

## Trustees' Annual Report to the Charity Commission (2025)

<b>Charity name:</b>	GIST Cancer UK
<b>Charity number:</b>	1129219
<b>Principal address</b>	3 Grange Court, The Street, Yatton Keynell, Chippenham, Wiltshire SN14 7BA
<b>Phone</b>	0300 400 0000
<b>Email</b>	admin@gistcancer.org.uk
<b>Website</b>	<a href="http://www.gistcancer.org.uk">www.gistcancer.org.uk</a>
<b>Trustees</b>	Nic Puntis (Chair) John South (Treasurer) Mark Atlay (Secretary) Cathy Hampshire (Vice-chair) Ros Langford David Lane Drewe Lacey Catherine Doyle (new appointee) Gareth Owen (new appointee)

This report meets the annual reporting requirements of the Charity Commission and provides a record for the Charity of its main activities, their effectiveness and other developments.

With effect from 7<sup>th</sup> October 2025, GIST Cancer UK (GCUK), changed its status to become a 'Charitable Incorporated Organisation (Foundation model)' and gained a new charity number (1215266). It used the template issued by the Charity Commission to undertake this change and, on submission, was given a new Charity number. Since the objects, priorities, activities and administration remained unaltered by the translation to the new charity, this report covers the operation of both the old and new charities to the end of 2025 to maintain its annual reporting cycle.

### 1 Objectives and Activities

#### 1.1 Overarching Purpose

The objectives of the new charity remained unaltered from those set out in the 'Deed of Trust' of the previous charity:

- To promote and protect the physical and mental health of patients with Gastro-intestinal Stromal Tumours (GISTs) in the UK through the provision of information, support, education and practical advice to them and their carers;
- The relief of sickness and the preservation of health in particular by promoting and supporting research with the publication of the useful results thereof and the development of more effective treatment and care for patients with GIST;
- To advance the education of the general public and health professionals in all areas relating to GIST.

#### 1.2 Mode of Operation

GCUK generally operates as in previous years. This is mainly through the unpaid work of the trustees who take a leading role in individual aspects of the charity's work. A few additional special volunteers provide essential support in specialist areas such as the Helpline, IT and Research.

GCUK contracts with specialist providers in other areas; for example, in relation to technical support for the website and the video-recording of presentations at patient meetings. It has no employees.

### 1.3 Main activities

In furtherance of its objects, the Charity has undertaken the following activities during the period covered by this report.

#### 1.3.1 New Registrations

New registrations occur via the GCUK website where registrants complete an online form to ensure GDPR compliance. They receive a follow-up call from a member of the helpline team and this can answer any immediate queries, help to allay fears and direct them to additional support when necessary. New registrants can opt to join the online forum and also receive details of forthcoming events.

	2025	2024	2023	2022	2021	2020
<b>Patients/carers</b>	148	158	124	120	166	28
<b>Fundraisers</b>	0	1	0	3	9	1
<b>Healthcare contacts</b>	10	5	11	29	59	30

New patient/carer registrations remain much as they were in the previous year.

There has been a slight increase in the number of healthcare contacts but identifying medical practitioners who are dealing with GIST patients remains a challenge as there are always retirements and career changes and no accessible central register. We rely on those in this category to contact us. Usually this is so that we can provide nurse practitioners with leaflets and other relevant information for their patients.

#### 1.3.2 Patient meetings

Three meetings were held during the year in line with normal practice. We hold these across the UK to make them as accessible to patients as possible. During 2025 events the following events were held. Each has input from GIST specialists and provides an opportunity for patients, their family and friends to share their experiences of living with a GIST.

##### Manchester (March 2025). (56 attendees)

- Dr Remus Seres, Research Fellow Medical Oncology @ The Christie - "MDT Process in GIST and Updates on Clinical Trials"
- Molly Guscott - BARTS Cancer centre. Chromosomal Instability (CIN) Research Project.
- Marion Oliver, Clinical Psychologist and GIST Patient- 'Sailing the Seven Cs with Psychology'

##### London (September 2025) (66 attendees)

- Prof Robin Jones Consultant Medical Oncologist -The Royal Marsden NHS Foundation Trust –What's new in GIST & its treatment; Using AI to detect & find patterns & suggest treatment; what we know & don't know about GIST & its treatment; why the nature of the mutation is important.
- GIST Funded Research on NK Cells. Jack Harrington – (Postdoctoral Research Fellow) & Matthew Blunt Associate Professor of Translational Immunology University of Southampton - tumour microenvironment and the PAWS GIST models
- GCUK developments including Charitable Status update, Patient Survey & Gagglemail Communication Tool Mark Atlay & Cathy Hampshire

- An Introduction to Welfare Benefits and Financial Support' Anna Ellis, Maggie's Centre
- **Edinburgh (December 2025) (35 attendees)**

We continue to be grateful to all the medical professionals and others who give up their time to speak at these events.

