



*Information, Counselling and
caring for those with Sickle Cell
Disorders and their families*

Charity Reg: 104 6631

The Sickle Cell Society

(A company limited by guarantee)

Report and Audited Financial Statements

Year Ended

31 March 2023

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2023

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The Sickle Cell Society

Company information for the year ended 31 March 2023

Patrons:

Mr Michael Parker CBE, President
Professor Dame Elizabeth Anionwu CBE
Baroness Dame Floella Benjamin OBE
Rt Hon. Lord Paul Boateng of Akyem
Mrs Millicent Simpson
Mr Derrick Evans MBE
Sir Lenny Henry CBE
Sir Clive Lloyd OBE
Sir Trevor Phillips OBE
Mrs Sherlene Rudder MBE
Ms Ellen Thomas
Ms Kym Mazelle
Mr John Regis MBE
Ms Dawn Butler MP
Mr Rudolph Walker CBE
Rev. Rose Hudson-Wilkins MBE

Trustees - Directors

Ms Michele Salter	Chair & Treasurer
Ms Carol Burt	
Dr Josephine Ruwende	To September 2022
Mrs Sheree Brooks	To September 2022
Mr Ganesh Sathyamoorthy	
Mr Shubby Osoba	
Mr Nathan Fordwor-Hepburn	
Ms Lisett Brown	From September 2022
Ms Zainab Garba-Sani	From September 2022
R Kilali Ominu- Evbota	From September 2022
Ms Claudette Allergyce	From September 2022

Staff

Mr John James OBE	Chief Executive
Ms Iyamide Thomas	NHS Engagement Lead
Ms Miriam Williams	Finance & Administrative Manager
Mr Matthew Neal	Media & Communications Officer – To April 2022
Mrs Clare Rudd	Interim Communications and Social Media Officer
Ms Tracy Williams	Give Blood Spread Love Project Manager
Mr Malcolm Hodnyl	Communications Manager – To March 2023
Ms Taja Morgan	Children's Activities Leader – To December 2022
Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation
Ms Michelle McFarlane	Helpline & Information Officer – From June 2022
Miss Keyah Miller	Helpline & Information Office – From May 2022
Oluwaseyi Afolabi	Parliamentary Officer for SCTAPPG
Sandra Reyes-Hayduk	Fundraising Manager
Deborah Armantrading	Fundraising & Volunteer Development Lead – To April 2022

Charles Agbede

Mr Juan Carlos Valero

Animation Project Co-ordinator

– To April 2022

Database & Communications

Officer - To February 2023

The Sickle Cell Society

Company information for the year ended 31 March 2023 (*continued*)

Registered address	Sickle Cell Society, 54 Station Road, London NW10 4UA
Telephone number	020 8961 7795
Fax number	020 8961 8346
Website and email address	www.sicklecellsociety.org, info@sicklecellsociety.org
Registered charity number	1046631
Company registration number	2840865
Auditor	PKF Littlejohn LLP, 15 Westferry Circus, Canary Wharf, London E14 4HD
Banker	National Westminster Bank, Park Royal Branch, Abbey Road, London NW10 7RA
Medical Advisors	<p>Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust</p> <p>Professor Dame Sally Davies Rector Cambridge University Cambridge</p> <p>Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London</p> <p>Professor Bernadette Modell Emeritus Professor, UCL, London</p> <p>Professor David Rees Consultant Haematologist Kings College Hospital, London</p> <p>Dr Allison Streetley Consultant in Public Health Public Health England</p> <p>Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals</p> <p>Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital</p>

The Sickle Cell Society

Company information for the year ended 31 March 2023 (*continued*)

Scientific advisors

Dr Mary Petrou
Director, Perinatal Centre
University London Hospital, London

Dr Kofi Anie MBE
Consultant Clinical Psychologist
NW London Hospitals NHS Trust

Dr Elizabeth Dormandy (Retired)
Consultant in Public Health

Keisha Osmond-Joseph
Barking, Havering and Redbridge
University Hospitals NHS Trust

Giselle Padmore-Payne
Croydon University Hospital

The Sickle Cell Society

Trustees' report for the year ended 31 March 2023

The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2023 and confirm that they comply with the requirements of the Companies Act 2006, the Charities Act 2011, as well as the Society's Memorandum of Association (Constitution), and the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard 102 applicable in the UK and Republic of Ireland (FRS 102).

These statements relate to the funds of the Society, its core activities, stakeholders, engagement and collaboration in research and development.

THE CONDITION

Sickle Cell Disorder is an inherited blood condition, which affects the red blood cells. One of the primary roles of the red blood cell is to carry oxygen from the lungs around the body.

In people with a sickle cell disorder, blood cells lose their round, flexible shape and instead become shaped like a crescent moon, or sickle. These abnormally shaped red blood cells become rigid and sticky. They break more easily, which leads to anaemia, and they stick together, blocking blood vessels.

When these blockages occur, they cause a great deal of pain, and this is called a 'sickle cell crisis', for the individual. A crisis can last a few hours, days or even weeks and often requires hospital admission where the individual will be treated with high potency painkillers. Management of painful crises can sometimes be carried out from home with mild pain killers.

Over time, people living with sickle cell disorder can experience damage to organs, such as the liver, kidneys, lungs, heart and spleen. As a result of these medical complications, a high proportion of the people living with the condition experience disability. There is no easy cure, and despite the progress made with bone marrow transplants for children and adults, there are risks and complications arising from transplantation.

Sickle cell disorder is one of the most common genetic inherited conditions in the UK and in the World. 1 in 77 babies tested in England were found to be sickle cell carriers (i.e. sickle cell trait)¹. Despite improvements in NHS specialised services and clinical care; poor service support, awareness and understanding of the condition remain long standing issues. This has been evidenced by recent Peer Reviews of NHS Sickle Cell Services and the Sickle Cell and Thalassaemia All Party Parliamentary Report: *No One's Listening*.

There is a national antenatal and newborn screening programme in England for sickle cell disorder. All pregnant women are offered screening to see if they carry a gene for sickle cell and if so screening is offered to the baby's father. Ante-natal screening can present parents with difficult and complex choices, particularly when parents and some health care professionals have little understanding of the condition. All newborn babies are also tested for the sickle cell gene.

OUR CORPORATE STATUS

The Sickle Cell Society was founded in 1979 by a group of healthcare professionals, individuals and families affected by sickle cell disorder. The Society was later established under a Memorandum of Association with the objects and powers of a charitable company and has been governed under those Articles of Association, since 1993. Under those Articles, the Society is limited by guarantee not having a share capital. Each member of the Society is liable to contribute £1 towards the liabilities of the Society in the event of liquidation.

The Society's charity registration number is 1046631 and the company registration number is 2840865. The Head Office is located at 54 Station Road, London, NW10 4UA.

source: NHS Sickle Cell and Thalassaemia (SCT) Screening Programme Data Report 2019 to 2020

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

OUR MISSION, AIMS AND OBJECTIVES

CHARITY OBJECTIVES

Our charitable purposes as set out in the objects contained in the Charity's Memorandum of Association are:

- To provide relief for persons with sickle cell disorders.
- The relief of poverty among members of the immediate family of persons who are suffering or who, immediately before their death, suffered from sickle cell disorders.
- The provision of recreational activities for affected individuals and their families.
- The improvement of public information, assisting in research into the causes, treatment of the condition and dissemination of such information.

The aims of the Charity are to assist and enable people with sickle cell disorder to realise their full potential. In order to achieve this, the Society's resources are used to undertake the following activities:

1. Annual Children's holiday and children's activities
2. Health Education and Information services including:
 - Leaflets, exhibitions, books, audio visual materials, conferences, seminars, workshops and partnership networking
 - Website, e-mail, newsletters, social media and communication activities
 - Patient and carer education days
 - Telephone helpline and information advice
3. Collaborating on medical and non-medical research on sickle cell with a wide range of stakeholders.
4. Assisting to influence statutory policy and programmes of the government, such as NHS Screening Programmes, National Institute for Health and Care Excellence (NICE) developments and work of the All Party Parliamentary Group (APPG) for Sickle Cell and Thalassaemia.
5. Developing strategic collaborations and partnerships both nationally and internationally.

HOW OUR ACTIVITIES DELIVER PUBLIC BENEFIT

The Trustees have given due consideration to the Charity Commission's published guidance on the operation of the public benefit requirements.

The Trustees are satisfied that the Society's aims outlined above continue to be met and satisfy the public benefit test by virtue of taking action to help people with sickle cell disorder and their families.

