

## Trustees' Annual Report to the Charity Commission (2022)

<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) Sharon Bethell (Vice-chair) Terry Weldon David Lane Terry Riley Jane Means Amalia Formoso Tony Manuel Jayne Bressington (resigned May 2022) Stella Turner (resigned March 2022) Vicky Jones (appointed September 2022) Ros Langford (appointed December 2022)

### 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 paid consultant coordinates the operation of the charity's Clinics, the Medical Advisory Board and other aspects of its work including the tissue bank, co-ordinating research activities and supporting patients' attendance at the PAWS-GIST clinic which is hosted by Dr Ramesh Bulusu at Addenbrookes hospital in Cambridge. GCUK contracts with specialist providers in other specialist areas for example in relation to technical support for the web site and other IT functions, video-recording of presentations at our patient meetings and administrative support.

#### 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 Registrations

New registrations are signposted to the GCUK website where they complete an online form to ensure GDPR compliance. The number of new registrations was down in 2022 compared to the previous year although higher than 2020. The impact of the Covid19 pandemic on the identification of new cancer patients in 2020 may be an underlying factor in these trends. Identifying medical practitioners who are dealing with GIST patients is an ongoing process taking retirements and career changes into account and the lack of any central register.

		2022	2021	2020
<i>Patients/carers</i>	New	120	166	28
	Total	632	-	-
<i>Fundraisers</i>	New	3	9	1
	Total	18	-	-
<i>Medical contacts</i>	New	29	59	30
	Total	129		

### 1.3.2 Patient-carer meetings

After restrictions placed on face-to-face meetings were removed, we were able to return to our pre-pandemic level of three in-person patient events per year. These were held in Bath in March (35 attendees), Liverpool in October (23 attendees) and Edinburgh in December (38 attendees). The opportunity of sharing experiences with other GIST patients and carers was valued. Topics covered included:

- **Patient driven research.** Chief Scientific Officer & Founding Director of RareCan - Professor Andy Hall
- **Generic Imatinib - Facts & Myths:** Consultant Oncologist - Dr Ramesh Bulusu and Sarcoma Specialist Pharmacist, Laura Ferro Lopez.
- **Managing a GIST - Where are we up to now?** Dr Nasim Ali - Consultant Medical Oncologist Clatterbridge Cancer Centre – Liverpool.
- **The Science behind why we do Molecular Testing.** Fiona McDonald - Genomics Programme Manager, The National Disease Registration Service.
- **A Patient's Perspective.** Jim Watson – A GIST Patient since 2016.

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.

### 1.3.4 Listserv

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.

### 1.3.5 PAWS-GIST clinics

There are some sub-variants of GIST which are rare and more difficult to treat by conventional methods. Collectively these are grouped as Paediatric, Adolescent, Wild-type and Syndromic GIST or PAWS-GIST patients. GCUK supports PAWS-GIST

clinics which are held at Addenbrookes Hospital, Cambridge under the Clinical direction of Dr Ramesh Bulusu. Twenty-three patients and their families were supported to attend the three PAWS-GIST clinics that were hosted during 2022.

### **1.3.6 Information**

Following an update of GIST Cancer UK's web site ([www.gistcancer.org.uk](http://www.gistcancer.org.uk)), the website for PAWS-GIST patients and associated clinicians ([www.pawsgistclinic.org.uk](http://www.pawsgistclinic.org.uk)) was reviewed and revised to provide a wider range of information of relevance to the PAWS-GIST community.

GIST Cancer UK provides a range of leaflets and other information aimed at patients, carers and health care practitioners ensuring that these remain up-to-date with the latest advice.

Dr Sadaf Haque (a GP and Cancer lead for Gloucestershire) launched our educational video for GP's and Primary Care Clinicians "Diagnosing GIST". This has been designed to raise awareness of the nature of GISTs and how patients might present to primary healthcare professionals such as GPs. The video can be access via our website and a supporting campaign to GPs has been instigated.

