

GIST Cancer UK

England & Wales · Charity number 1129219

Details

Other names GIST SUPPORT UK, GCUK, GSUK

Status Registered

Legal form Other

Registered 2009-04-20

Register [View on the Charity Commission register](#)

Contact

Address 3 Phillips Grove
Yatton Keynell
Chippenham
Wiltshire
SN14 7FA

Phone 0300 400 0000

Email admin@gistcancer.org.uk

Website www.gistcancer.org.uk

Activities

Objects: A) TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF PATIENTS WITH GASTRO-INTESTINAL STROMAL TUMOURS (GIST) IN THE UNITED KINGDOM THROUGH THE PROVISION OF INFORMATION, SUPPORT, EDUCATION AND PRACTICAL ADVICE TO THEM AND THEIR CARERS B) 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 C) TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC AND HEALTH PROFESSIONALS IN ALL AREAS RELATING TO GIST

Activities: We give support and (non-medical) advice to patients and their carers affected by gastro-intestinal stromal tumours. We do this by means of a website, and by providing telephone and email help. We also run patient support meetings, and represent patients' interests with health professionals, government agencies and pharmaceutical companies.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups, The General Public/mankind

Geography

- **Area of benefit:** THE UNITED KINGDOM
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£105,397	£150,451	-	-
2024-12-31	£107,347	£198,962	-	-
2023-12-31	£99,240	£85,083	-	-
2022-12-31	£144,982	£93,506	-	-
2021-12-31	£108,920	£100,145	-	-
2020-12-31	£78,130	£64,130	-	-

Trustees

Name	Role	Appointed
NICOLAS FRANCIS PUNTIS	Chair	2013-04-26
Cathy Hampshire		2024-01-23
David Lane		2022-01-07
Dr Mark Atlay		2021-09-06
Drewe Lacey		2023-07-14
John South		2019-07-13
Rosalind Langford		2023-01-12

GIST Cancer UK

England & Wales - Charity number 1129219

Accounts

Trustees' Annual Report to the Charity Commission (2025)

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

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

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

1 Objectives and Activities

1.1 *Overarching Purpose*

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

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

1.2 *Mode of Operation*

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

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

1.3 Main activities

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

1.3.1 New Registrations

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

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

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

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

1.3.2 Patient meetings

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

Manchester (March 2025). (56 attendees)

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

London (September 2025) (66 attendees)

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

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

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

1.3.3 Helpline

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

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

1.3.4 Online forum

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

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

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

1.3.5 PAWS-GIST clinics

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

1.3.6 Information

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

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

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

1.3.7 Research

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

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

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

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

1.3.8 National GIST Biobank

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

1.3.9 Other activities

The following additional activities have been undertaken during the year:

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

1.4 Public Benefit

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

1.5 Policy on grant making

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

1.6 Policy on social investment including program related investment

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

1.7 Contribution made by volunteers

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

2 Achievements and Performance

2.1 Charitable activities undertaken

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

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

- Confidential Helpline (ca 500 contacts).
- Private online email forum enabling those with GISTs and their carers to access online support and guidance and share experiences (ca 2000 posts).
- Access to up-to-date booklets and information on a range of issues relating to GISTs (see <https://www.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 GIST treatments.
- The Charity attends national and international conferences to represent the interests of GIST patients, identify research and learn of new and forthcoming drug trials.
- There were no safeguarding or other issues requiring reporting during the year.

2.2 Achievements against objectives set

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

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

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

2.3 *Performance of fundraising activities against objectives set*

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

2.4 *Investment performance against objectives*

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

3 **Financial Review**

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

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

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

GCUK holds reserves for two main reasons:

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

3.3 *Amount of reserves held*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

4 **Structure, Governance and Management**

4.1 *How is the charity constituted?*

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

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

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

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

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

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

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

4.4 *Relationship with any related parties*

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

4.5 *Operation of the Board*

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

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

4.6 *Policies and Procedures*

The Board has the following policies and procedures in place:

GCUK has the following approved policies:

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



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

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

5 Declarations

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Nic Puntis	Mark Atlay
Position	Chair	
Date	7 th May 2026	7 th May 2026

