

## Trustees' Annual Report to the Charity Commission (2023)

<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>	<a href="http://www.gistcancer.org.uk">www.gistcancer.org.uk</a>
<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 (appointed June 2023) Jane Means (resigned July 2023) Terry Weldon (resigned October 2023) Vicky Jones (resigned September 2023)

This report meets the annual reporting requirements of the Charity Commission and provides a record for the Charity of its main activities during the year and 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 operates mainly through the unpaid work of the trustees and other volunteers. Trustees take a leading role in individual aspects of the charity's work. A part-time paid consultant supports aspects of the charity's work including the operation of the PAWS-GIST clinics, coordinating the Medical Advisory Board, the monitoring of funded research, and the development of the National GIST Biobank.

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 objectives, 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 receive details of forthcoming events.

	2023	2022	2021	2020
<b>Patients/carers</b>	124	120	166	28
Total	730	632	-	-
<b>Fundraisers</b>	0	3	9	1
Total	12	18	-	-
<b>Medical contacts</b>	11	29	59	30
Total	105	129	-	-

New registrations remain steady at around 120 per year after being lower in 2020 (ascribed to covid-19) and being slightly higher in 2021 (possibly as a result of a post pandemic increase in the identification of GIST cancers). This represents ca 20% of those identified with a GIST cancer each year.

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.

#### 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 2023 events were held in London in April (41 attendees), Leeds in October (53 attendees) and Edinburgh in December (26 attendees). 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:

- The Cambridge Experience of managing GISTs (Dr Ramesh Bulusu)
- Recently completed and ongoing trials (Andrea Napolitano)
- PAWS-GIST Update (Dr Ramesh Bulusu)
- Side Effects Management (Dr Alex Lee)
- GIST Management – A brief history from before active drugs, to Imatinib, then other drugs and now to current clinical trial questions (Professor Dan Stark)
- The Psychological impact of Diagnosis and Treatment of GIST (Marion Oliver)

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 100 – 120 calls per month.

As part of a review of this aspect of our provision we are exploring working with the Helplines Partnership to ensure that it reflects sectoral best practice.

#### **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 are typically 100 – 150 posts to the forum each month.

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

There are some types of GIST which are more difficult to treat by conventional methods. Collectively these are grouped as Paediatric, Adolescent, Wild-type and Syndromic GIST or PAWS-GISTs.

GCUK provides financial support for PAWS-GIST clinics for those with GISTs in this category. The clinics are run by the NHS through Cambridge University Hospital Trusts and held at Addenbrookes Hospital, Cambridge under the Clinical direction of Dr Ramesh Bulusu. Twenty-eight patients and their families were supported to attend the three PAWS-GIST clinics that were hosted during 2023 (cf 23 the previous year).

#### **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. Work has commenced on updating two of these: the trifold A4 information leaflet and GIST for Beginners.

We have introduced a quarterly 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 twice during the year and provides valuable advice to the charity on medical issues and on priorities for research and research funding. We are indebted to those who give their time to provide this service and help guide our activities.

#### **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. No new research grants were made during the year. We have identified ways in which we can promote the availability of research funds to potential researchers and will be implementing these during 2024.

#### **1.3.9 National GIST Biobank**

During the year, GCUK completed arrangements with the Royal Marsden Hospital to establish the National GIST Biobank. This will provide an important repository of GIST tissue samples for use by researchers. The Biobank will be funded by the Charity for

three years to ascertain the level of demand for tissue samples and the value for money of continued funding.

#### **1.3.10 Other activities**

The following additional activities have been undertaken during the year:

- Implementation of the Charity Aid Foundation (CAF) Deposit Platform to allow for the better management of cash reserves. As a result of this we have closed some bank accounts and are now receiving interest on our savings.
- The Board approved a revised Expenses Policy.
- The Board undertook a major review of its three-year strategy with input from patients and carers. The new strategy will be implemented from 2024.

#### **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.

## **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 120 participants).
- Confidential Helpline (ca 1000 contacts).
- Private online email forum enabling those with GISTs and their carers to access online support and guidance and share experiences.
- Three PAWS-GIST clinics (each with around 10 participants).
- Access to booklets and information on a range of issues relating to GISTs (see <https://www.gistcancer.org.uk/publications/> )
- Continued funding of established small-scale research initiatives.
- 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*

As a small charity, relying on the good will of its volunteers, GCUK does not have a set of annual objectives. However, it is now at the end of a four-year strategy and has developed and approved a strategy for 2024-2027. The following summarises progress in respect of each of the three strands of the current strategy.