### **1.3.3 Helpline**

We provide access to a Helpline enabling patients and carers to talk to someone with first-hand experience of GIST cancer in confidence. Although not staffed by health care practitioners, the Helpline provides advice and guidance or re-direct calls to specialists when appropriate. Monitoring the number of callers is made difficult by the similarity of our number to that of another organisation, however, we typically receive over 500 calls each year.

This year we have revised our procedures for the recording of calls and introduced DBS checks for those providing support.

### **1.3.4 Online forum**

One of the major ways in which we support GIST cancer patients and their carers is through the provision of a private email discussion forum which provides 24/7 access to hundreds of other GIST patients and carers. GCUK controls access to this space to ensure that it is restricted to GIST patients and their direct supporters, and moderates discussions.

The forum which is often described by users as “a lifeline” is actively used to discuss issues affecting patients including symptoms and their treatments, side-effects, treatment centres and other related topics.

During the year we moved to a new application giving better support for online discussions. Typically, there are around 2000 posts to the forum each year.

### **1.3.5 PAWS-GIST clinics**

These clinics provide direct and specialist support to patients for whom standard treatments often do not work. GCUK has no direct responsibility for the PAWS-GIST clinics which are operated at Addenbrookes Hospital and is currently seeking to confirm their status so that it can continue to advertise them to patients and support its website.

### **1.3.6 Information**

The main means of communicating with GIST patients, carers and others with an interest on this cancer are through our web site ([www.gistcancer.org.uk](http://www.gistcancer.org.uk)) and the corresponding one for the PAWS-GIST clinic ([www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk)). We continue to ensure that the material accessible through the sites is accurate, current and relevant to the needs of patients and carers.

GIST Cancer UK provides a range of leaflets and other information aimed at patients, carers and health care practitioners ensuring that these remain current. During the year we produced a revised version of our booklet ‘*Eating after GI surgery*’. We also provided updated information on a range of topics of relevance to patients including on travel insurance and dealing with the side-effects of drug treatment.

We continue to produce a regular newsletter to keep patients and carers abreast of developments in the charity and in research and other topics of relevance to our community.

### **1.3.7 Research**

Previously GCUK has a Medical Advisory Board which met formally once during the year and provided key advice via email on areas such as bids for research funding.

However, it became increasingly difficult to sustain the operation of this body given other pressures on the time of the consultants and academics who make up its membership.

We now work more closely with our sister charity SarcomaUK using their Medical Advisory Board and procedures to advertise and review research proposals. In addition, we have a specialist team who maintain an oversight of research developments funded by GCUK and published by the wider research community.

GCUK funds a number of research projects into GIST cancers which aim to understand their causes and identify improved treatments. We also fund projects supporting the mental health and well-being of patients. Some of these are jointly funded with SarcomaUK.

### **1.3.8 National GIST Biobank**

GCUK continues to fund the National GIST Biobank based at the Royal Marsden hospital. This provides a resource for researchers wishing to work with GIST cancer cells. We are working to ensure the bank is fully stocked with all GIST mutations and to promote its use amongst the research community.

### **1.3.9 Other activities**

The following additional activities have been undertaken during the year:

- Developing detailed risk assessments for the major aspects of the charity's work.

## **1.4 Public Benefit**

In deciding on activities and in the compilation of this annual report (see section 1.3 above) the Trustees have had regard to the guidance issued by the Charity Commission on public benefit and in particular that on reporting (PB3).

## **1.5 Policy on grant making**

Our policy on grant-making remains the same as in previous years. GCUK makes no grants to individuals in respect of living with a GIST. It does remunerate, on request, patients and carers for the costs of travel to its meetings and to clinics, and has approved a process for supporting travel arrangements for other treatment related processes such as travel to specialist treatment centres where there is a clear need for assistance.