HOW WE ARE ORGANISED

The Memorandum of Association, as amended in 2013, allows a maximum of 10 individuals from the membership and externally, to be selected on to the Board of Trustees each year, to serve for up to 3 years per term for a maximum of 3 terms (i.e. 9 years). The Trustees of the Society are also the Directors of the Charity. In addition, a pool of Advisors and Patrons selected by the Board for their individual professional and community standing, strategically support the Trustees, volunteers and staff.

The Board meets monthly and sub-committees and ad-hoc working groups complement meetings.

The Chief Executive heads a small team of paid staff in addition to a pool of volunteers and is responsible with the Trustees for the strategic direction and for the day-to-day operational activities of the organisation. The Chief Executive reports to the Chair of the Board. The policy for setting the pay and remuneration of the Chief Executive and employees is set by the Board and benchmarked to equivalent sized charities.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2023

Board development

The Board of 9 Trustees, excluding vacant positions, has 2 members with sickle cell disorder and 5 Trustees are also carers for family members with sickle cell. The Board undertook board development training during 2022/2023. All new trustee appointments are open to members and non-members of the Society. All trustee recruitment is by advertisement and application. An interview panel organised by the Chair interviews all shortlisted applicants.

All new trustees undergo an induction programme including meetings with the Chair and Chief Executive. New Trustees are also provided with Charity Commission guidance and information for trustees, together with a copy of the Nolan principles and code of conduct.

SUMMARY REVIEW OF 2022/23

It has been another positive and transformative year for our Charity. We have made steady and consistent progress, allowing us to grow and provide better support for the sickle cell community.

We are immensely proud of our achievements, especially considering the challenges posed by the cost of living crisis and the enduring impact of the Covid-19 pandemic on our Society, staff, volunteers, and the sickle cell community. We would like to express our deep appreciation to our staff, volunteers, Trustees, Patrons, donors, and supporters for their unwavering support.

The year started with significant changes in leadership on the Board of Trustees. We were delighted to welcome our new Chair, Michele Salter, who brings a wealth of expertise and a fresh perspective to the role, having previously served as Vice-chair and Treasurer. We were also pleased to introduce several new Trustees, who bring diverse skills and experiences to further enrich our governance. We are excited about the valuable contributions they will make to our mission and the sickle cell community.

The year also marked the relaunch of our Children and Young Person's mentoring scheme, providing invaluable guidance and support to 10-24 year olds in the sickle cell community. Due to the success of the programme in the City and Hackney neighbourhoods, we were able to roll this mentoring scheme out across the whole of East London. We are thrilled to see the positive impact this program has had on the lives of those involved.

In a remarkable milestone, we celebrated the first adult with SCD who underwent a successful stem cell transplant, funded by the NHS. This breakthrough not only gives hope to individuals living with sickle cell but also opens up new possibilities for treatment and improved quality of life. This came after the previous year's news of the first new treatment in 20 years for sickle cell becoming available on the NHS – and gave hope that with our efforts in awareness raising, campaigning and using the hard hitting evidence in the 'No-one's listening' report, we can continue to make life changing contributions to the sickle cell community for years to come.

Our blood screening and donation programmes continued apace, delivering incredible impact right from the preconception stage, and throughout the lives of those affected by the condition. Changes in the blood donation rules during the year enabled more black donors to give blood, increasing momentum in our 'Give Blood Spread Love' blood donation programme. Our screening programme was able to continue its outreach work in person again, and progress vital research work with the NHS into making sure the service accurately matches user needs.

Our annual Children's holiday took place online, and proved again to be a great success. Parents reported the value of being part of a community that lets them know they are not alone, and reported feeling supported by the vital work of the Society.

Looking ahead to the next year, we remain committed to our strategic ambitions for the sickle cell community. Our work is driven by our dedication to you and our shared vision of progress and support. While we anticipate challenges stemming from the cost of living crisis, we also embrace the positive

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

SUMMARY REVIEW OF 2022/23 (*continued*)

developments arising from our ground-breaking Sickle Cell and Thalassaemia All Party Parliamentary report ; "No One's Listening." Collaborating with NHS England, Haemoglobinopathy Coordinating Centres (HCCs), and the new Integrated Care Boards (ICBs), we will actively work towards transforming care and outcomes for people living with sickle cell and their families, making a lasting and positive difference in their lives.

Michele Salter
Chair

John James OBE
Chief Executive

KEY HIGHLIGHTS FROM THE YEAR 2022/2023

STAKEHOLDER RELATIONSHIPS

Stakeholder relationships are a key part of the Society's work, connecting our work with national, local and global partnerships.

The Society continued its important relationship with sickle cell patients across the UK and the rest of the world as well as with our members and support groups in the UK.

The Society also continued to develop strategic alliances with partners, including Rare Diseases UK, Genetic Alliance, the Anthony Nolan Trust and the Specialised Healthcare Alliance. Board members and staff are part of the committees of the Alliances, influencing their strategic direction.

The Society worked effectively with the NHS Sickle Cell and Thalassaemia Screening Programme, continuing the joint programme of work in collaboration with the UK Thalassaemia Society.

Our partnerships extend to many organisations including National Council for Voluntary Organisations (NCVO); UK Forum on Haemoglobinopathies; National Voices; NHS Blood and Transplant; NHS Trusts; NHS England; UK Health Security Agency (UKHSA); National Institute for Health and Care Excellence (NICE); Medicines and Healthcare Products Regulatory Agency (MHRA); Sickle Cell & Thalassaemia Association of Counsellors (STAC) and other voluntary and statutory organisations involved with sickle cell.

The Society also worked together with a range of research and improvement organisations, collaborating towards better understanding of Sickle Cell. These collaborations included the National Haemoglobinopathies Panel (NHP) and their constituent Health Coordinating Centres (HCCs) National Institute for Health Research (NIHR) NHS Boards, EMA (European Medicines Agency), NHS Blood and Transplant (NHS BT) Clinical Trials Unit, University College London (UCL), National Institute of Clinical Excellence (NICE) and Genomics England. This is not an exhaustive list, but it illustrates the breadth of engagement regarding research and improvement.

The Society has also continued working closely with the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG) through our work as secretariat and with our Parliamentary Officer. The SCTAPPG aims to raise awareness and prioritise sickle cell disorder and other haemoglobin disorders on the political platform. Later in this report, a full summary of the work of the SCTAPPG including its seminal No One's Listening Report will be covered, including progress on the report's recommendation during 2022/2023.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2023

MEMBERSHIP & SUPPORT GROUP BASE

The Sickle Cell Society has maintained its free membership policy and the membership gained in 2022/23 stands at 413 for a total of 2,932.

We are always looking for new members to join the Society, inviting people to join through our website, social media, and at events and talks.

Sickle Cell Society members receive two print or PDF newsletters a year as well as a monthly e-newsletter and other emails about various projects and events.

The Sickle Cell Society is the national umbrella for over 40 independent support groups, voluntary organisations and statutory centres across the UK.

MEDIA & COMMUNICATION

The Communications and Social Media Office has continued to work on growing the Society's presence across social media platforms including Facebook, Twitter, Instagram, and LinkedIn. The Society has seen a steady growth in social media followings.

- The Society's Instagram (@sicklecelluk) gained 474 followers.
- The Society's Twitter (@SickleCellUK) gained 809 followers.
- The Society's Facebook (Sickle Cell Society UK) gained 678 followers.
- The Society's LinkedIn (Sickle Cell Society) gained over 1,444 followers.

The Sickle Cell Society website received, on average, 23,000 views per month.

HELPLINE AND INFORMATION SERVICE

The Helpline and Information service continues to provide a service for the Sickle Cell Community, Healthcare Professionals and a range of other stakeholders. We have improved the systems and tools we use to gain feedback about our service from our service users. This feedback allows us to identify the key areas where we can improve our performance and service.

We are identifying our Key Performance Indicators (KPIs) to ensure the service we provide is aligned with our charity goals. We do this by assessing call response time, call volume, quality and quantity of call content and resolution rate. This data allows us to identify key areas of success, alongside areas which may need improvement. We revisit this data each quarter to see how we can improve and learn moving forward.

We have participated in several face-to-face events by providing an information stand and materials. For example, for Black History month we attended many events and had the opportunity to network with and provide support to service users and other professionals.

We collaborated with the British Armed Forces and participated at an event where we provided materials on sickle cell anaemia and sickle cell carriers. This has helped the Army to increase their knowledge around how best to support sickle cell carriers as they go through the army recruitment and training process.

Having a stall at such events allows us to interact directly with large employers, gaining helpful and direct feedback on how best we can support the sickle cell community.