GCUK

Accounts

31 December 2025

GIST Cancer UK
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 2025

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

GCUK
Balance Sheet
as at 31 December 2025

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

GCUK

Accounts

31 December 2025

GIST Cancer UK
31 December 2024

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Foxwise Accountancy Ltd
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GCUK
Income and Expenditure Account
for the year ended 31 December 2025

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GIST Cancer UK

England & Wales - Charity number 1129219

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Trustees' Annual Report to the Charity Commission (2024)

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Charity number:	1129219
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Phone	0300 400 0000
Email	admin@gistcancer.org.uk
Website	www.gistcancer.org.uk
Trustees	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
Patients/carers	158	124	120	166	28
Fundraisers	1	0	3	9	1
Healthcare contacts	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) and the corresponding one for the PAWS-GIST clinic (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/carer 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
Three patient/carer meetings	12 th April (Cardiff), 5 th October (London). 1 st December (Scotland)
Produce regular newsletter	Newsletter in production – typically 2/3 editions pa depending on need.
Develop and implement plan for review of existing written resources	Plan developed. ‘Tri-fold leaflet’ and ‘Gist For Beginners’ have been revised.
Revise website to include steps on patient journey	New website live
Revise online forum	In development
Review Helpline and associated procedures	Underway and support being sought from the HelpLines Partnership (HLP) so that we can benchmark against sectoral best practice.
Identify, with patients and carers, range of additional resources of potential use	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
Review patient and carer needs and identify and evaluate existing external resources	‘Finding My Way’ resource under active exploration
Pilot support mental health and wellbeing support mechanisms.	GCUK has decided not to progress with this and instead direct patients to existing specialist resources.
Identify research priorities	Priority areas identified and incorporated into Sarcoma UK bidding priority document.
Seek research proposals in identified areas possibly through partners	New research projects identified and funded
Evaluate written resources in line with development plan	GfB and Trifold leaflets evaluated with input from patient panel.
Identify lead and develop plan to support patient access to clinical trials	Complete with support from RareCan
Identify strategic partners in UK.	Discussions held with SarcomaUK and closer working underway notably in the area of research currently.
Identify a volunteer coordinator and develop plan for volunteering support	Work on the Helpline (largely staffed by volunteers) has taken priority. Volunteering policy approved by Board.
Review existing practices and develop a targeted approach to fundraising	Fundraising levels remain relatively constant but new avenues being explored.
Ensure administrative and support arrangements sustain efficient and effective operation in line with one-charity ethos	Complete and being monitored to ensure charity’s needs are met.

2.3 Performance of fundraising activities against objectives set

GCUK does not currently have set objectives for fundraising and their achievement. It relies largely on the fundraising activities of 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

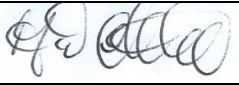
The Charity does not have explicit policies in place in the following areas requiring reporting by the Charity Commission:

- 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

Signature(s)		
Full name(s)	Nic Puntis	Mark Atlay
Position	Chair	

Date

	12 th August 2025
--	------------------------------

GCUK

Accounts

31 December 2024

GIST Cancer UK
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

	2024	2023
	£	£
INCOME		
Donations - GCUK	87,987	91,309
Interest	19,360	7,931
	<u>107,347</u>	<u>99,240</u>
EXPENDITURES		
Research Purchases		
Research	166,530	33,218
	<u>166,530</u>	<u>33,218</u>
Direct Expenses		
Publicity/Goods for Sale	6,741	-
	<u>6,741</u>	<u>-</u>
Overheads		
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>
(Loss)/profit	<u>(91,615)</u>	<u>14,157</u>

GCUK
Balance Sheet
as at 31 December 2024

	2024	2023
	£	£
Assets		
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>
Liabilities		
Trade creditors	358	-
	<u>358</u>	<u>-</u>
	<u>620,232</u>	<u>711,847</u>
Net business assets represented by		
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

31 December 2024

GIST Cancer UK
31 December 2024

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06 June 2025

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GIST Cancer UK

England & Wales - Charity number 1129219

Accounts

Trustees' Annual Report to the Charity Commission (2023)

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	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
Patients/carers	124	120	166	28
Total	730	632	-	-
Fundraisers	0	3	9	1
Total	12	18	-	-
Medical contacts	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) and the corresponding one for the PAWS-GIST clinic (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/carer 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.

