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 Cancer UK banks with HSBC

<b>Account Name:</b>	<b>GIST Cancer UK</b>	<b>PAWS-GIST</b>
Account number:	90078689	20345547
Sort code:	404157	404157

Please quote either "GCUK 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 Cancer 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.

More ways to help fundraise can be found at

<https://www.gistcancer.org.uk/donations-support-fundraising/>





## Useful links

**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.  
[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. GCUK 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  
[www.liferaftgroup.org](http://www.liferaftgroup.org) dedicated to making a difference in the lives of GIST patients.



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

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

**Instagram:** [@gistcanceruk](https://www.instagram.com/gistcanceruk)

# 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.

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@gistcancer.org.uk](mailto:admin@gistcancer.org.uk). Jayne is very experienced in assisting patients who wish to donate their tissue for research

## NOBODY WANTS GIST TUMOURS WE DO...

### NATIONAL GIST TISSUE BANK

**GIST RESEARCH WILL PROGRESS FASTER IF THERE IS A GOOD SUPPLY OF GIST TISSUE**

**Rare Intramucosal Bruner Tumours (GIST) are rare.**  
Around 800 new patients are diagnosed with GIST cancer in the UK each year.

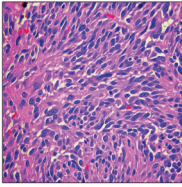
**The national GIST tissue bank is based at The Royal Marsden, London.**

**What does this mean for you?**

- This bank is a valuable resource that supports GIST cancer research locally, nationally and internationally.
- It provides researchers with a diverse selection of high-quality GIST tumour specimens and clinical data obtained by dedicated tissue bank staff who follow strict procedures and ethical guidelines.
- Research will progress faster if there is a good supply of GIST tissue upon which to test potential treatments and develop new diagnostic tests.

**How will the Tissue Bank Operate?**  
Operating within the Royal Marsden in London, the GIST Tissue Bank coordinates the collection, storage and distribution of a variety of biopsies including fresh, frozen and paraffin blocks in addition to blood samples and clinical data.


Working in collaboration with pathologists, medical oncologists, surgeons and other hospital personnel, specially trained staff obtain patient consent, collect samples and assemble clinical information about each donor and their corresponding specimens.



**HOW YOU CAN HELP THE GIST TISSUE BANK...**  
If you are a GIST patient who has had or are about to have a GIST tumour removed.

Please request that some of your tumour tissue is either sent to or registered with the **National GIST tissue bank**.

**CONTACT INFORMATION**  
**website:** [www.givemysample.org.uk/national-gist-tissue-bank](http://www.givemysample.org.uk/national-gist-tissue-bank)  
**contact person:** Janine Salter  
**address:** Biobank Manager  
Royal Marsden Hospital,  
Fulham Road, London,  
SW3 6JJ  
**phone:** 0208 6486011 / 0208 661 3568  
**email:** [biobank@rmh.nhs.uk](mailto:biobank@rmh.nhs.uk)



**National GIST Tissue Bank**  
Sincere thanks to Professor Andrew Hall,  
Janine Salter and Dr Robin Jones – Principle Investigator

## NATIONAL GIST TISSUE BANK

### INFORMATION FOR CLINICAL STAFF



**Access to primary clinical samples**  
(tumour and matched normal blood) is vital to progress our understanding of rare tumours such as **GIST**.

With your help we can grow a national collection of samples available to anyone with a good quality research proposal.

Please try to assist in this research by sending samples to the:

**National GIST biobank**

**If you have samples to donate/register please contact:** Janine Salter  
[biobank@rmh.nhs.uk](mailto:biobank@rmh.nhs.uk)  
0208 6486011 / 0208 661 3568

**For details of the consent and donation process see:**  
[www.gistcancer.org.uk/national-gist-tissue-bank](http://www.gistcancer.org.uk/national-gist-tissue-bank)

**FREQUENTLY ASKED QUESTIONS...**

**Has ethical approval been obtained to do this study?** Yes  
The Royal Marsden Biobank is a REC approved Research Tissue Biobank which allows collection from any Trust within the NHS from patients of all ages.

**Is the Biobank covered by an HTA licence?** Yes  
Samples are collected under an HTA research licence.

**Will we need to obtain an HTA licence?** No  
As long as samples can be transported within 7 days of being made available for research.

**Will I have to obtain informed consent to use the samples in research?** Yes  
A full protocol with the necessary forms can be sent on request.

**Will my R&D department need to approve the collection of samples?** No  
But they will need to be informed that collection is intended.

**What kind of samples do you need?**  
Ideally we would like samples of:

- fresh frozen tumour
- a stain H&E slide and
- a matched sample of normal blood
- clinical data

**Will we have to pay for transport?** No  
We will meet all the costs associated with transport.

**What should we do if our hospital already operates a GIST tissue bank locally?**  
Please make sure that your samples are registered with the National GIST Tissue bank at the Royal Marsden.

Principle Investigator - Dr Robin Jones  
Sarcoma Unit, Royal Marsden Hospital, Fulham Road, London, SW3



**gist cancer uk**  
Reg Charity No. 1238933

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.gistcancer.org.uk](http://www.gistcancer.org.uk)

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