The helpline staff are sickle cell community advocates, working hard to provide individual support our service users with their challenges with access to the correct medical, educational, employment, housing, and benefits support. We do this face-to-face, by phone and email.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2022

EDUCATION / INFORMATION AND AWARENESS

The Society continues to honour the United Nations declaration of World Sickle Cell Day on 19th June each year by celebrating the day and raising awareness of sickle cell disorder through various initiatives within the local community. This year we did this with awareness and education videos and graphics published on our social media channels as well as making them available for others to use and share.

We also participated and promoted 'Wear Red for Sickle Cell' an awareness initiative to get as many people as possible wearing red and starting conversations around sickle cell.

We also ran and took part in a range of events on and around World Sickle Cell Day. These included:

- A new initiative in collaboration with Novartis and the Voice Newspaper – The Code Red Campaign
- Collaboration with the Mayor of the London Borough of Waltham Forest to raise awareness of sickle cell across the borough including local schools
- A global awareness raising webinar in collaboration with the Sickle Cell Foundation of Nigeria

Our awareness work within Industry included a presentation to the Global team of Global Blood Therapeutics (GBT) about the work of the organisation as well as a lunch and learn about the Society to a USA industry partner; Imara. Despite the challenges of Covid19, lots of other awareness activities took place such as a presentation and stand at the global Academy for Sickle Cell and Thalassaemia Conference (ASCAT) and awareness work with St John's Ambulance staff and public health students at Greenwich University.

The Society continued to be the leading public source for information on sickle cell at national and international levels by providing information, advice and referral service in response to thousands of letters, email requests and telephone calls. The Society has also been raising awareness through online platforms in the form of informational graphics, tweets, Facebook and Instagram posts, as well as the Society's website which receives on average over 33,000 views per month.

Staff, Trustees and Volunteers continued to provide awareness talks and presentations within local and national businesses, schools, universities, churches, government and corporate organisations in order to raise awareness of sickle cell disorder and the important work of the Society.

The Society continued to engage with various press and media, facilitating patients, staff and other stakeholders to take part in interviews, news features and other media discussions.

The Society ran a range of education events specifically about Coronavirus (COVID-19) & Sickle Cell Disorder as well as education events on the importance of vaccination, with clinical leaders and patients.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

WORK ON BEHALF OF THE NHS SCREENING PROGRAMME

The Screening Programme

The Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) continued work on the collaborative project with the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) which the Programme officially commissioned from the Societies in August 2018. The current commission ends 10 August 2023 and the Society has submitted an Expression of Interest to continue this work.

In the wake of the COVID-19 pandemic, the project team continued to deliver the revised project objectives for antenatal and newborn screening in England virtually and later commenced in-person outreach.

Key Project Achievements:

- SCS transcribed and analysed three online focus group discussions conducted with a total of 20 individuals (mothers, fathers and non-parents) who gave valuable user perspective on their experiences of screening, particularly on how newborn sickle cell carrier or positive (i.e. baby has the condition) results should be communicated. The focus group analysis then formed part of a joint report with UKTS launched at a screening conference on 18 April.
- The SCS presented its work at two training sessions the NHS SCT Screening Programme conducted for nurses, midwives and health visitors involved in the screening pathway.
- The SCS has input feedback from our '*No One's Listening*' report to the current revision of the NHS SCT Screening Programme e-learning resource for health professionals, to help them address any inequalities in service provision.
- SCS was a member of NHS England and NHS Improvement (NHSEI) task and finish workstream for 'Preconception, Antenatal, Newborn and Maternity' which is part of NHSEI's review of the sickle cell pathway that aims to improve user experience and address inequalities.
- SCS is represented on a King's College research project investigating stakeholder views on prenatal therapy for sickle cell, which aims to cure affected babies in the womb using stem cell transplant / gene therapy.
- SCS recorded a comprehensive sickle cell podcast for the Department for Environment, Food and Rural Affairs (DEFRA) which was shared with its 30,000 staff.
- SCS raised awareness of sickle cell and screening by: public talks (5) newsletter articles (3), Newspaper article (1), Workshops (3) Webinars /Conferences (1).

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

CHILDREN'S ACTIVITIES

We have continued to successfully deliver virtual children's activities for young people with Sickle Cell. We were also able to extend our activities until 31 March 2023. From January 2023 - 31st March 2023 we ran specific teenage transition workshops for children and young people. We commissioned professional guest speakers to lead these workshops.

The activities we ran last year included:

Zumba Classes
African-Caribbean cooking classes
Quiz and creative writing workshop
Black History Month events
Storytelling
Cloth Making
Drama
Arts and crafts

Feedback from families included:

- *Thank you for these great opportunities.*
- *He was very happy and smiling. He was very excited and was happy for the rest of the day.*
- *The guest speakers were amazing. They shared useful information. The Q&A was very informative too. I like the fact that they had prepared a resource pack for us to have.*
- *The event was well organised and speakers were great.*
- *Thank you for organising this event, which was very informative.*
- *Everything was perfect!*
- *Great idea to have these workshops. I am really enjoying them. Thank you*
- *I feel like it's very helpful and informative and I only wish I'd had this experience sooner!*
- *It was very good to hear about other people's experiences and also how to advocate for yourself.*

We will continue to explore how we can continue and develop these children's activities for all children and young people living with sickle cell.

CHILDREN'S HOLIDAY 2022

The Virtual Children's Holiday in 2022 took place from the evening of Friday 5th August to Sunday 7th August. 45 families took part, including 54 children with sickle cell, 44 siblings and 59 parents, with families joining us from all across the UK - everywhere from Plymouth to Carlisle. We had 20 volunteers helping us make the magic happen, as well as 21 workshop practitioners and 1 BSL interpreter. It was a unique and joyful weekend of education, conversation, excitement and fun!

This year, like last year, the Children's Holiday was delivered virtually via Zoom, with an accompanying activity box full of self-led activities. The children were split into 5 'cabins' so that they had ample time for small group chats: Bears (4-6yrs), Zebras (7-9yrs), Tigers (10yrs), Giraffes (11yrs), Lions (12-15yrs). Alongside the children's programme we ran a programme for parents and a special session for siblings.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

CHILDREN'S HOLIDAY (Continued)

Activities during the busy weekend included:

Getting To Know You Games
Sickle Cell Education
Meet The Animals
Theatre Workshop and Performance with Anyebe Anteyi (actor with sickle cell)
Morning Stories with Chitra Soundar and Jenica Leah
Indoor Gardening
Zendoodling
Learn to Juggle
Yoga
Relaxation/Meditation
Family Empowerment: We Are Enough
Theraplay
Make and Chat drop in
Singing
Spoken Word with Desree
Virtual Adventure Race
Biscuit Decorating
LEGO Building
Become Brave and Great with Laughology
Know Your Nutrition

Song Writing
Arts and Crafts
Parent Mindfulness
Sibling Wellbeing Session

The families had a marvellous time and 93% are interested in attending another children's holiday in the future, with particular interest in an in-person offering. We found it was particularly valuable to involve the parents and siblings in the programme this year and this is something we will aim to continue.

The highlight of the holiday, reported across the board, was the positive community that we created and the families knowing that they are not alone. We received some lovely feedback, some of which is shared below:

"It honestly has been life changing for my daughter and as a mother I feel supported and cared about. It's difficult having a child with sickle cell and all of these things ease the pain" - Parent

"Thank you all so much for allowing my family to be part of a community. A community that I can relate to and grow from. A community that lets me know that me and my family are not alone. A community that is doing their very best to improve the quality of life that children with sickle and their family experience. Keep up the great and important work because it is totally needed." - Parent

"I can wholeheartedly say that the children's holiday has been a huge catalyst for my 7 year old sickle cell warrior not feeling so isolated by having the condition, and also getting a better understanding of how to best live a wholesome life. Seeing other warriors gave her a sense of belonging and not feeling like she's the only person to be affected. Thank you SO much for all the hard work. It blew us both away and we can't wait to be able to join one again in future." - Parent

"These holiday clubs make having sickle cell less of an issue and more of a superpower." - Parent

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2023

PARLIAMENTARY & POLICY WORK

The Sickle Cell & Thalassemia APPG

The year 2022/23 has been a notable year for the work of the Sickle Cell & Thalassemia APPG (SCTAPPG). This stems directly from the launch of the 'No One's Listening' APPG report in November 2021. The Society has continued working closely with the SCTAPPG through our work as secretariat and with our Parliamentary & Policy Officer. The SCTAPPG aims to raise awareness and promote sickle cell disorder and other haemoglobin disorders on the political agenda. Accountability is achieved through the SCTAPPG's Chair, Janet Daby MP.

