THE SICKLE CELL SOCIETY

England & Wales · Charity number 1046631

Details

Status	Registered
Legal form	Charitable company
Company number	02840865
Registered	1995-05-22
Register	View on the Charity Commission register

Contact

Address	Sickle Cell Society 54 Station Road London NW10 4UA
Phone	020 8961 7795
Email	info@sicklecellsociety.org
Website	www.sicklecellsociety.org

Activities

Objects: THE CHARITY'S OBJECTS ("OBJECTS") ARE:(1) THE RELIEF OF PERSONS LIVING WITH SICKLE CELL DISEASE;(2) 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 DISEASE;(3) THE PROVISION OF FACILITIES FOR RECREATION OR OTHER LEISURE TIME OCCUPATION FOR SUCH PERSONS AND FOR SUCH IMMEDIATE MEMBERS OF THEIR FAMILIES HAVING NEED OF SUCH FACILITIES BY REASON OF THEIR YOUTH, AGE, INFIRMITY, OR DISABLEMENT, POVERTY OR SOCIAL ECONOMIC CIRCUMSTANCES WITH THE OBJECT OF IMPROVING THE CONDITIONS OF LIFE FOR SUCH PERSONS;(4) TO ADVANCE PUBLIC EDUCATION IN SICKLE CELL DISEASE BY CARRYING OUT OR ASSISTING IN CARRYING OUT RESEARCH INTO THE CAUSES, EFFECTS AND TREATMENT OF SICKLE CELL DISEASE AND TO DISSEMINATE USEFUL RESULTS OF SUCH RESEARCH.

Activities: Information, counselling, caring and advocacy support for those with sickle cell disorders and their families.

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Classification

- **How:** Makes Grants To Individuals, Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability, The Prevention Or Relief Of Poverty, Arts/culture/heritage/science, Amateur Sport
- **Who:** Children/young People, Elderly/old People, People With Disabilities, People Of A Particular Ethnic Or Racial Origin, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,116,532	£1,106,824	£1,463,843	15
2024-03-31	£992,499	£727,145	£1,143,828	13
2023-03-31	£773,597	£644,188	£878,474	11
2022-03-31	£871,742	£676,961	£749,065	13
2021-03-31	£328,580	£605,374	£554,284	12

Trustees

Name	Role	Appointed
Claudette Allerdyce		2022-09-09
Dr Kilali Basoene Ominu-Evbota		2022-09-10
Dr Matthew Sowemino		2025-06-30
Julia McLarty		2023-05-01
Lisett Brown		2022-09-10
Lorraine Mattis		2025-11-01
Vinice Thomas		2025-11-01
Zainab Garba-Sani		2022-09-10

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THE SICKLE CELL SOCIETY

England & Wales - Charity number 1046631

Accounts



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 2025

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2025

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The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2025

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 – To 31 March 2025
	Dr Matthew Sowemimo	Chair – From July 2025
	Ms Julia McLarty	Treasurer
	Ms Carol Burt	
	Mr Ganesh Sathyamoorthy	
	Mr Nathan Fordwor-Hepburn	
	Ms Lisett Brown	
	Ms Zainab Garba-Sani	Vice Chair
	Dr Kilali Ominu- Evbota	
	Ms Claudette Allerdyce	
	Ms Lanre Ogundimu	
Staff	Mr John James OBE	Chief Executive
	Ms Iyamide Thomas	NHS Engagement Lead
	Ms Miriam Williams	Finance & Administrative Manager
	Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation
	Ms Michelle McFarlane	Helpline & Information Officer
	Ms Keyah Miller	Helpline & Information Office
	Ms Oluwaseyi Afolabi	Parliamentary Officer for SCTAPPG – To December 2024
	Ms Sandra Reyes-Hayduk	Fundraising Manager
	Ms Addassa Follet	Sickle Cell Children &Young People Mentoring Programme Manager (London)
	Ms Sarah Babalola	Give Blood Spread Love Manager
	Ms Paula Shutt	Communications Manager
	Ms Rachel Simpson	Communication Officer
	Ms Rashae Peart	Sickle Cell & Genomics England Partnership Manager
	Ms Adelaide Houlette	Sickle Cell Children & Young People Mentoring Manager (NW England) From June 2024

