

Trustees' Annual Report to the Charity Commission (2021)

Charity name:	GIST Cancer UK
Charity number:	1129219
Principal address	3 Phillips Grove, Yatton Keynell, Chippenham, Wiltshire, SN14 7FA
Phone	0300 400 0000
Email	admin@gistcancer.org.uk
Website	www.gistcancer.org.uk
Trustees (as 31 st Dec. 2021)	Nic Puntis (Chair) Jayne Bressington (PAWS-GIST Director) John South (Treasurer) Mark Atlay (Secretary) Sharon Bethell Stella Turner Terry Weldon Terry Riley Jane Means Amalia Formoso Tony Manuel

1 Objectives and Activities

1.1 Overarching Purpose

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

- To promote and protect the physical and mental health of patients with Gastro-intestinal Stromal Tumors (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. The Charity contracts with specialist providers to augment its work for example in relation to technical support for the web site and other IT functions, video-recording of presentations, and admin support.

1.3 Main activities

In furtherance of its objectives the Charity has undertaken the following activities during the period covered by this report. It should be noted that the pandemic had a significant impact on the charity during this period particularly in its ability to hold face-to-face meetings to support patients and their carers and in terms of fundraising.

In 2021 we registered 166 **new** patients or carers on the GCUK Database up from 28 in 2020 although it is interesting to note that no new registrations were received between mid-June and December 2020, possibly due to the national lockdown restrictions and hence a dramatic reduction in cancer referrals/diagnosis during that period. We also registered 59 new hospital contacts (up from 30 in 2020). In 2021 we registered 9 new fundraisers (up from 1 in 2020).

1.3.1 Patient-carer meetings

Two meetings were held for patients and their carers (April with 70 people in attendance and October 2021 when 45 attended). Because of the pandemic these were held online rather than face-to-face and were of a shorter duration than normal meetings and we were unable to convene our usual meeting in Scotland.

Feedback from participants was positive although they reported that they missed the opportunity of sharing experiences provided by normal meetings. Topics covered included:

- The use of Radiotherapy in GIST Cancer treatment.
- How clinical trials work.
- Personal experiences of clinical trials
- The special needs of GIST patients during the pandemic and lockdown
- Continuing to work when having a GIST diagnosis.

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

1.3.2 Helpline

We provide access to a helpline enabling patients and carers to talk to someone in confidence. Although not staffed by health care practitioners, we can provide advice and guidance or re-direct calls when appropriate. Calls to our helpline increased considerably during Covid 19.

1.3.3 Listserv

One of the major ways in which we support patients and their carers is through the provision of a private email discussion forum. GCUK controls access to this space to ensure that only GIST patients and their carers can gain access and moderates day-to-day comments. The forum is actively used to discuss a range of issues including symptoms, treatments and their side-effects and other relevant topics

1.3.4 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 (Carney's Triad and Carney-Stratakis Syndrome) or PAWS-GIST patients. GCUK runs PAWS-GIST clinics at Addenbrookes Hospital, Cambridge to help and support patients through contact with medical specialists.

Two clinics were run during the year. Normally GCUK would aim to run three such clinics each year, but these were affected by the pandemic and none had been run the previous year. The PAWS-GIST website is regularly updated and offers valuable help and information to PAWS-GIST Patients and carers.

1.3.5 Information

GCUK has significantly improved its web site (www.gistcancer.org.uk) so that it provides a wider range of information of relevance to the GIST community. We also provide a range leaflets and other information aimed at patients, carers and health care practitioners ensuring that these remain up-to-date with the latest advice.

1.3.6 Research

GCUK funds a number of small-scale research projects into GISTs and their treatment. 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 peptide PET/CT to develop theranostic applications in wild-type gastrointestinal stromal tumours (GISTs).
- Pilot Study - Altered RNA methylation in SDH deficient gastrointestinal stromal tumours
- In addition, GCUK is working with staff at the Royal Marsden Hospital to establish a Tissue Bank for use by researchers.

1.3.7 Other major activities during 2021

The following additional activities have been undertaken during the year:

- Ensuring compliance with the General Data Protection Regulations
- Approving the GCUK reserves Policy

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 its currently considering extending its arrangements in this area in line with its objectives.

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, 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.

- Two patient/carer meetings involving 115 participants
- Helpline contacts
- Operating an online mailbase enabling those with GISTs and their carers to access online support and guidance and the sharing of experiences
- Two PAWS-GIST clinics
- 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
- Contributions to the activities of national and international cancer groupings

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 in the middle of a four-year strategy which runs from 2019 – 2022 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.

SUPPORT for patients	
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 forum, Facebook, Twitter and/or Instagram	Operational
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	Remains an aim but affected by pandemic in 2021. Two online conferences and two PAWS-GIST clinics ran.
RESEARCH for a cure	
Make GIST tissues samples available to researchers by supporting the GIST Tissue Bank	Progress underway but Tissue Bank not yet fully established.
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
INFORMATION and AWARENESS	
Ensure an educational video is available to all GP's	Video production delayed by pandemic but close to completion and should be available in 2022.
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 – although ensuring we have an accurate list of current GIST professionals requires ongoing work.