Interest in the work of the SCT APPG continues to grow with the Secretariat tracking noticeable increases in those who have signed up to attend meetings. Meeting discussions remain constructive and the SCT APPG continues to provide an invaluable platform for patients, clinicians, MP's and other stakeholders to communicate. Patients, stakeholders, parliamentarians and other stakeholders have provided positive feedback on the continued work and management of the SCT AOOG.

The key functions of the SCTAPPG parliamentary work:

- Organise and execute four SCTAPPG meetings a year, plus one Annual General Meeting
- Organise any relevant Emergency General meetings
- Manage SCTAPPG secretariat services
- Communicate SCTAPPG secretariat activity to politicians, stakeholders, Sickle Cell Society (SCS) and other interested parties
- Influence, build and manage effective relationships
- Maintain records of meetings and communications
- Pursue the implementation of the recommendations of the 'No One's Listening' report
- Provide awareness raising sessions on Sickle Cell and the work of the SCTAPPG to various stakeholders and groups
- Direct patient support

SCT APPG AGM

The SCT APPG held its Annual General Meeting in Parliament on Wednesday 22nd July 2022. After many dedicated years as the Chair of the APPG, Pat McFadden MP stood down due to the pressures of his Shadow Cabinet role. We would like to take this opportunity in our annual report to thank Pat McFadden MP for all his excellent contribution to the work of SCTAPPG.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

PARLIAMENTARY & POLICY WORK (Continued)

Janet Daby MP was successfully elected as the new Chair. New officers were elected to the APPG, the full current list of SCT APPG officers is as follows;

- Janet Daby MP - Chair
- Pat Mc Fadden MP
- Paulette Hamilton MP
- Baroness Thornton
- Baroness Ludford
- Marsha DeCordova MP
- Greg Clark MP
- Florence Eshalomi MP
- Bell Ribeiro-Addy MP
- Bambos Charalambous MP

The meeting covered updates on progress since the launch of the 'No One's Listening Report. The new Chair, Janet Daby MP also shared the forward look of the work of the APPG which will focus on following up the implementation of the report's recommendations alongside a wider area of work to improve sickle cell care in the UK.

No One's Listening Report

Since the launch of the report in November 2021 there have been notable milestones achieved as the SCTAPPG continues to follow up the implementation of the report's recommendations. We were pleased with the substantial national media coverage which the report received when it was published. Similarly, the Westminster Hall Debate held in Parliament on Sickle Cell healthcare was a welcome milestone after the launch of the report.

November 2022 marked the one year anniversary of the report and some of the key achievements can be summarised as follows;

- A commitment from the Nursing and Midwifery Council to review the teaching and training of nurses in Sickle Cell.
- Dr Bola Owolabi, Director for National Healthcare Inequalities Improvement Programme, is leading on the NHS review of the entire Sickle Cell pathway.
- The launch of the NHS campaign, '*Can you tell it's Sickle Cell?*' The campaign was aimed at clinicians and healthcare workers alongside the general public.
- The NHS Race and Health Observatory research project compiled their initial report. Highlights include looking at digital transformations to improve sickle cell care, recommendations to redesign Sickle Cell services, creation of standardised care guidelines for clinicians and healthcare workers and development of wearable technology for Sickle Cell patients.
- The launch of the Spectra Optia patient survey project seeking to improve access to automated red blood cell exchange.

It is important to note that improvements to Sickle Cell healthcare have never been more important due to the cost of energy crisis, costs of living crisis, NHS blood shortages and NHS strikes. All factors impact directly on the lives of those who live with Sickle Cell.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2023

PARLIAMENTARY & POLICY WORK (Continued)

Over a year on from the launch of the report, the Society continues to learn of failures in the healthcare of Sickle Cell patients. Changes to improve Sickle Cell services within many Trusts remains slow, with very little change in others. There remains much work to be done to realise the report recommendations throughout Trusts in England. It is for these reasons that the work of the SCTAPPG continues and the implementation of the report's recommendations will remain the focal area of work for 2023 and onwards.

Going Hybrid

The SCT APPG held its first hybrid meeting on Monday 19th December 2022. Parliamentary requirements stipulate that all APPG meetings must be held physically since the lifting of Covid-19 social distancing protocols. It became apparent that with schedule demands, childcare responsibilities, geographical location and the challenges for less able bodied and unwell attendees – creating a virtual joining option for meetings was a necessity.

The logistics were organised between the Parliamentary and Policy Officer and office of Janet Daby MP. The meeting worked well and received generally good feedback. Areas for improvement were noted and a series of ongoing improvements will be scheduled to continually improve the experience of virtual attendees.

SCTAPPG & Key Policy Partners

- Vulnerable Groups to the Pandemic APPG
- Rare Diseases APPG
- Transplantation APPG
- Genetic Alliance APPG
- Thalassemia APPG
- Ethnicity Transplantation & Transfusion APPG
- Prescription Alliance: a group of over 50 charities and organisations calling for the Government to review the prescription charges exemption list in England, so people with long-term conditions can access their vital medications for free.
- Anthony Nolan: specialist charity campaigning for stem cell transplants.
- Specialised Health Care Alliance: a coalition of patient-related groups and corporate supporters with a strong record of campaigning on behalf of people with rare and complex conditions in need of specialised care.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

GIVE BLOOD, SPREAD LOVE, ENGLAND

Give Blood, Spread Love

Give Blood, Spread Love (GBSL) works with Black African and Caribbean heritage communities to raise awareness of sickle cell disease; explain why people living with sickle cell need ethnically matched blood, and encourages people from these backgrounds to become regular, lifesaving blood donors. We achieve this by engaging with our target communities through events with corporate organisations, community associations, sport and leisure agencies and faith groups where we share our important messages and calls to action.

Social media and online engagement remains a significant part of GBSL, supporting us to reach younger audiences and connect to many thousands of people with our easily accessible information on sickle cell, blood donation and related topics.

Our volunteer team, the Give Blood Squad, comprised of blood donors and blood recipients, and those with a personal connection to sickle cell, are essential to this work, bringing the authenticity of lived experience to our campaigns.

Our achievements in 2022/2023 include:

Face-to-face events: We attended 29 events and spoke to 2,640 people. These events included successful partnerships with Leicestershire Police, Morrisons grocery retailer, and 10 gyms/ health clubs in our target geographical areas.

Expert-led online workshops: We held 9 workshops, some with the input of our partner organisations and supporters, including the Huddersfield-based community organisation, Pursuit of Happiness, and the social enterprise, Creative Access. Topics included: 'Boosting Iron Levels', 'Managing Sickle Cell in the Workplace', 'Men's Mental Health' and 'What Happens at a Blood Donation Session.'

Blood donation awareness sessions: We delivered 7 of these sessions to our partner organisations to develop their knowledge of blood donation, the need for ethnically matched blood, and to discuss the best way to tackle the barriers that can prevent our target audience from registering to donate.

Online events: We took part in online events attended by 453 people. These events were most frequently staff awareness/ training days organised by NHS Foundation Trusts, Local Authorities, and corporate organisations.

Recruitment: We recruited 340 new blood donors, primarily through our face-to-face activities. This method of engagement has proven to be the most successful way to encourage people to start their blood donation journeys. The direct contact we provide helps us to build peoples' interest and confidence in blood donation and demonstrate the real benefit ethnically matched blood has for so many people living with sickle cell.

Online engagement resources: We developed 110 new resources, including 8 promotional films that we shared across our digital media and sent directly to our partner organisations to support our awareness raising and recruitment activities.

Promotion: GBSL featured in 2 TV interviews, 3 online media articles, 3 print articles, 1 radio interview, and 1 podcast. Our volunteer team were most often at the centre of these appearances, sharing their experiences of living with sickle cell, receiving lifesaving blood transfusions and/or being a repeated blood donor.

Volunteers: We held 4 volunteer support sessions to enable our team to speak confidently about blood donation and the need for more Black African/Caribbean donors. Our volunteers donated 311 valued volunteer hours to Give Blood, Spread Love over the year.

Social media: Our social media channels continued to develop their reach, and we have 1,479 followers on our Instagram account, @givebloodspreadlove. The account features engaging educational material on sickle cell and blood donation, personal testimonies from our volunteer team, along with messages and films featuring influential community figures..

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

GIVE BLOOD SPREAD LOVE (Continued)

This year we were delighted to work with the Bishop of Willesden, Lusa Nsenga-Ngoy, who kindly shared his experience of giving blood for the first time with GBSL's followers. We have reached over 60,000 people across all our social media accounts.