SUPPORT for patients	
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
RESEARCH for a cure	
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
INFORMATION and AWARENESS	
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

Signature(s)		
Full name(s)	Nic Puntis	Mark Atlay
Position	Chair	
Date		

GCUK

Accounts

31 December 2023

GIST Cancer UK
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 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

	2023	2022
	£	£
INCOME		
Donations - GCUK	91,309	144,132
Interest	7,931	850
	<u>99,240</u>	<u>144,982</u>
EXPENDITURES		
Research Purchases		
GCUK - Consultancy	-	12,000
GCUK - Research	33,218	43,521
	<u>33,218</u>	<u>55,521</u>
Direct Expenses		
Publicity/Goods for Sale	-	4,794
	<u>-</u>	<u>4,794</u>
Overheads		
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>
Profit	<u>14,157</u>	<u>51,476</u>

GCUK
Balance Sheet
as at 31 December 2023

	2023	2022
	£	£
Assets		
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>
Liabilities		
Trade creditors	(2)	2,281
	<u>(2)</u>	<u>2,281</u>
	<u>711,847</u>	<u>697,690</u>
Net business assets represented by		
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

GIST Cancer UK
31 December 2021

Independent Examiners Report of the Trustees of GIST Cancer UK

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GCUK
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as at 31 December 2023

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Other current assets and prepayments	2,206	3,510
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Net business assets represented by		
Capital account:		
Brought forward	697,690	646,213
Net profit	14,157	51,476
	<u>711,847</u>	<u>697,690</u>

GIST Cancer UK

England & Wales - Charity number 1129219

Accounts

Trustees' Annual Report to the Charity Commission (2022)

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	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 McRonald - 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), the website for PAWS-GIST patients and associated clinicians (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.

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	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
RESEARCH for a cure	
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
INFORMATION and AWARENESS	
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

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

GCUK

Accounts

31 December 2022

GIST Cancer UK
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 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

	2022	2021
	£	£
INCOME		
Donations - GCUK	144,132	108,882
Interest	850	38
	<u>144,982</u>	<u>108,920</u>
EXPENDITURES		
Research Purchases		
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>
Direct Expenses		
Publicity/Goods for Sale	4,794	671
	<u>4,794</u>	<u>671</u>
Overheads		
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>
Profit	<u>51,476</u>	<u>8,777</u>

GCUK
Balance Sheet
as at 31 December 2022

	2022	2021
	£	£
Assets		
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>
Liabilities		
Trade creditors	2,279	-
	<u>2,279</u>	<u>-</u>
	<u>697,690</u>	<u>646,214</u>
Net business assets represented by		
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

GIST Cancer UK
31 December 2021

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as at 31 December 2022

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Net business assets represented by		
Capital account:		
Brought forward	646,214	637,436
Net profit	51,476	8,777
	<u>697,690</u>	<u>646,214</u>

GIST Cancer UK

England & Wales - Charity number 1129219

Accounts

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.

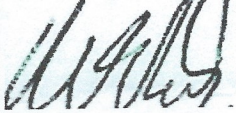
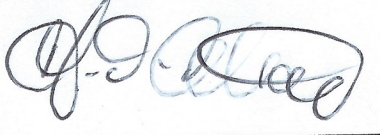
Sadly, in March, we lost James Palgrave due to GIST Cancer. James was involved with GCUK for many years and helped us enormously with our IT Function. He will be sorely missed.

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

GIST Cancer UK
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 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

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/>	<hr/>
	108,920	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/>	<hr/>
	69,486	43,714
Direct Expenses		
Publicity/Goods for Sale - GCUK/PAWS	671	1,940
	<hr/>	<hr/>
	671	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	8,775	13,820

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>

GIST Cancer UK

England & Wales - Charity number 1129219

Accounts

GIST CANCER UK Annual Report for 2020

Trustees 2020:	Nic Puntis (Chair) Jayne Bressington (Vice Chair & Patient Director PAWS-GIST) Sheena Kynoch (Secretary) John South (Treasurer) David Falconer (Treasurer) Stella Turner Terry Weldon James Palgrave Terry Riley Jane Means Amalia Formoso Tony Manuel (Shadow Treasurer)
Special volunteers 2020:	Lena Stoll Laura Brown Marion Oliver David Robinson Karen Langdon
Life President	Judith Robinson

2020 was indeed a very unusual year for everyone on our planet. The COVID-19 pandemic disrupted most walks of life and created significant levels of anxiety and uncertainty, particularly for cancer patients.