<b>SUPPORT for patients</b>	
Telephone helpline - manned by patients with first-hand experience of GIST	Fully operational
Online – we enable patients and carers to share their experiences using an e-mail forum, Facebook, Twitter and/or Instagram	Fully operational
E-mail helpline – for all those enquiring about GIST cancer	Fully operational
Face-to- face – two patient conferences in England and one in Scotland plus three PAWS-GIST clinics each year	Fully operational
<b>RESEARCH for a cure</b>	
Make GIST tissues samples available to researchers by supporting the GIST Tissue Bank	Completed and fully operational
Provide grants for research into GIST cancer	Operational
Raise funds to ensure the continuance of research	Operational
Monitor research projects funded by GCUK	Operational
Support the PAWS-GIST initiative	Fully operational
<b>INFORMATION and AWARENESS</b>	
Ensure an educational video is available to all GP's	Complete and operational
Maintain up to date GCUK & PAWS-GIST websites	Operational – websites have been revamped and information updated.
Maintain & expand a range of brochures providing information about GIST cancer and managing the disease.	Full range of resources now available.
Ensure GIST professionals have access to our literature for their patients	Complete – ensuring we have an accurate list of current GIST professionals is an ongoing activity.

## 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.

## 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 will enable a return on its reserves to be achieved during the forthcoming years.

### 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 2022 financial year was £585,381 (cf £697,690 for 2022 and £646,215 for 2021). These funds are distributed across various categories as set out in the Charity's Reserves Policy

- **Operational Costs** – 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 (£50,000).
- **Designated Funds** – that the charity is committed to contractually and are costs that need to be met at some stage in the future (£189,361).
- **Restricted Funds** – funds the charity has set aside for schemes yet to be approved contractually but are nonetheless formally allocated for a purpose (£53,303).
- **Unrestricted Funds** – essentially the Charity's reserve (£292,687).

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

The charity generates money through fundraising activities by individuals.

#### 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 gained over £10k from interest on its investments. Previously this had been effectively zero.

#### 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 2023).

Receiving less funding or fewer public donations	High
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 lack of funding from Pharma has raised the level for the receipt of funding from Medium to High. The Board continues to monitor this and to seek new sources of funding to enable it to continue its activities. Its current level of reserves means that it can continue to operate on current funds for at least a three year period.



## **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.

### **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.

### **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 started to explore working more collaboratively with other charities with similar aims and expects to see the outcomes of this initiative during 2024.

### **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 new trustees.

Three Board members decided not to renew their trusteeship when their period of appointment came to an end and one trustee became uncontactable and their trusteeship was terminated. There was one new appointment to the Board. At the end of the year the Board was actively recruiting for replacements to bring membership back to ca 12.

## 5 Declarations

The Board of Trustees declare that they discussed and approved this report together with the annual accounts at their meeting in April 2024.

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>		



GCUK

Accounts

31 December 2023

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

I report on the accounts of the charity for the year ended 31 December 2023.

**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

26 April 2024

**GCUK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2023**

	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
<b>INCOME</b>		
Donations - GCUK	91,309	144,132
Interest	7,931	850
	<u>99,240</u>	<u>144,982</u>
<b>EXPENDITURES</b>		
<b>Research Purchases</b>		
GCUK - Consultancy	-	12,000
GCUK - Research	33,218	43,521
	<u>33,218</u>	<u>55,521</u>
<b>Direct Expenses</b>		
Publicity/Goods for Sale	-	4,794
	<u>-</u>	<u>4,794</u>
<b>Overheads</b>		
Patient/Carer Meeting Costs	15,383	6,771
Meeting Costs - Trustee Meeting	4,354	-
Patient Clinics	8,501	6,830
Courier Services	1,176	-
Admin Support	-	230
Post	261	555
Stationery	140	158
Telephone	405	398
Web Hosting	6,535	4,667
Accountancy	1,857	2,080
Insurance	466	421
Sundry	1,623	1,823
Just Giving	562	-
Travel and Subsistence	10,274	8,696
Subscriptions & Memberships	50	242
Bank Charges	278	-
Bank, credit card and other finance charges	-	320
	<u>51,865</u>	<u>33,191</u>
	<u>85,083</u>	<u>93,506</u>
<b>Profit</b>	<u>14,157</u>	<u>51,476</u>

**GCUK**  
**Balance Sheet**  
**as at 31 December 2023**

	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
<b>Assets</b>		
HSBC - PAWS/GIST 547	240,094	138,986
HSBC - GCUK 689	70,423	227,666
HSBC - GIST Support UK 670	63,024	162,192
Nationwide - GCUK 514	-	76,730
HSBC - PAWS GIST Community - 469	100	4,788
Shawbrook Bank - PAWS/GIST 621	-	86,099
Flagstones	336,000	-
Other current assets and prepayments	2,206	3,510
	<u>711,845</u>	<u>699,971</u>
<b>Liabilities</b>		
Trade creditors	(2)	2,281
	<u>(2)</u>	<u>2,281</u>
	<u>711,847</u>	<u>697,690</u>
<b>Net business assets represented by</b>		
Capital account:		
Brought forward	697,690	646,213
Net profit	14,157	51,476
	<u>711,847</u>	<u>697,690</u>

GCUK

Accounts

31 December 2023

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

I report on the accounts of the charity for the year ended 31 December 2023.

**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.

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**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.

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**GCUK**  
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