Feedback from our stakeholders:

"With huge thanks to you and your fantastic team! People found it incredibly informative – we already have people who have registered to become blood donors!" **Corporate organisation.**

"Fantastic combination of information, personal lived experiences, and ACTION!! Thanks so much!" **Event attendee.**

"This has been an excellent session. Very informative and I love the 'Awareness into Action' slogan. It is what inclusion and removing barriers is all about." **Event attendee.**

"I've just signed up to be a blood donor and booked into a session near my home. Thank you for such an informative and touching session." **Event attendee.**

SCD AND PRIAPISM: WHAT PATIENTS (BOYS AND MEN) AND THEIR CARERS NEED TO KNOW.

We have begun work to develop nationally and internationally accessible and age relevant e-materials for the education of patients affected by priapism and their carers. Priapism is an unwanted, persistent erection. An Ischaemic Priapism (IP) is most commonly seen in SCD patients and is extremely painful.

The work we have initiated aims to:

- Increase awareness and educate carers, boys and men with SCD of priapism with easy to understand and assimilate, age appropriate educational tools;
- Educate patients on simple measures that can be undertaken at home to terminate an acute episode of priapism; and
- Reduce complications resulting from patients presenting late to their GP with SCD related priapism.

The project is making good progress. We hope to have educational materials that can be used by parents and adult men as well as healthcare professionals during the new financial year 2023/2024.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

GRANTS AND DONATIONS

During the year the Society made funding applications towards core and restricted projects and initiated or nurtured relationships to help to continue to deliver services. The Society received income of £85,696 from corporate supporters and £52,962 from Trust & Foundations during the year 2022/2023.

See full list of unrestricted donations of £500 and over listed in note 15.

Black History Month

During Black History Month (BHM) 2022, a remarkable £20,000 in total was raised to support the work of the SCS. This is an incredible achievement and a substantial increase from the circa £5,000 raised during BHM 2021.

Contributing a generous £11,521, corporate donations remain our most successful, accounting for 58% of our total BHM income. Additional income came as a result of external fundraising initiatives such as the 8 collection tins lent during October and the varied fundraising enquiries received through the website. Through the website too, 33 generous individuals gave a total of £6,407 and 6 new JustGiving pages were created between September and October, generating a further £573.

Amongst the Corporates supporting us for BHM for the second year running is Knight Frank LLP with a very generous donation of £3,800 along with a Metro Bank employee raffle which raised £2,976.

Supporting us for the first time is Tecan Group Ltd, based in Switzerland, and whose employees participated in a number of challenge events to raise £3,929 and Fiserv which hosted an art auction to raise £1,000.

Over the course of the BHM period our staff members had over 20 speaking engagements arranged in conjunction with BHM. The events were requested from a variety of organisations nation-wide, showing our ever-increasing reach to all corners of the UK. They included churches, museum, prisons, corporates etc.

All in all, there is a noticeable interest in engaging with the SCS during BHM on a continued basis. These, often new, relationships have the potential to create future opportunities in both public and private sectors.

CONTRACTS

The Sickle Cell Society continued contract work with Public Health England (PHE) during the financial year.

The Sickle Cell & Thalassaemia Outreach & Engagement Project is a Public Health England (PHE) funded project in which the Sickle Cell Society works in partnership with the NHS Sickle Cell and Thalassaemia Screening Programme and United Kingdom Thalassaemia Society. Total gross income for this financial year is £124,916.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2023

PLANS FOR THE FUTURE

The trustees and staff have worked together to create our new strategy for the next year to 31 March 2024. In doing so we reflected on our journey over the last three years and envisioned what success would look like for the future.

Our five strategic commitments for the next year are;

1. Enabling Support Networks
2. Building effective partnerships
3. Achieving impact and sustainability with limited resources
4. Managing our stakeholders
5. Enabling resilient patients and communities

We will be revisiting our strategy having regard to the global impact of the covid pandemic and the way in which it has affected the way we work with our SCD community and other stakeholders, our financial outlook and adjust accordingly with regard to the economic and pandemic context.

TREASURER'S REPORT

It was another challenging year but also an exciting one for the Sickle Cell Society. We are still experiencing the financial impact of the Covid 19 pandemic as well as the ending of some grant funding but we are managing these ongoing challenges carefully and successfully. It is also evident that there are ever growing demands on our small staff and volunteer team. Nonetheless, with their commitment and dedication together with support from my Trustee colleagues, we have provided continuous support to the sickle cell community throughout the year.

At the start of the year the Sickle Cell Society set a budget with a control deficit of £211,714. This would appear high, however, £126,004 of the budgeted expenditure was financed from the restricted funds and funds received in previous year(s). The mitigated deficit control total for 2022/2023 was therefore only £85,710. Despite the challenges faced throughout the year, I am pleased to report the financial year ended with a surplus of £79,410. This was made possible because of better than expected income and underspend on our total expenditure for the year compared to the budget.

As ever, I would like to take this opportunity to thank all our staff, and volunteers for their personal support and commitment to the work of the Sickle Cell Society. I would also like to thank my trustee colleagues for their contributions and stewardship and, of course a big thank you to our donors, members, supporters and friends for your unwavering support and indeed, patience throughout the year.

Following my appointment as Chair at the start of the year, I will be relinquishing my role as Treasurer of the Sickle Cell Society. It was a pleasure serving as the Treasurer for the Sickle Cell Society over the years and I feel privileged to continue to serve the Sickle Cell Society in my new role as your Chair.

I look forward to 2023/2024 and for your continued support.

Michele Salter
Chair & Treasurer

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2022

STATEMENT OF FINANCIAL POLICIES

Investment Policy

The Trustees have the power to invest in such assets as they see fit, except for trading purposes. The Society sometimes needs to react very quickly to particular emergencies and has a policy of keeping any surplus funds in short-term deposits, which can be accessed readily. To ensure financial security, the Society needs to secure additional unrestricted funds.

Reserves Policy

The Trustees of the Sickle Cell Society have set a free reserves policy (which represents total unrestricted funds less tangible fixed assets) of maintaining a minimum of three months of the Society's total unrestricted expenditure which was £114,157 at 31 March 2023. This policy was met during the financial year to 31 March 2023, with year-end free reserves of £471,852 (2022 - £345,698), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2022/2023 to ensure that it is appropriate and aligned to the Society's financial performance, assessment of risk and future strategy.

Risk Management

The Trustees actively review the major risks, which the Society faces on a regular basis and aim to maintain our free reserves at the levels stated in the above reserves policy. Combined with our annual review of the controls over key financial systems, they aim to provide sufficient resources in the event of adverse conditions. The Trustees have also examined other operational risks that we face and confirm that they have established systems to mitigate the significant risks. The main risk is the volatile (short term funding) financial environment in which the Society operates.

This volatility is compounded by the current political and economic climate, notably the economic circumstances resulting from the impacts of Brexit and COVID-19. This uncertainty is likely to continue: our focussed approach on strong financial management, good governance and review of our reserves policy will help us to mitigate this risk.

A fundraising strategy is in place to increase the levels of unrestricted income. The aim is to reverse the current unacceptably high grant-dependent "gearing" and increase the level of unrestricted income reserve, and continued improvement in financial performance.

Financial review

Income this year stands at £773,597 which is £98,145 less than the previous year's results. This has been achieved from restricted grant payments of £160,928 and £612,669 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools, training and consultancy, legacy, gift aid and communities and contract services.

During the year the unrestricted funds incurred a net income of £156,042 (2021/22: net income of £137,600).

The majority of grants coming into the Society remain under restricted funds to deliver the objectives of the Society. During the year the restricted funds experienced a deficit before transfers of £26,633 (2021/22: surplus of £57,181). The total restricted reserves at the end of the year were £216,791 (2021/22: £148,253).

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2022

FUNDRAISING STATEMENT

We would like to thank you personally for all the generous support our fundraisers have provided to the Sickle Cell Society. Without your help, we would not be able to carry on with the crucial work that we do.

The Sickle Cell Society is bound by the Code of Practice dictated by the Fundraising Regulator and should abide by the ethical standards set by the Regulator. We pride ourselves through our fundraising endeavours to maintain the highest standards possible in order to meet the regulations set. Our approach has always been to safeguard those who are most vulnerable from inappropriate fundraising practices.

We realise that fundraising is one of the key ways in which we interact with our supporters, donors and the general public. Therefore, the approach we have as a charity is one which ensures that the reputation of the Society is maintained at a high level. At the Society, we are professional in how we communicate with you and strive to an approachable and professional Society. Thus, free membership of the Society includes opt-ins for contact with us and withdrawal from such contact can be easily requested.

We have a Fundraising Working Group that includes Trustee representation, which reports on fundraising performance and related fundraising policy and practice matters to the Board of Trustees. We believe this level of governance also allows us to oversee compliance with the regulatory standards.