During this year we saw a marked increase in GIST patient registrations with GIST Cancer UK and our helpline and private patient forum (listserve) were buzzing as patients sought help and also shared their experiences with others in our community. It has been amazing to see everyone pulling together to support one another to overcome obstacles during this difficult time and our support services being so well used.

Our Trustees held four board meetings during the year, twice in person, before the pandemic and twice via MS Teams, our newly installed virtual meeting platform. The implementation of our new back-office systems which includes MS Teams has been incredibly timely. Sincere thanks go to James Palgrave who worked tirelessly to overhaul and implement our new systems.

We welcomed Tony Manuel, Terry Riley and Jane Means as new Trustees. Victoria Bassett resigned as a Trustee in June 2020 and we thank her for her dedicated service to the charity for the past five years.

Sadly, in October, our Treasurer David Falconer passed away, having lost his battle with Lung Cancer. David was involved in the GIST Cancer Arena for over 20 years and will be sorely missed.

Our work to support GIST Patients and Carers continues and to this end we managed to host one Patient/Carer meeting in London, in March 2020, just before the National Lockdown. This meeting was extremely well attended and the feedback that we received was very complimentary. The topics covered being both scientific/educational; to bring everyone up-to-date on GIST clinical trials, as well as covering strategies for coping in relation to eating/nutrition and the emotional side of being a GIST patient and carer.

A video of our meeting can be found here:

<https://www.gistcancer.org.uk/patient-meetings-2020/>

We are grateful to all the medical professionals who give up their time to speak at our events. Unfortunately, the ongoing Covid-19 situation has meant that we were unable to convene further Patient/Carer meetings so we focused on boosting our support services by the development of GIST patient videos on a range of relevant topics in addition to our Patient/Carer forum, helpline and the provision of literature.

COVID-19 cancelled our PAWS-GIST clinics during 2020 so we are exploring every option to start the clinics again in 2021. The clinic website www.pawsgistclinic.org.uk continues to offer valuable help and information.

Further to donations and fundraising from our fantastic supporters we were able to approve four GIST/PAWS-GIST research grants during 2020 which amount to a total of £102,896.

£78,373 was granted for ground breaking PAWS-GIST research projects.

£24,523 was granted to extend the SSGXXII Scandinavian 3 versus 5 years adjuvant imatinib study in the UK, enabling more eligible UK GIST patients to join this study.

We continue to support the National GIST Tissue Bank which includes the specialist courier costs for tissue transfers when rare samples are donated by patients from operations in other parts of the UK. The Tissue Bank is hosted at The Royal Marsden under the direction of Professor Robin Jones, Janine Salter and the brilliant biobank team.

All of our literature was re-branded to our new GIST Cancer UK name and continues to be available both in print and online via our website.

We have added Instagram and LinkedIn to our social media platforms and our social media team have continued to grow our community via these media.

Despite face-to-face meetings being impossible for most of 2020, our Trustees, participated in NICE & Scottish Medicines Consortium reviews of treatments for GIST, as well as meetings and conferences with National and International patient advocate and medical groups. All aimed at raising awareness, gathering useful information and opening opportunity for collaboration that will further GIST research to improve treatments and find a cure.

Finally, we are extremely grateful for the continued charitable grants received from various Pharmaceutical Companies for our patient support activities and for the tremendous Fund-raising efforts of all our supporters. GIST Cancer UK Trustees are all volunteers and without this support our ability to provide our services would be impossible.

2020 marks the eleventh year since GIST Cancer UK registered as a charity and is the tenth anniversary of the launch of our PAWS-GIST initiative. We have come a long way in that time with modest resources and I am very proud of what we have achieved.

Thank you to everyone who continues to support our work. Your donations and support allow us to continue our work for the direct benefits of GIST patients.

Nic Puntis

Chairman of Trustees
GIST Cancer UK
January 2021

GCUK

Accounts

31 December 2020

GCUK
31 December 2020

Independent Examiners Report of the Trustees of GIST Cancer UK

I report on the accounts of the charity for the year ended 31 December 2020.