Ms Adefemi Odesanmi	Advocacy Link Worker – From July 2024
Ms Liana Tinica	Fundraising & Database Officer – From August 2024
Ms Rachel Cobham	Volunteer Co-ordinator – From September 2024
Mrs Anna Shelmerdine	Mentor Administrator (NW England) From: November 2024
Ms Hannah Sharp	Project Manager – Race Health Observatory (RHO) Transitions Project – From March 2025

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2025

Registered address	Sickle Cell Society, 54 Station Road, London NW10 4UA
Telephone number	020 8961 7795
Website and email address	www.sicklecellsociety.org, info@sicklecellsociety.org
Registered charity number	1046631
Company registration number	2840865
Independent Auditor	PKF Littlejohn LLP, 15 Westferry Circus, Canary Wharf, London E14 4HD
Banker	National Westminster Bank, 520 High Road, Wembley, HA9 7BZ
Medical Advisors	Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust Professor Dame Sally Davies Rector Cambridge University Cambridge Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London Professor Bernadette Modell Emeritus Professor, UCL, London Professor David Rees Consultant Haematologist Kings College Hospital, London Dr Allison Streetly Consultant in Public Health Public Health England Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital

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 Division 3 - Childrens Acute Services The Royal Wolverhampton Hospitals NHS Trust

The Board of Trustees of the Sickle Cell Society present their annual report and audited financial statements for the financial year ended 31 March 2025 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.

SUMMARY REVIEW OF 2024/25

A Year of Challenges, Change and Community Strength

This year has brought both significant highs and challenging lows for the sickle cell community, shaped by major shifts in treatment access, increased public visibility, and powerful collective advocacy. At the same time, as a charity, we have taken an inward look at our strategy and systems to ensure we are fit for the future and resilient in a rapidly changing healthcare landscape.

We undertook a period of reflection, working as a Board and with our staff team to explore where our strategic priorities lie. As demand for our expertise continues to grow, we recognise the importance of refining our direction to ensure that our future strategy reflects the needs of the sickle cell community, aligns with our charitable aims, and responds to the evolving external environment.

Toward the end of this reporting period, the Prime Minister announced plans to abolish NHS England, with its functions to be absorbed into the Department of Health and Social Care over a two-year period. The changes aim to reduce bureaucracy and redirect funding toward frontline services. Integrated Care Boards (ICBs) have also been asked to cut their budgets by 50%, and a public consultation on the NHS's 10-year plan is currently underway—signalling a period of far-reaching reform across the health system.

This announcement has understandably raised concerns at the Society. NHS England is a key partner in funding and shaping some of our programmes, and lead the wide-ranging sickle cell care transformation programme. These changes require us to make broader considerations as we develop our strategic plans, ensuring we remain agile and well-positioned to influence policy and protect progress made in sickle cell care.

In reality, we are busier than ever—and more determined than ever—to ensure sickle cell remains high on the healthcare policy agenda in the UK.

Internally, we made important investments to strengthen our systems. We introduced a new CRM system, improving how we manage data, enhancing our compliance with data protection regulations, and supporting staff in their day-to-day work. This investment will enable us to better manage the growing number of people we support, collaborate with, and engage through our programmes.

Looking ahead to the next financial year, we will focus further on our technology infrastructure—reducing the disruptions we've faced in recent years and ensuring our systems are strong and reliable enough to carry us forward, especially as we approach 50 years as a charitable organisation later this decade.

We have also made progress in improving the systems that underpin our volunteer programme. Our dedicated and enthusiastic volunteers support a wide range of activities, and we have focused on building

better tools to recruit, retain, and support them. Our goal is to provide meaningful and rewarding experiences that reflect the vital contribution they make.

As our impact has grown, so too has the need to expand our staff team to meet the needs of new areas of work. This includes improving healthcare outcomes for young people transitioning from paediatric to adult services, supporting people with complex welfare and benefits needs, and advocating for those living with sickle cell in the prison system. These are critical areas where our expertise and compassion can make a real difference.