Over the course of the year, the Society monitored our fundraising actions closely and can report that we received no complaints in relation to any fundraising activities.

During the year we have used the service of Charity Fundraising Ltd, specifically to assist us with our applications for funding from a range of Trusts and Foundations. This has been a professional and productive relationship.

We are committed as a Charity to outstanding fundraising conduct and believe that over the year the Society can be proud of its actions in this arena.

To coincide with our three year organisational strategy we also adhered to our three year 2020/2023 Fundraising strategy.

Charity Governance Code

Sickle Cell Society recognises that good governance in a charity is fundamental to its success. The Sickle Cell Society and its Trustees are continually working towards the highest standard of governance, by reference to the principles and recommended practice of the Charity Governance Code and the Nolan Principles of Public Service.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2023

Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for the year.

In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Financial statements are published on the charity's website in accordance with legislation in the United Kingdom governing the preparation and dissemination of financial statements, which may vary from legislation in other jurisdictions. The maintenance and integrity of the charity's website is the responsibility of the trustees. The trustees' responsibility also extends to the ongoing integrity of the financial statements contained therein.

Provision of information to auditors

So far as each of the Trustees is aware at the time the report is approved:

- There is no relevant audit information of which the Society's auditors are unaware; and
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

In preparing this report the Trustees have taken advantage of the small company exemptions provided by section 415A of the Companies Act 2006.

By order of the Trustees

Michele Salter
Chair

Date:

The Sickle Cell Society

Independent auditor's report for the year ended 31 March 2023

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF THE SICKLE CELL SOCIETY

Opinion

We have audited the financial statements of The Sickle Cell Society (the 'charitable company') for the year ended 31 March 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the trustees' report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the trustees' report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

The Sickle Cell Society

Independent auditor's report (continued) for the year ended 31 March 2023

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which includes the strategic report and the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the strategic report or the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

The Sickle Cell Society

Independent auditor's report (continued) for the year ended 31 March 2023

- We obtained an understanding of the charitable company and the sector in which it operates to identify laws and regulations that could reasonably be expected to have a direct effect on the financial statements. We obtained our understanding in this regard through discussions with management, industry research, application of cumulative audit knowledge and experience of the sector.
- We determined the principal laws and regulations relevant to the charitable company in this regard to be those arising from Companies Act 2006, the Charities Act 2011 and relevant employee and tax legislation.
- We designed our audit procedures to ensure the audit team considered whether there were any indications of non-compliance by the charitable company with those laws and regulations. These procedures included, but were not limited to enquiries of management and review of minutes.
- We also identified the risks of material misstatement of the financial statements due to fraud. We considered, in addition to the non-rebuttable presumption of a risk of fraud arising from management override of controls, that there is judgement and estimation involved in the recognition of grant income. We have, for a sample of grant income, reviewed agreements to ensure that income, including accrued and deferred income, have been accounted for in accordance with the financial reporting framework.
- As in all of our audits, we addressed the risk of fraud arising from management override of controls by performing audit procedures which included, but were not limited to: the testing of journals; reviewing accounting estimates for evidence of bias; and evaluating the business rationale of any significant transactions that are unusual or outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone, other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Alastair Duke (Senior Statutory Auditor)
For and on behalf of PKF Littlejohn LLP
Statutory Auditor

15 Westferry Circus
Canary Wharf
London E14 4HD

The Sickle Cell Society

Statement of financial activities

for the year ended 31 March 2023
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2023 £	Total Funds 2022 £
Income:					
Voluntary Income	3	607,707	160,928	768,635	871,627
Investment income	4	4,962	-	4,962	115
Total income		612,669	160,928	773,597	871,742
Expenditure					
Costs of raising funds					
Fundraising costs	5	194,993	7,789	202,782	197,588
Charitable activities					
Campaign	5	118,181	83,222	201,403	204,220
Direct services group		84,109	30,019	114,128	113,397
Provision of information and advice		45,366	35,948	81,314	118,518
Children's Activities & Holiday		13,978	30,583	44,561	43,238
Total expenditure	5	456,627	187,561	644,188	676,961
Net income for the year before transfers		156,042	(26,633)	129,409	194,781
Transfer between funds		(95,171)	95,171	-	-
Net movement of funds in year		60,871	68,538	129,409	194,781
Reconciliation of funds					
Total funds brought forward	14	600,812	148,253	749,065	554,284
Total funds carried forward	14	661,683	216,791	878,474	749,065

The Society had no recognised gains or losses during the year other than those shown above. All the above results are derived from continuing activities.

The notes on pages 30 to 44 form part of these financial statements.

The Sickle Cell Society

Balance sheet at 31 March 2023

Company number 2840865	Note	2023 £	2023 £	2022 £	2022 £
Tangible fixed assets					
Tangible assets	9		180,800		215,114
Current assets					
Debtors and prepayments	10	158,406		44,906	
Cash and cash equivalents	12	706,464		690,697	
		864,870		735,603	
Creditors - amounts falling due within one year					
Creditors	13	167,196		201,652	
Net current assets			697,674		533,951
Total assets less current liabilities			878,474		749,065
Represented by:					
Unrestricted funds	14		652,650		560,812
Designated Funds			9,033		40,000
Restricted funds	14		216,791		148,253
			878,474		749,065

These accounts have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006 and constitute the annual accounts required by the Companies Act 2006 and are for circulation to members of the company.

The accounts were approved and authorised for issue by the Board on behalf by:

and signed on its

Trustee

Trustee

Michele Salter

The notes on pages 30 to 44 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows for the year ended 31 March 2023

	Note	2023 £	2023 £	2022 £	2022 £
Cash generated in operating activities	19		11,545		276,462
Cash flows from investing activities					
Interest income		4,962		115	
Payments to acquire tangible fixed assets		(740)		(216,792)	
Net cash from investing activities			4,222		(216,677)
Increase in cash and cash equivalents in the year			15,767		59,785
Cash and cash equivalents at the beginning of the year	12		690,697		630,912
Cash and cash equivalents at the end of the year	12		706,464		690,697

The notes on pages 30 to 44 form part of these financial statements.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2023

1 Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The Sickle Cell Society meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s). There are no areas of critical estimate or significant judgement that affects the preparation of these financial statements.

Going Concern

The Board of Trustees have produced a forecast for the next 12 months from the date of the financial statement was authorised. This forecast takes into account the potential loss of income as a result of the COVID-19 pandemic and its impact on grants as well as other restricted and unrestricted income. To mitigate the impact on the Charity's income and expenditure, the board has taken action to deliver revenue savings. The Society is actively applying for new grants and exploring new fundraising opportunities for the financial year 2023/2024. In parallel, we are also developing a new 3 year fundraising strategy for the organisation. The forward look forecast for the next 12 months shows that the Charity has sufficient funds and reserves to enable us to meet our obligations as they fall due for a period of at least 12 months from the date when the financial statement is authorised for issue. As such, the board is satisfied that the organisation has adequate resources to continue to operate for at least the next twelve months. For this reason, we continue to adopt the going concern basis for preparing these financial statements.

Stock

Stocks of publications and other material are shown at the lower of cost and net realisable value.

Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Donations in kind are included in the accounts at market value.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2023 (*continued*)

1 Accounting policies (*continued*)

Deferred income

Income is only deferred when either the donor specifies that the grant or donation must only be used in future accounting periods, or the donor has imposed conditions which must be met before the Society has unconditional entitlement.

Tangible fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Fixtures, fittings and equipment	-	25% straight line
Leasehold Improvements	-	Shorter of ten years or lease term

Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred and includes attributable VAT which cannot be recovered. Costs of raising funds comprise the costs associated with the Society's fund raising activities.

Expenditure on charitable activities comprises those costs incurred by the Society in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Allocation of Support and Governance costs

All costs are allocated between the expenditure categories of the Society on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly; others are apportioned on an appropriate basis as set out in Note 5. Governance costs include those costs associated with meeting the constitutional and statutory requirements of the Society and include the audit fees and costs linked to the strategic management of the Society.

Operating leases

Assets held under lease arrangements where the title to the equipment remains with the lessor are classified as operating leases by the charity. Rental charges are charged on a straight line basis over the term of the lease.

Pension costs

The Society operates a defined contribution pension scheme. The pension costs charge represents contributions paid during the year. The pension scheme's assets are held separately from those of the society and are managed by independent fund managers, who alone are responsible for matters of investment policy and the actual payment of the pensions to the persons so entitled to it.

Restricted funds

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is identified to the fund.

Unrestricted funds

Unrestricted funds are donations and other income receivable or generated for the objects of the Society without further specified purpose and are available for use at the discretion of the Trustees in furtherance of the general objectives of the Society.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2023 (continued)

Accounting policies (continued)

Designated Funds

Designated Funds are funds earmarked by Trustees for a particular purpose.

