

## Trustees' Annual Report to the Charity Commission (2024)

<b>Charity name:</b>	GIST Cancer UK
<b>Charity number:</b>	1129219
<b>Principal address</b>	3 Phillips Grove, Yatton Keynell, Chippenham, Wiltshire, SN14 7FA
<b>Phone</b>	0300 400 0000
<b>Email</b>	admin@gistcancer.org.uk
<b>Website</b>	www.gistcancer.org.uk
<b>Trustees</b>	Nic Puntis (Chair) John South (Treasurer) Mark Atlay (Secretary) Tony Manuel (Vice-chair) Sharon Bethell Amalia Formoso Ros Langford David Lane Terry Riley Drewe Lacey Cathy Hampshire (appointed January 2024)

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

### 1 Objectives and Activities

#### 1.1 Overarching Purpose

The objectives of GIST Cancer UK (GCUK), as set out in its 'Declaration of Trust', remain unaltered:

- 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 and research.

Previously GCUK had paid a part-time consultant to support the operation of the PAWS-GIST clinics, coordination of the Medical Advisory Board, the monitoring of funded research, and the development of the National GIST Biobank. However, this role was discontinued. The National GIST Biobank is now established at the Royal Marsden hospital and the charity continues to provide financial support to its operation but specialist administrative support is provided by the hospital. The Charity has no responsibility for the operation of the PAWS-GIST clinics and only promotes the clinics through funding the associated website and via links from its own website. Other matters previously covered by this consultancy have been taken on by trustees.

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.

### 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. New registrants can opt to join the online forum and also receive details of forthcoming events.

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

New patient/carer registrations have increased by 25% over the previous year. The high number in 2021 had been possibly ascribed to a post pandemic increase in the identification of GIST cancers. There is no nationally available data on the number of GISTs identified each year so it remains unclear whether this increase is as a result of increased cases or increased awareness of the charity.

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. The regular decline in the number of new healthcare registrants is a concern.

#### 1.3.2 Patient-carer meetings

Three in-person patient events 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 2024 events were held in Cardiff in April (28 attendees), in London in October (50 attendees) and Edinburgh in December.

As usual those attending appreciated the opportunity they provided to share experiences with other GIST patients and carers as well as learning of developments in GIST management and treatment. Topics covered at these events included:

**Dr Lesley Storey** - Senior Lecturer in Psychology, Anglia Ruskin University Cambridge. Qualitative analysis about quality of life with a GIST diagnosis

**Dr Zoë Walters, PhD, FHEA** - Associate Professor in Translational Epigenomics, Cancer Sciences, Faculty of Medicine, University of Southampton. Research into the Tumour Microenvironment for GIST

**Dr Betsan Thomas** - Consultant Clinical Oncologist, Velindre Centre. Latest treatments, trials and research at Velindre.

**Professor Robin Jones** Consultant Medical Oncologist, Royal Marsden Hospital - Clinical Trials in GIST

**Deborah Warner**, Registered Nutrition Scientist - Nutrition for Cancer Patients

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, we provide 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 company, however, we typically receive around 500 calls each year.

We are now working with the Helplines Partnership to ensure that our associated procedures reflect sectoral best practice in this area.

### **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 carers and moderates day-to-day discussions. This 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. There were 1877 posts to the forum during the year.

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

As noted earlier in this report, GCUK now has no direct association with the PAWS-GIST clinics although it is entirely supportive of their aims and of the support they provide patients attending.

### **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. The GIST Cancer UK website underwent a major redevelopment during the course of the year to make it more targeted to the needs of patients.

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 revised versions of two of these: the *trifold A4 information leaflet* and *GIST for Beginners*.

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 Medical Advisory Board**

The Medical Advisory Board met formally once during the year and also provided key advice via email on areas such as bids for research funding. We are indebted to those who give their time to provide this service and help guide our activities. However, it is becoming increasingly difficult to sustain its operation given other pressures on the time of the consultants and academics who make up its membership. The Charity is exploring other means by which its remit can be fulfilled.

### **1.3.8 Research**

GCUK funds a number of small-scale research projects into GIST cancers which aim to understand their causes and identify improved treatments. During the year we worked closely with SarcomaUK utilising their processes for eliciting and assessing

potential research projects. This proved successful with three new research projects being solely funded or jointly funded with SarcomaUK.

#### **1.3.9 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.

#### **1.3.10 Other activities**

The following additional activities have been undertaken during the year:

- The development of a comprehensive approach to Risk Assessment.
- A major review of existing policies.

#### **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**

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 help-line 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 It 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 ca 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 1900 messages).
- Access to booklets and information on a range of issues relating to GISTs (see <https://www.gistcancer.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 new 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.

## 2.2 *Achievements against objectives set*

The charity had a new strategy covering the period from 2024 to 2027 which includes annual operational targets. The following summarises progress in respect of each of the three strands of the current strategy.