## **1.6 Policy on social investment including program related investment**

GCUK makes no social investments defined as 'a class of assets that comprises investments undertaken for both a financial return and to (in whole or part) further the investing charity's charitable aims and objectives.'

## **1.7 Contribution made by volunteers**

GCUK relies on volunteers for much of its provision to support those with a GIST. This includes trustees and special volunteers, who give their time for free, those who provide core activities such as the Helpline and managing the day-to-day activities of the Charity. In addition, many patients and their carers and friends volunteer to support fund-raising and related activities. As a small, focussed, charity GCUK does not have an extensive number of volunteers.

# **2 Achievements and Performance**

## **2.1 Charitable activities undertaken**

GCUK's work during the year has had the following benefits to those with a GIST cancer and to wider society.

- Three patient/carers meetings (involving over 100 participants).

- Confidential Helpline (ca 500 contacts).
- Private online email forum enabling those with GISTs and their carers to access online support and guidance and share experiences (ca 2000 posts).
- Access to up-to-date booklets and information on a range of issues relating to GISTs (see <https://www.giscancer.org.uk/publications/> )
- Funding of new and continuing research initiatives with major national researchers.
- Contributions to the activities of national and international cancer groupings.
- Stakeholder participation in NICE technology appraisals of GIST treatments.
- The Charity attends national and international conferences to represent the interests of GIST patients, identify research and learn of new and forthcoming drug trials.
- There were no safeguarding or other issues requiring reporting during the year.

## 2.2 Achievements against objectives set

The charity had a new strategy covering the period from 2024 to 2026 which includes annual operational targets. The following summarises progress in respect of each of the three strands of the current strategy which will continue into 2026.

Aim	Progress
Three patient/carers meetings	March (Manchester), September (London). December (Edinburgh)
Produce regular newsletter	3 editions produced and circulated to all patients registered.
Develop and implement plan for review of existing written resources	<i>Eating after GI surgery</i> and 'No Stomach' amalgamated and revised with patient and healthcare professional input.
Revise website to include steps on patient journey	Website live and continuously updated
Revise online forum	Revised and operational.
Review Helpline and associated procedures	Reviewed, revised and new processes instigated..
Identify, with patients and carers, range of additional resources of potential use	Guidance on Travel insurance and dealing with common side-effects produced. Further resources in development in response to patient feedback including around mental health and well-being
Review patient and carer needs and identify and evaluate existing external resources	Constant part of our review mechanisms which included a survey of all patients.
Pilot support mental health and wellbeing support mechanisms.	GCUK has decided not to progress with this and instead direct patients to existing specialist resources.
Identify research priorities	Priority areas identified and incorporated into Sarcoma UK bidding priority document. Regular funding of research activities to the value of ca £100k p.a.
Seek research proposals in identified areas possibly through partners	New research projects identified and funded through SarcomaUK research funding process.
Evaluate written resources in line with development plan	Under constant review and development plan in place.
Identify lead and develop plan to support patient access to clinical trials	Complete with support from RareCan
Identify strategic partners in UK.	Discussions held with SarcomaUK and closer working underway notably in the area of research. Also development opportunities being explored with other charities and with international GIST patient advocacy groups.

Identify a volunteer coordinator and develop plan for volunteering support	Volunteering policy approved and in operation.
Review existing practices and develop a targeted approach to fundraising	Fundraising levels remain relatively constant and new avenues being explored.
Ensure administrative and support arrangements sustain efficient and effective operation in line with one-charity ethos	Complete and being monitored to ensure Charity's needs are met.

### 2.3 *Performance of fundraising activities against objectives set*

GCUK does not currently have set objectives for fundraising and their achievement. It relies largely on the fundraising activities of individual GIST patients and their friends and family. Minor grant from Pharma received but general funding from Pharma companies remains difficult to obtain. Annual levels of funding from donations remain relatively constant.

### 2.4 *Investment performance against objectives*

The Charity introduced the use of the Charities Aid Foundation (CAF) platform to better manage its financial reserves. This has led to a significant increase in funding arising from the interest on deposits.

## 3 **Financial Review**

### 3.1 *Review of the charity's financial position at the end of the period*

GCUK remains in a good financial position with sound finances that would allow it to operate for a two-year period even if no further income was received.

### 3.2 *Statement explaining the policy for holding reserves stating why they are held*

GCUK holds reserves for two main reasons:

- To ensure that there are sufficient funds to support the medium-term viability of the charity.
- To ensure that there are funds to support activities, such as research projects, that are funded for several years.