Respective responsibilities of trustees and examiner

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ALICJA MOGG

Foxwise Accountancy Ltd
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18 February 2021

GCUK
Profit and Loss Account
for the year ended 31 December 2020

	2020	2019
	£	£
Income		
Donations - GCUK	47,690	116,565
Donations - PAWS	30,032	20,217
Interest	408	2,559
	<hr/>	<hr/>
	78,130	139,341
Research Purchases		
General Research - GCUK	6,733	10,560
Research and Consultancy - GCUK	9,982	35,800
Research and Consultancy - PAWS	26,999	7,335
	<hr/>	<hr/>
	43,714	53,695
Direct Expenses		
Publicity/Goods for Sale - GCUK/PAWS	1,940	5,200
	<hr/>	<hr/>
	1,940	5,200
Overheads		
Motor Expenses - GCUK/PAWS	668	1,393
Entertainment/Subsistance - GCUK/PAWS	435	1,045
Travel Meeting Costs - GCUK/PAWS	466	1,755
Hotel Costs - GCUK/PAWS	1,218	3,103
Meeting Costs - 2018 - London GCUK/PAWS	4,722	3,139
Meeting Costs - 2018 Manchester - GCUK/PAWS	-	4,875
Meeting Costs - Autumn/Cardiff - GCUK/PAWS	95	-
Meeting Costs - Autumn 20 Bath	845	-
Meeting Costs - Winter/Scotland - GCUK/PAWS	-	4,534
Meeting Costs - Trustee Meeting	-	375
Spring Clinic - PAWS	-	4,934
Courier Services - GCUK/PAW	-	2,383
Post - GCUK/PAW	552	284
Printing - GCUK/PAWS	3,724	728
Stationery - GCUK/PAWS	672	234
Telephone - GCUK/PAW	368	216
Web Hosting - GCUK/PAW	800	2,888
Accountancy - GCUK/PAWS	1,764	1,380
Insurance - GCUK/PAWS	392	341
Sundry - GCUK/PAWS	275	-
Genetic Alliance Membership Fee	50	172

GCUK
Profit and Loss Account
for the year ended 31 December 2020

Just Giving	216	400
ESMO	23	-
Sponsored Event Admission Fee - Ride London	-	1,282
Travel Costs - GSUK/PAWS	1,221	4,805
Cancer 52 Membership	150	150
Bank Charges	-	9
Suspense & Mispostings	-	(11)
	<hr/>	<hr/>
	18,656	40,414
	<hr/>	<hr/>
	64,310	99,309
	<hr/>	<hr/>
Profit	13,820	40,032

GCUK
Balance Sheet
as at 31 December 2020

	2020	2019
	£	£
Assets		
Trade debtors	5	-
HSBC - PAWS/GIST 547	183,286	184,928
HSBC - GIST 689	200,952	200,740
HSBC - Gist Support UK 670	79,280	65,496
Nationwide - GIST 514	76,730	76,730
HSBC - PAWS GIST Community - 469	12,085	9,623
Shawbrook Bank - GIST/PAWS 621	86,099	86,099
	<u>638,437</u>	<u>623,616</u>
Liabilities		
Trade creditors	1,000	-
	<u>1,000</u>	<u>-</u>
	<u>637,436</u>	<u>623,616</u>
Net business assets represented by		
Capital account:		
Brought forward	623,616	583,584
Net profit	13,820	40,032
	<u>637,436</u>	<u>623,616</u>

GCUK

Accounts

31 December 2020

GCUK
31 December 2020

Independent Examiners Report of the Trustees of GIST Cancer UK

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18 February 2021

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	1,940	5,200
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	<hr/>	<hr/>
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	<hr/>	<hr/>
	64,310	99,309
	<hr/>	<hr/>
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GCUK
Balance Sheet
as at 31 December 2020

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	£	£
Assets		
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HSBC - PAWS GIST Community - 469	12,085	9,623
Shawbrook Bank - GIST/PAWS 621	86,099	86,099
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	<u>1,000</u>	<u>-</u>
	<u>637,436</u>	<u>623,616</u>
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Capital account:		
Brought forward	623,616	583,584
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