### **1.3.7 Research**

GCUK funds a number of small-scale research projects into GIST cancers aiming to understand their causes and uncover improved treatments. Currently these include:

- Wildtype SDH Deficient GIST in the UK; A review of clinical course, genetics, epigenetics and metabolomics.
- Next generation sequencing of WT GIST's to identify therapeutic targets.
- Derivation, maintenance and characterisation of cell lines from biopsies of PAWS-GIST
- Research to investigate the potential of Gallium-68 (68Ga) DOTA-conjugated peptidePET/CT to develop theranostic applications in wild-type gastrointestinal stromal tumours (GISTs).
- Pilot Study - Altered RNA methylation in SDH deficient gastrointestinal stromal tumours
- SSGXXII Scandinavian 3 versus 5 years adjuvant imatinib study - funding to extend the UK arm of this trial for further years enabling the recruitment of additional UK GIST patients to this Europe-wide study.

Progress on these projects was significantly hampered by the Covid pandemic when laboratories closed and clinicians were re-deployed to frontline Covid patient management.

The following additional activities have been undertaken during the year:

- Streamlining of procedures.
- Revisions to the Social Media Policy.
- Continuing work to implement the Charity Aid Foundation (CAF) Deposit Platform for managing cash reserves.
- Development of an approach to involving patients and carers more systematically in the work of the charity.
- Approval of arrangements for providing financial support to patients in need.
- A review of the range of skills and experiences of trustees to ensure that the Board remained well equipped to undertake its responsibilities as a charity.
- A review of the side-effects arising from the introduction of generic brands of the main drug used for GIST treatment. This involved a survey of our member community. The results have been used to inform prescribing practice.

#### 1.4 Public Benefit

In deciding on activities and in the compilation of this annual report, the Trustees have had regard to the guidance issued by the Charity Commission on public benefit (available at <https://www.gov.uk/government/publications/public-benefit-an-overview/public-benefit-an-overview>)

#### 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 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 society as a whole.

- Three patient/carer meetings involving 96 participants.
- Helpline contacts
- Operating an online email forum enabling those with GISTs and their carers to access online support and guidance and the sharing of experiences
- Three PAWS-GIST clinics each with around 10 participants
- Revised guidance on a range of issues relating to GISTs (see <https://www.gistcancer.org.uk/publications/> )
- Continued funding of small-scale research initiatives
- Raising awareness of GISTs amongst healthcare practitioners including a short video for GPs
- Contributions to the activities of national and international cancer groupings
- Stakeholder participation in NICE technology appraisals of new GIST treatments

### 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 started the process of developing its next strategy. 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	Operational
Online – we enable patients and carers to share their experiences using an e-mail	Operational

forum, Facebook, Twitter and/or Instagram	
E-mail helpline – for all those enquiring about GIST cancer	Operational
Face-to- face – two patient conferences in England and one in Scotland plus three PAWS-GIST clinics each year	Operational
<b>RESEARCH for a cure</b>	
Make GIST tissues samples available to researchers by supporting the GIST Tissue Bank	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	Operational
<b>INFORMATION and AWARENESS</b>	
Ensure an educational video is available to all GP's	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 the achievement of any such objectives. It is currently developing a more systematic approach to fundraising to help support its activities.

### 2.4 *Investment performance against objectives*

Rates of return on investments have been low and the charity has been considering how best to manage its reserves to ensure that returns are maximised whilst risks are spread. Routinely managing reserves across multiple bank accounts currently creates additional work for volunteer trustees and limits the charity's ability to exploit investment opportunities. It is preparing for the introduction of use of the Charities Aid Foundation (CAF) platform to better manage financial reserves and expects this to be operational in 2023.

## 3 **Financial Review**

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

GCUK is in a good financial position with sound finances that would allow it to operate for a three-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 £697,690 (cf £646,215 for 2021).

The Board approved a new Reserves Policy during the year which recognises the following categories of funds with the level of reserves under each heading indicated (as of December 2021):

- **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 (£61,000).
- **Designated Funds** – that the charity is committed to contractually and are costs that need to be met at some stage in the future (£231,563).
- **Restricted Funds** – funds the charity has set aside for schemes yet to be approved contractually but are nonetheless formally allocated for a purpose (£91,215).
- **Unrestricted Funds** – essentially the Charity's reserve (£262,435).

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

The charity generates money through fundraising activities and receives financial support from various Pharmaceutical Companies.

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

Currently GCUK does not have any financial 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 2022). There are no major risks of concern.