Accounting Estimates and Key Judgements

In the process of applying the charity's accounting policies described in this note, judgements and estimates are made that have an effect on the reported amounts of assets, liabilities, revenue and expenses during the reporting period. Significant estimates made in the course of preparing the financial statements include the recognition of grant income and cost allocation for which the accounting policies have been noted above.

2 Legal status of the Society

The Society is a company limited by guarantee and has not share capital, domiciled in England and Wales, company registration number 2840865. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the Society.

3 Voluntary Income

	Unrestricted £	Restricted £	Total 2023 £	Unrestricted £	Restricted £	Total 2022 £
Donations and legacies	482,791	-	482,791	441,483	-	441,483
Grants	-	136,963	136,963	-	165,964	165,964
Capital Income						
NCIL – Brent	-	23,965	23,965	-	69,264	69,264
The Clothworkers Foundation	-	-	-	-	50,000	50,000
The Bernard Sunley Foundation	-	-	-	-	10,000	10,000
Contract Income	124,916	-	124,916	134,916	-	134,916
Other Income	-	-	-	-	-	-
	<u>607,707</u>	<u>160,928</u>	<u>768,635</u>	<u>576,399</u>	<u>295,228</u>	<u>871,627</u>

4 Investment income

	Unrestricted 2023 £	Unrestricted 2022 £
Bank and COIF deposit interest	4,962	115
	<u>4,962</u>	<u>115</u>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2023 £	Total 2022 £
Costs of raising funds					
Fundraising costs	66,968	54,866	80,948	202,782	197,588
Charitable activities					
Campaign	2,727	118,279	80,397	201,403	204,220
Direct services group	68,570	-	45,558	114,128	113,397
Provision of information and advice	18,471	30,384	32,459	81,314	118,518
Children's Activities & Holiday	18,948	7,825	17,788	44,561	43,238
Total expenditure	175,684	211,354	257,150	644,188	676,961

Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2023 £	Total 2022 £
Charitable activities						
Fundraising costs	7,789	25,600	28,257	19,301	80,947	70,647
Campaign	7,736	25,426	28,065	19,170	80,397	73,020
Direct services group	4,384	14,408	15,904	10,863	45,558	40,545
Provision of information and advice	3,123	10,266	11,331	7,739	32,459	42,376
Children's Activities & Holiday	1,712	5,626	6,209	4,241	17,788	15,459
Total support costs	24,744	81,327	89,767	61,314	257,150	242,047

Total expenditure in the year to 31 March 2023 was £644,188 (2022: £676,961) of which £456,627 (2021: £438,914) was unrestricted and £187,561 (2022: £238,047) was restricted.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2023 (continued)

6 Staff cost and numbers	2023	2022
	£	£
Wages and salaries	260,334	280,225
Social security	24,022	23,648
Pension	16,765	47,828
	<hr/>	<hr/>
	301,121	351,701
	<hr/>	<hr/>

The average number of employees during the year was 11 (2022:13).

No employee earned more than £60,000 per annum (2022: None).

No remuneration has been paid to the Trustees other than reimbursement for travel to 1 trustee (£1,798) and membership cost to Association of Chairs membership (£55) totalling £1,853 (2022: £227).

The key management personnel of the Society comprise of the Chief Executive Officer. The total employee benefits of the key management personnel of the Society are £45,667 salary and £4,925 NI, total - £50,592 (2021: £78,097).

7 Net Income for the year	2023	2022
	£	£
Is stated after charging:		
Depreciation on owned assets	35,054	19,904
Auditors' remuneration (including VAT):		
- Audit fees	11,231	10,920
Equipment rental	5,637	3,800
Property Lease/Rent – 56 Station Road	9,600	9,600
	<hr/>	<hr/>

8 Taxation

The Society is a charity within the meaning of Para 1 Schedule 6 Finance Act 2010. Accordingly, the company is potentially exempt from taxation in respect of income or capital gains with categories covered by chapter 3 of Part 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. No tax charge arose in the period.

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

9 Tangible Fixed Assets

	Leasehold Improvements	Furniture & Equipment	Total
	£	£	£
Cost			
At beginning of year	200,772	156,572	357,344
Additions	-	740	740
Disposals	-	(88,321)	(88,321)
	<hr/>	<hr/>	<hr/>
At end of the year	200,772	68,991	269,763
	<hr/>	<hr/>	<hr/>
At beginning of year			
	9,093	133,137	142,230
Charge for the year	27,279	7,774	35,054
Disposal		(88,321)	(88,321)
	<hr/>	<hr/>	<hr/>
At end of the year	36,372	52,591	88,963
	<hr/>	<hr/>	<hr/>
Net Book Value			
AS at 31 March 2023	164,400	16,400	180,800
	<hr/>	<hr/>	<hr/>
As at 31 March 2022	191,676	23,435	215,114

All of the above assets were used for direct charitable purposes during the year.

10 Debtors

	2023 £	2022 £
Grants and donations receivable (note 11)	144,819	20,819
Prepayments	13,587	24,087
	<hr/>	<hr/>
	158,406	44,906
	<hr/>	<hr/>

11 Grants & Legacy receivable

	2023 £	2022 £
Public Health England (PHE)	20,819	20,819
Geno mics England	74,000	-
	50,000	-
Legacy	<hr/>	<hr/>
	144,819	20,819
	<hr/>	<hr/>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

12 Cash and cash equivalents

	2023 £	2022 £
Cash in hand	338	196
NatWest Reserve Account	548,922	538,670
NatWest Current Account	100	100
COIF Charities Deposit Fund	153,202	150,533
Paypal	3,902	1,198
	<u>706,464</u>	<u>690,697</u>

13a Creditors - amounts falling due within one year

	2023 £	2022 £
Trade creditors	70,262	83,072
Accruals and deferred income	96,934	118,580
	<u>167,196</u>	<u>201,652</u>

13b Deferred Income Reconciliation

	2023 £	2022 £
Balance as at 1 April	53,952	17,044
Amount Released to Income	(53,952)	(17,044)
Amount Deferred in the year	27,995	53,952
	<u>27,995</u>	<u>53,952</u>
Balance as at 31 March	<u>27,995</u>	<u>53,952</u>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

14 Analysis of charitable funds

	Balance	Movement in funds			Balance
	1 April	Income	Expenditure	Transfers	31 March
	2022				2023
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	-	9,630	14,299	4,669	-
Jeans for Genes	11,580	-	11,580	-	-
Research	45,227	-	-	-	45,227
Helpline Worker	-	-	35,948	35,948	-
CLAHRC	2,995	-	-	-	2,995
London borough of Hackney	-	-	412	412	-
GMSN – Children’s Activity	5,937	10,346	16,283	-	-
APPG for Sickle Cell & Thalassaemia	-	18,000	27,013	9,013	-
Refurbishment Income	-	23,965	600	-	23,365
NHS England	2,500	-	-	-	2,500
Mentoring Programme	7,060	-	18,027	10,967	-
Give Blood Spread Love	1,727	24,987	60,876	34,162	-
Public Awareness Campaign – Priapism	71,227	-	2,523	-	68,704
Genomics England	-	74,000	-	-	74,000
Restricted funds	148,253	160,928	187,561	95,171	216,791
Unrestricted funds	560,812	612,669	456,627	(64,204)	652,650
General fund					
Designated Funds	40,000	-	-	(30,967)	9,033
Total funds	749,065	773,597	644,188	-	878,474

£20,000 and £10,967 was released from the designated funds to support Give Blood Spread Love and Mentoring Projects during the year.