### 3.3 *Amount of reserves held*

The total amount of funds at the end of the 2024 financial year is shown in the following table with previous years for comparison.

End of Year	Funds held (£)
2025	575,176
2024	627,602
2023	585,381
2022	697,690
2021	646,215

These funds are distributed across various categories as set out in the Charity's Reserves Policy

- **Operational Funds** – this is an estimate of a sum required to manage the charity operationally for 24 months to allow a period of stability if a particular set of circumstances arise e.g. no income (£200,000).
- **Designated Funds** – that the charity is committed to contractually and are costs that need to be met at some stage in the future and **Restricted Funds** – funds the charity has set aside for schemes yet to be approved contractually but are



nonetheless formally allocated for a purpose (Designated and restricted funds are £202,330 and £100,000 respectively).

- **Unrestricted Funds** – essentially the Charity’s reserve (£77,712).

The reduction in overall resources in the bank accounts was planned for and arises because GCUK is now funding several research projects each with significant financial investment. The Board regularly monitors the financial situation.

### 3.4 *The charity’s principal sources of funds (including any fundraising)*

The charity generates money through fundraising activities by individuals. We receive occasional grants from Pharma companies with interest in the treatment of GISTs. This year we received one such grant.

### 3.5 *Investment policy and objectives including any social investment policy adopted*

During 2023 the Charity commenced using the Charity Aid Foundation’s platform to manage its assets. This allowed for a more effective allocation of funds to interest earning accounts whilst enabling the GCUK to maintain control of its financial investments. During the year, due to the use of the CAF platform and to higher interest rates, the Charity currently gains a return rate of around 4.5% on its investments.

### 3.6 *A description of the principal financial risks facing the charity*

The Charity’s financial risk register identifies the following risks and their associated level (December 2025).

Receiving less funding or fewer public donations	Medium
Losing money through inappropriate investments	Low
Reliance on a few sources for income	Low
Inaccurate and/or insufficient financial information	Low
Inadequate reserves and cash flow	Low
Undertaking activities outside the normal nature and scale of the charity	Low

The limited of funding from Pharma means that more needs to be generated from donations and fundraising to ensure the longer-term financial stability of the charity. The Board continues to monitor this position carefully and to seek new sources of funding to enable it to continue its activities.

## 4 **Structure, Governance and Management**

### 4.1 *How is the charity constituted?*

The Charity was originally established in 2009 through a ‘Declaration of Trust’. The name was subsequently changed from GIST Support UK to GIST Cancer UK in August 2018 and minor changes were made to the declaration in September 2022 and notified to the Charity Commission.

During 2025, the Charity changed its status to a Foundation Charitable Incorporated Organisation.

Trustees are largely drawn from GIST patients and their families who indicate their willingness to contribute at events and activities or through a general request to the registered database. Trustees serve for a three-year period but can be re-elected. There is no limit to the number of times a trustee can be re-elected.

### 4.2 *Policies and procedures adopted for the induction and training of trustees*

There is a standard procedure for the induction of new trustees designed to ensure that they are familiar with the working of the charity and the expectations of trustees as set out by the Charity Commission.

#### *4.3 The charity's organisational structure and any wider network with which the charity works*

GCUK has no subsidiaries and all decisions are taken by the Board of Trustees or by designated Trustees in respect of their specialist areas and reported to the Board.

#### *4.4 Relationship with any related parties*

GCUK has no formal relationships with other parties but works collaboratively with other charities who have an interest in GIST cancer. During the year, the charity has continued to explore working more collaboratively with other charities with similar aims.

#### *4.5 Operation of the Board*

The Trustees met four times during the year, twice in person and twice remotely via MS Teams.

There were two new appointments to the Board. We are looking to return the membership of the Board to ten to twelve (it is currently nine).