Aim	Progress
<b>Three patient/carer meetings</b>	12 <sup>th</sup> April (Cardiff), 5 <sup>th</sup> October (London). 1 <sup>st</sup> December (Scotland)
<b>Produce regular newsletter</b>	Newsletter in production – typically 2/3 editions pa depending on need.
<b>Develop and implement plan for review of existing written resources</b>	Plan developed. ‘Tri-fold leaflet’ and ‘Gist For Beginners’ have been revised.
<b>Revise website to include steps on patient journey</b>	New website live
<b>Revise online forum</b>	In development
<b>Review Helpline and associated procedures</b>	Underway and support being sought from the HelpLines Partnership (HLP) so that we can benchmark against sectoral best practice.
<b>Identify, with patients and carers, range of additional resources of potential use</b>	For 2025 - Not yet fully initiated but ‘Finding My Way’ resource under active exploration which would fill a significant gap around mental health and well-being
<b>Review patient and carer needs and identify and evaluate existing external resources</b>	‘Finding My Way’ resource under active exploration
<b>Pilot support mental health and wellbeing support mechanisms.</b>	GCUK has decided not to progress with this and instead direct patients to existing specialist resources.
<b>Identify research priorities</b>	Priority areas identified and incorporated into Sarcoma UK bidding priority document.
<b>Seek research proposals in identified areas possibly through partners</b>	New research projects identified and funded
<b>Evaluate written resources in line with development plan</b>	GfB and Trifold leaflets evaluated with input from patient panel.
<b>Identify lead and develop plan to support patient access to clinical trials</b>	Complete with support from RareCan
<b>Identify strategic partners in UK.</b>	Discussions held with SarcomaUK and closer working underway notably in the area of research currently.
<b>Identify a volunteer coordinator and develop plan for volunteering support</b>	Work on the Helpline (largely staffed by volunteers) has taken priority. Volunteering policy approved by Board.
<b>Review existing practices and develop a targeted approach to fundraising</b>	Fundraising levels remain relatively constant but new avenues being explored.
<b>Ensure administrative and support arrangements sustain efficient and effective operation in line with one-charity ethos</b>	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 individuals with a GIST and their friends

and family. Previous funding from Pharma companies has been more 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 (£)
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 £265,036).
- **Unrestricted Funds** – essentially the Charity's reserve (£162,566).

#### 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 interests in the treatment of GISTs.

#### 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 4.3% 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 2024).

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 *Description of charity's trusts:*

The Charity was 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. No changes have been made in the current year.

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

GCUK is constituted as trustees incorporated as a body.

Note: The charity is currently considering changing to a Foundation Charitable Incorporated Organisation.

### 4.3 *Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees*

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.

### 4.4 *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.

### 4.5 *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.

### 4.6 *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.

### 4.7 *Operation of the Board*

The Trustees met four times during the year, twice in person and twice remotely via MS Teams. In addition, there was a special virtual meeting of the Board to consider the funding of research.

There was one new appointment to the Board. We are still looking to return the membership of the Board to twelve.

#### 4.8 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 Equality Diversity and Inclusion - May 2021
- 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

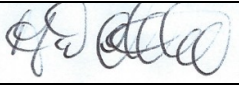
The Charity does not have explicit policies in place in the following areas requiring reporting by the Charity Commission:

- 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 March 2025.

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	



Date

	12 <sup>th</sup> August 2025
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GCUK

Accounts

31 December 2024

**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 2024**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
<b>INCOME</b>		
Donations - GCUK	87,987	91,309
Interest	19,360	7,931
	<u>107,347</u>	<u>99,240</u>
<b>EXPENDITURES</b>		
<b>Research Purchases</b>		
Research	166,530	33,218
	<u>166,530</u>	<u>33,218</u>
<b>Direct Expenses</b>		
Publicity/Goods for Sale	6,741	-
	<u>6,741</u>	<u>-</u>
<b>Overheads</b>		
Patient/Carer Meeting Costs	14,249	19,737
Patient Clinics	-	8,501
Courier Services	-	1,176
Post	-	261
Stationery	-	140
Telephone	329	405
Web Hosting	472	6,535
Accountancy	1,575	1,857
Insurance	494	466
Sundry	238	1,623
Just Giving	-	562
Travel and Subsistence	7,426	10,274
Cancer 52 Membership	300	-
Subscriptions & Memberships	608	50
Bank Charges	-	278
	<u>25,691</u>	<u>51,865</u>
	<u>198,962</u>	<u>85,083</u>
<b>(Loss)/profit</b>	<u>(91,615)</u>	<u>14,157</u>

**GCUK**  
**Balance Sheet**  
**as at 31 December 2024**

	<b>2024</b> £	<b>2023</b> £
<b>Assets</b>		
HSBC - GCUK 689	217,963	310,522
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	3,505	2,201
	<u>620,590</u>	<u>711,847</u>
<b>Liabilities</b>		
Trade creditors	358	-
	<u>358</u>	<u>-</u>
	<u>620,232</u>	<u>711,847</u>
<b>Net business assets represented by</b>		
Capital account:		
Brought forward	711,847	697,689
Net (loss)/profit	(91,615)	14,157
	<u>620,232</u>	<u>711,847</u>

GCUK

Accounts

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