2.3 Performance of fundraising activities against objectives set

GCUK does not currently have set objectives for fundraising and, achievement of any such objectives would have been considerably impacted by the pandemic. However, it is currently considering 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 has been considering the use of the Charities Aid Foundation (CAF) platform to better manage financial reserves and expects to make a decision early in 2022.

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 the reserves at the end of the 2021 financial year was £646,212.

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. 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. No other amendments to the original Declaration have been made.

4.2 How is the charity constituted?

GCUK is a 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 carers who indicate their willingness to contribute at events and activities or through a general request to the mailbase. Trustees serve for a three-year period but can be re-elected. The Charity is currently undertaking a review of the experience of its Board members utilising resources supplied by the Charity Commission.

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. The trustees attend relevant meetings to raise awareness of this rare Cancer and to gather useful information to share with our Patient Community. During 2020 we attended various meetings including Cancer 52 Meetings and European Network meetings.

4.7 Operation of the Board

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

Sheena Kynoch stood down as a Trustee. Sheena was a Trustee of the Charity since its inception and carried out many roles, including the very demanding role of Secretary. Sheena will be sorely missed and fondly remembered and we hope to see her at future Patient & Carer Meetings. We welcomed Mark Atlay as a new Trustee, taking over the role of Secretary.

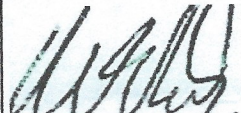
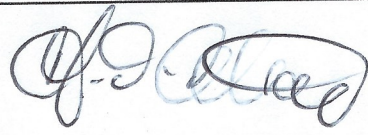
Sadly, in March, we lost James Palgrave due to GIST Cancer. James was involved with GCUK for many years and helped us enormously with our IT Function. He will be sorely missed.

Medium	Receiving less funding or fewer public donations
Low	Losing money through inappropriate investments
Low	Reliance on a few sources for income
Low	Inaccurate and/or insufficient financial information

5 Declarations

The Board of Trustees declare that they discussed and approved this report together with the annual accounts at their meeting in July 2022.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Nic Puntis	Mark Atlay
Position (eg Secretary, Chair, etc)	Chair	Secretary
Date	01.10.22	

GCUK

Accounts

31 December 2021

Independent Examiners Report of the Trustees of GIST Cancer UK

I report on the accounts of the charity for the year ended 31 December 2021.

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 Charitiy 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.

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21 June 2022

GCUK
Profit and Loss Account
for the year ended 31 December 2021

	2021	2020
	£	£
Income		
Donations - GCUK	86,494	47,690
Donations - PAWS	22,388	30,032
Interest	38	408
	<hr/> 108,920	<hr/> 78,130
Research Purchases		
General Research - GCUK	2,948	6,733
Research and Consultancy - GCUK	40,321	9,982
Research and Consultancy - PAWS	26,217	26,999
	<hr/> 69,486	<hr/> 43,714
Direct Expenses		
Publicity/Goods for Sale - GCUK/PAWS	671	1,940
	<hr/> 671	<hr/> 1,940
Overheads		
Motor Expenses - GCUK/PAWS	487	668
Entertainment/Subsistance - GCUK/PAWS	24	435
Travel Meeting Costs - GCUK/PAWS	463	466
Hotel Costs - GCUK/PAWS	3,258	1,218
Meeting Costs - Patient Meetings	182	-
Meeting Costs - 2018 - London GCUK	-	4,722
Meeting Costs - Autumn/Cardiff - GCUK	-	95
Meeting Costs - Autumn 20 Bath	870	845
Meeting Costs - Trustee Meeting	1,631	-
Post - GCUK/PAWS	1,041	552
Printing - GCUK/PAWS	2,979	3,724
Stationery - GCUK/PAWS	413	672
Telephone - GCUK/PAWS	596	368
Web Hosting - GCUK/PAWS	11,875	800
Accountancy - GCUK/PAWS	2,774	1,764
Insurance - GCUK/PAWS	397	392
Sundry - GCUK/PAWS	2,629	275
Genetic Alliance Membership Fee	50	50

GCUK
Profit and Loss Account
for the year ended 31 December 2021

Just Giving	238	216
ESMO	-	23
Travel Costs - GSUK/PAWS	45	1,221
Cancer 52 Membership	-	150
Bank, credit card and other finance charges	36	-
	<hr/>	<hr/>
	29,988	18,656
	<hr/>	<hr/>
	100,145	64,310
	<hr/>	<hr/>
Profit	<hr/>	<hr/>
	8,775	13,820
	<hr/>	<hr/>

GCUK
Balance Sheet
as at 31 December 2021

	2021	2020
	£	£
Assets		
Debtors	-	5
HSBC - PAWS/GIST 547	139,185	183,286
HSBC - GCUK 689	218,497	200,952
HSBC - GIST Support UK 670	112,749	79,280
Nationwide - GCUK 514	76,730	76,730
HSBC - PAWS GIST Community - 469	12,954	12,085
Shawbrook Bank - PAWS/GIST 621	86,099	86,099
	<u>646,212</u>	<u>638,437</u>
Liabilities		
Trade creditors	-	1,000
	<u>-</u>	<u>1,000</u>
	<u>646,212</u>	<u>637,437</u>
Net business assets represented by		
Capital account:		
Brought forward	637,437	623,616
Net profit	8,775	13,820
	<u>646,212</u>	<u>637,437</u>