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

## 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. In September 2022 minor changes were made to the declaration. These included:

- A change of the recorded name of the charity in the Declaration from GIST Support UK to GIST Cancer UK in line with the previous change agreed by the Board and notified to the charity commission.
- Removal of the names of the trustees from the Declaration as these were the original members at the time of the establishment of the charity. Names of the current trustees were added as an appendix.
- Removal of references to dates of legislation to ensure that the Deed was future proofed against any such changes.



- iv. An amendment to the process for record keeping to reflect developments in IT and to state that all records will be approved by the Board and confirmed in subsequent minutes.

#### *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 carers 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. The trustees attend relevant meetings to raise awareness of this rare cancer and to gather useful information to share with our Patient Community. During 2022 we attended relevant meetings with a variety of organisations nationally and internationally.

#### *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 were two special virtual meetings of the Board to consider new trustees and the change to the Declaration.

Stella Turner and Jayne Bressington stood down from the Board. They had made a significant contribution to the strategic direction of the Board during their lengthy appointments. Jayne's commitment to the charity will continue through her consultancy role enabling her wisdom and extensive knowledge and experience to be used to support GIST cancer patients and particularly those with PAWS-GIST.

Ros Langford and Vicky Jones, who bring personal experiences of GIST joined the GCUK Board whose numbers remain at twelve.

## 5 Declarations

The Board of Trustees declare that they discussed and approved this report together with the annual accounts at their meeting in October 2023.

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Nic Puntis	Mark Atlay
<b>Position (eg Secretary, Chair, etc)</b>	Chair	
<b>Date</b>		



GCUK

Accounts

31 December 2022

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

I report on the accounts of the charity for the year ended 31 December 2022.

**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

17 August 2023

**GCUK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2022**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>INCOME</b>		
Donations - GCUK	144,132	108,882
Interest	850	38
	<u>144,982</u>	<u>108,920</u>
<b>EXPENDITURES</b>		
<b>Research Purchases</b>		
GCUK - Consultancy	12,000	2,948
GCUK - Research	43,521	40,321
Research and Consultancy - PAWS	-	26,217
	<u>55,521</u>	<u>69,486</u>
<b>Direct Expenses</b>		
Publicity/Goods for Sale	4,794	671
	<u>4,794</u>	<u>671</u>
<b>Overheads</b>		
Patient/Carer Meeting Costs	6,771	6,915
Patient Clinics - GIST/PAWS	6,830	-
Admin Support	230	-
Post	555	1,041
Printing	-	2,979
Stationery	158	413
Telephone	398	596
Web Hosting	4,667	11,875
Accountancy	2,080	2,774
Insurance	421	397
Sundry	1,823	2,629
Genetic Alliance Membership Fee	-	50
Just Giving	-	238
Travel Costs - GSUK/PAWS	8,696	45
Cancer 52 Membership	150	-
Subscriptions & Memberships	92	(2)
Bank, credit card and other finance charges	320	36
	<u>33,191</u>	<u>29,986</u>
	<u>93,506</u>	<u>100,143</u>
<b>Profit</b>	<u>51,476</u>	<u>8,777</u>

**GCUK**  
**Balance Sheet**  
**as at 31 December 2022**

	<b>2022</b> <b>£</b>	<b>2021</b> <b>£</b>
<b>Assets</b>		
HSBC - PAWS/GIST 547	138,986	139,185
HSBC - GCUK 689	227,666	218,497
HSBC - GIST Support UK 670	162,192	112,749
Nationwide - GCUK 514	76,730	76,730
HSBC - PAWS GIST Community - 469	4,788	12,954
Shawbrook Bank - PAWS/GIST 621	86,099	86,099
Other current assets and prepayments	3,510	-
	<u>699,969</u>	<u>646,214</u>
<b>Liabilities</b>		
Trade creditors	2,279	-
	<u>2,279</u>	<u>-</u>
	<u>697,690</u>	<u>646,214</u>
<b>Net business assets represented by</b>		
Capital account:		
Brought forward	646,214	637,436
Net profit	51,476	8,777
	<u>697,690</u>	<u>646,214</u>

GCUK

Accounts

31 December 2022

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

I report on the accounts of the charity for the year ended 31 December 2022.

**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;**

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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.

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**Independent examiner's statement**

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**GCUK**  
**Balance Sheet**  
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