#### *4.6 Policies and Procedures*

The Board has the following policies and procedures in place:

GCUK has the following approved policies:

- GCUK Code of Conduct - July 2024
- GCUK Complaints Policy - January 2024
- GCUK Confidentiality Policy - July 2024
- GCUK Grievance and Disciplinary Policy - July 2024
- GCUK Expenses and Exceptional Support Policy - January 2023
- GCUK Fundraising Policy - January 2024
- GCUK IT Policy - September 2022
- GCUK Privacy Policy- July 2024
- GCUK Representative and Volunteer Policy - July 2024
- GCUK Reserves policy - October 2024
- GCUK Safeguarding Policy - July 2024
- GCUK Social Media Policy - January 2022
- GCUK Whistleblowing Policy - July 2024
- GCUK Working with Companies Policy - October 2023

The Charity does not have explicit policies in place in the following areas requiring reporting by the Charity Commission:


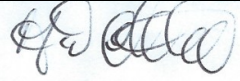
- Internal charity financial controls policy and procedures (Although aspects are covered in the Expenses and Reserves policies)
- Serious incident policy and procedures (operation of the Charity is unlikely to be affected by a serious incident, other aspects are covered by our Risk Framework)
- Investing charity funds policy and procedures (Covered in the Reserves Policy).
- Campaigns and political activity policy and procedures (The charity does not directly engage in campaigns and political activity)
- Bullying and harassment policy and procedures (The Charity has no employees; aspects are covered in the Grievance and Disciplinary Policy and Representative and Volunteer Policy)
- Engaging external speakers at charity events policy and procedures (Speakers are almost entirely medical professionals or those working within healthcare or university research settings).



## 5 Declarations

The Board of Trustees declare that they discussed and approved this report at their meeting in April 2026.

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Nic Puntis	Mark Atlay
<b>Position</b>	Chair	
<b>Date</b>	7 <sup>th</sup> May 2026	7 <sup>th</sup> May 2026

GCUK

Accounts

31 December 2025

**Independent Examiners Report of the Trustees of GIST Cancer UK**

I report on the accounts of the charity for the year ended 31 December 2024.

**Respective responsibilities of trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

**It is our responsibility to;**

1. examine the accounts under section 145 of The Charities Act
2. to follow the procedures laid down in the general directions given by the Charity Commission (under section 145 (5) (b) of the Charities Act) and
3. to state whether particular matters have come to my attention

**Basis of independent examiner's statement**

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes review of the accounting records kept by the charity and a comparison of the accounts presented with those records.

It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

**Independent examiner's statement**

In connection with my examination, no matter has come to my attention

1. which give me reasonable cause to believe that in any material respect the requirements to keep accounting records in accordance with section 130 of the Charities Act to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or
2. to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

**ALICJA MOGG**

Foxwise Accountancy Ltd  
22a Burton Street  
Melton Mowbray  
Leicestershire  
LE13 1AF

06 June 2025

**GCUK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2025**

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
<b>INCOME</b>		
Donations - GCUK	87,963	87,987
Interest	17,434	19,360
	<u>105,397</u>	<u>107,347</u>
<b>EXPENDITURES</b>		
<b>Research Purchases</b>		
Research	112,084	166,530
	<u>112,084</u>	<u>166,530</u>
<b>Direct Expenses</b>		
Publicity/Goods for Sale	4,092	6,741
	<u>4,092</u>	<u>6,741</u>
<b>Overheads</b>		
Patient/Carer Meeting Costs	17,960	14,249
Stationery	389	-
Telephone	607	329
Web Hosting	-	472
Accountancy	1,566	1,575
Insurance	508	494
Sundry	1,255	238
Travel and Subsistence and Expenses	11,580	7,426
Cancer 52 Membership	-	300
Subscriptions & Memberships	336	608
Bank, credit card and other finance charges	74	-
	<u>34,275</u>	<u>25,691</u>
	<u>150,451</u>	<u>198,962</u>
<b>Loss</b>	<u>(45,054)</u>	<u>(91,615)</u>

**GCUK**  
**Balance Sheet**  
**as at 31 December 2025**

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
<b>Assets</b>		
HSBC - GCUK 689	173,442	217,963
HSBC - GIST Support UK 670	63,024	63,024
HSBC - PAWS GIST Community - 469	100	100
Flagstones	336,000	336,000
Other current assets and prepayments	2,612	3,505
	<u>575,176</u>	<u>620,592</u>
<b>Liabilities</b>		
Trade creditors	-	360
	<u>-</u>	<u>360</u>
	<u>575,176</u>	<u>620,232</u>
<b>Net business assets represented by</b>		
Capital account:		
Brought forward	620,232	711,846
Net loss	(45,054)	(91,615)
	<u>575,176</u>	<u>620,232</u>

GCUK

Accounts

31 December 2025



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