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

14 Analysis of charitable funds (*continued*)

Analysis of charitable funds – previous year

	Balance 1 April		Movement in funds			Balance 31 March	
	2021	Income	Expenditure	Transfers	Fixed Asset Funding Transfer	2022	
	£	£	£	£	£	£	
Restricted funds							
Children Holiday scheme	-	7,755	11,785	4,030	-	-	
Roald Dahl's Marvellous Children's Charity	268	-	268	-	-	-	
Jeans for Genes	11,580	-	-	-	-	11,580	
Research	45,227	-	-	-	-	45,227	
Helpline Worker	-	-	42,867	42,867	-	-	
CLAHRC	2,995	-	-	-	-	2,995	
London borough of Hackney	8,395	-	10,765	2,370	-	-	
GMSN – Children's Activity	9,815	11,846	15,724	-	-	5,937	
APPG for Sickle Cell & Thalassaemia	-	20,000	32,773	12,773	-	-	
Refurbishment Income	92,633	129,264	26,276	5,151	(200,772)	-	
Heritage Lottery fund	28,043	306	31,187	2,838	-	-	
NHS England	2,500	-	-	-	-	2,500	
Digital Marketing – Blood Donation	8,966	-	13,299	4,333	-	-	
Mentoring Programme	7,060	-	-	-	-	7,060	
Give Blood Spread Love Public Awareness Campaign – Priapism	-	51,057	49,330	-	-	1,727	
	-	75,000	3,773	-	-	71,227	
Restricted funds	217,482	295,228	238,047	74,362	(200,772)	148,253	
Unrestricted funds	336,802	576,514	438,914	(114,362)	200,772	560,812	
General fund							
Designated Funds	-	-	-	40,000	-	40,000	
Total funds	554,284	871,742	676,961	-	-	749,065	

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2022 (*continued*)

14 Analysis of charitable funds (*continued*)

Restricted Funds

The purpose of each of the restricted funds is as follows:

Annual Children's Holiday scheme

The funding provides respite for parents, carers and families. Each year the Society takes up to 30 children with sickle cell on a residential holiday for a fun packed and educational week. During 2022-2023 the Society held a virtual holiday for the second year because of the pandemic. A grant of £9,630 was received from Global Blood Therapeutics (GBT) towards 2022 Children's Holiday Activities and £4,669 was transferred from the unrestricted funds to help fund the 2022 Children's Holiday.

Roald Dahl's Marvellous Children's Charity

The funding for production of 'Did you know' Booklets, the DVD 'Pamela's Story' and Day Trip.

Jeans for Genes Campaign

We contacted the funders during 2022-23 and have returned the underspend from funding received towards volunteering of £11,580 on the funders instruction.

Research and Development

The Society is increasingly actively involved with research and development initiatives at different levels with the NHS, Academic Institutions and Industry. These funds will be used as a contribution to support our funding applications to fund Research and Development bursaries. The applications are in development and will be submitted to potential funders during the year.

Helpline Worker

To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families. A transfer of £35,948 was made from the unrestricted funds in 2022/23 to carry out this service.

Mentoring Project

Young Person's Mentoring Scheme aims to improve the health and wellbeing of young people living With sickle disorder in East London. Restricted grant of £7,060 was received for Imara and £10,967 from the designated funds was used to carry out this service.

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)

The SCTAPPG Project is continue to provide the secretariat of the SCTAPPG. Two restricted grants of £18,000 was awarded by GBT and Vertex respectively. £9,013 was transferred from the unrestricted to help carry out this service.

London Borough of Hackney

The Society has been commissioned by the London Borough of Hackney to deliver a programme of community activities and engagement sessions for people living with SCD and their families, in the borough.

CLAHRC, LSHTM and Sickle Cell Society Collaborative Project

Following the work of the BUPA-funded 'Self Over Sickle' project which provides advice, support and testimonials for young adults around transition, this work will drive visibility of the person behind the sickle cell via an ad campaign in London and aim to build confidence of young adults with the condition via an online resource pack signposting services and techniques to enhance one's quality of life living with sickle cell.

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2022 (*continued*)

14 Analysis of charitable funds (*continued*)

Office Refurbishment

Phase 1 of the Sickle Cell Society Headquarters refurbishment has now been completed. We are currently seeking funding towards Phase 2 work. £23,965 was received from Brent Council – NCIL towards the Project's Manager cost, however the project is now on pause until further funding is secured.

Give Blood Spread Love and Digital Marketing – Blood Donation

Digital Marketing – Blood Donation complement the Give Blood Spread Love programme which aims to increase the number of black people donating blood in areas beyond South London. Give Blood, Spread Love uses new media to build awareness, share facts, breakdown myths and direct people to sign up to the blood donation register online, and go a step further by asking peers to do the same.

Public Awareness Campaign – Priapism

Public Healthcare Awareness Campaign (specifically of priapism targeting Healthcare professionals, young boys, men and parents). Funding was provided by Boston Scientific International to help to support this project.

Genomics England

We have secured funding from Genomics England to appoint a new SCS/Genomics England Partnership role for 18 months. Over that time we plan to deliver a priority setting exercise for future genomics research into SCD.

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

15 Unrestricted donations, legacies and fundraising - £500 & Over

IBB Law - Legacy	78,052
Payroll Giving	60,793
BB Merchant Service	39,260
Just Giving	34,751
Garfield Weston Foundation	30,000
Facebook International	13,260
Capital Group	5,700
Matthew Bower	5,000
The Stafford Trust	5,000
CEX LTD	4,205
Bloomberg LP	4,124
Tecan Group Ltd	3,929
Knight Frank LLP	3,800
Paypal	3,753
Westcliff High School for Girls	3,269
Daniel Olumese	3,000
Hat Trick Productions	3,000
Metro Bank	2,876
Amazon Core Europe	2,430
Giving.com ltd	2,003
MBCC	2,000
Sanius Health	2,000
Talbots - Legacy	2,000
Efthymia Marcou	1,919
Main Account - ITV	1,725
The Rochester Grammar School	1,289
David Prendergast	1,178
Edgar M Cornelius	1,100
Wallington High School for Girls	1,062
Oluwalosemilore Agbaje-Williams	1,036
Fiserv	1,026
L Bedeau	1,000
Nest Performance	1,000
Simply Sayo LTD	1,000
We Are Couch	1,000
Wright Restaurants Ltd	1,000
St George's University - Student Union	918
Oliviet F Brown	840
Duncan Jones	813
Charities Aid Foundation (America)	794
Dojo	757
GSK IHC Ltd	750
Masonic Charitable Foundation	750

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (continued)

Unrestricted donations, legacies and fundraising - £500 & Over (continued)

The Freemasons' Grand Charity	750
Usborne Publishing Ltd	750
Dylan Bamidele	747
Cece Philips	730
Balham & Tooting Community Association (BATCA)	700
HMP Frankland	653
Novo Nordisk Ltd	600
The London Metal Exchange	600
Southend High School for Girls	590
Sacred Heart of Mary Girl's School	586
The Hyde Group	565
New Testament Church of God Ilford	550
Fort Pitt Grammar School	514
Bowling &Co - Legacy	500
British Society for Haematology	500
Canterbury Christ Church University	500
Cavendish Homecare	500
Coca-Cola Europacific Partners	500
Endemol UK Plc	500
HSBC Bank PLC	500
Intuit QuickBooks	500
Queen Street Baptist Church	500
The FA	500

16 Analysis of net assets between funds

			2023
	Unrestricted	Restricted	Total
	£	£	Funds
			£
Tangible assets	180,800	-	180,800
Current assets	648,079	216,791	864,870
Current liabilities	(167,196)	-	(167,196)
	<hr/>	<hr/>	<hr/>
Net assets	661,683	216,791	878,474
	<hr/>	<hr/>	<hr/>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2023 (*continued*)

Analysis of net assets between funds – previous year

	Unrestricted	Restricted	2022 Total Funds
	£	£	£
Tangible assets	215,114	-	215,114
Current assets	587,350	148,253	735,603
Current liabilities	(201,652)	-	(201,652)
	<hr/>	<hr/>	<hr/>
Net assets	600,812	148,253	749,065
	<hr/>	<hr/>	<hr/>

17 Transfer between funds

During the year the Trustees agreed a transfers of £95,171 (2021: £74,362) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding. Transfers were made to Children' s Holiday, Helpline Services, London Borough of Hackney, APPG for Sickle Cell & Thalassaemia Project, Mentoring Project and Give Blood Spread Love & Digital Marketing Projects. Transfers were made to the following projects as a requirement of part funding: The Sickle Cell Society part funded London Borough of Hackney, transfers were made to Projects of £4,669, £35,948, £412, £9,013, £10,967 ND £34,162 respectively to carry out the projects during 2022/2023.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2023 (*continued*)

18 Leasing commitments

The Society is committed to make the following minimum lease payments under operating leases for equipment:

	2023	2022
	£	£
Commitments expiring:		
Within 1 year	14,268	11,651
Within 2 to 5 years	42,583	23,807
	<hr/>	<hr/>
	57,051	35,458
	<hr/>	<hr/>

19 Reconciliation of operating result to net cash inflow from operating activities

	2023	2022
	£	£
Net Movements in Funds	129,409	194,781
Depreciation	35,054	14,904
Interest income	(4,962)	(115)
(Increase)/Decrease in debtors	(113,500)	(12,066)
(Decrease) in creditors	(34,456)	(78,958)
	<hr/>	<hr/>
Net cash generated from operating activities	11,545	276,462
	<hr/>	<hr/>

20 Related party transactions

There are no related party transactions requiring disclosure in this financial year.