Our work in the community has continued to have a strong impact. We attended 59 blood donation events this year to encourage more donors from Black heritage communities, helping to improve blood matching for people with sickle cell. The majority took place in London, the area of highest prevalence of sickle cell, with others held across the UK and online, helping us reach a wider audience and grow awareness nationally.

We've seen the case for structured peer support for children and young people strengthen, with 300 referrals in London during the reporting period. We were delighted to progress work to extend the peer support programme to Sheffield, Liverpool and Manchester and widen access to this proven programme for young people with sickle cell across south Yorkshire and the North West.

The programme was brought to life through a powerful video released in January 2025, helping to showcase positive role models for young people.

We were delighted to bring 100 people together for a summer weekend family retreat in Shropshire, made up of 27 family units, each with at least one child living with sickle cell. The retreat was once again a great success, with both parents and children highlighting the joy, sense of community, and valuable connections formed with others facing similar experiences. Many reported long-lasting benefits to their wellbeing and support networks as a result.

In September 2024, we were dismayed by Pfizer's sudden global withdrawal of Voxelotor (OXBRYTA®)—a move that followed the earlier loss of the new Novartis drug, Crizanlizumab, leaving patients with even fewer options for safe and effective sickle cell treatments. Our public statement on 26 September captured the frustration felt by the community, as two decades of progress in treatment innovation were effectively erased in just a few months. The lack of clarity on the decision further deepened feelings of mistrust and vulnerability in the community.

There was hope in the form of the Vertex treatment, Casgevy (Exa-Cel), a potential breakthrough gene therapy, as it progressed through the NICE appraisal process. We remained engaged throughout, with a final committee meeting held on 10 October 2024, and a landmark approval decision announced on 31 January 2025. The announcement dominated national media, with extensive coverage across print, online, and TV platforms throughout the day—a vital moment in placing sickle cell in the national conversation. The news was welcomed enthusiastically across the sickle cell community by patients, community advocates and health professionals alike.

We launched a collaborative project with Genomics England and the James Lind Alliance (JLA) to develop a Priority Setting Partnership (PSP) focused on sickle cell genomics. This initiative brings together patients, carers, and clinicians to identify and prioritise the most important unanswered questions for future research.

The project aims to deepen understanding of the role of genomics in sickle cell and explore how genomic research can lead to improved outcomes for those affected by the condition.

Our growing reputation as a centre of excellence in sickle cell advocacy, campaigning and community-led action continued to attract global interest. In August 2024, we were pleased to welcome Dr Staci D. Arnold—

Paediatric Haematologist, Co-Director of the Curative Therapies for SCD Program at Children's Healthcare of Atlanta, and Associate Professor of Paediatrics at Emory University School of Medicine. During her visit to our offices, Dr Arnold engaged deeply with our work and approach to emerging therapies. She expressed enthusiasm for incorporating insights from our model into her own practice in the United States.

As well as having a presence at influential international events and conferences, we continued our work as a member of the Sickle Cell Disease Coalition based in the USA. The Coalition brings together global stakeholders to advance research, increase awareness, promote access to high-quality care, and accelerate the development of new therapies. We contributed a UK perspective and helped to ensure that the voices of people living with sickle cell are represented in shaping international priorities.

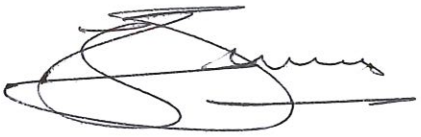
In the UK, we joined the new *Sickle Cell Alliance*, working with NHS and academic partners to drive innovation and investment in sickle cell research. The Alliance combines the expertise of clinicians, researchers, educators and patient advocates to enhance research, funding, and patient support for the global sickle cell community.

It has been a full and rewarding 12 months. Fittingly, the reporting year began with a moment of recognition, as our CEO John James was named in Sanius Health's global list of the most influential people in sickle cell. Over the summer, our visibility continued to grow through impactful projects, collaborations, and extensive coverage surrounding developments in gene therapy and the launch of a sickle cell related drama series.

This increased public profile adds to what we've built over the past 46 years. Through sustained effort, we have gained access to centres of power and influence and built a strong profile and reputation —and with the addition of new highs in visibility has come a year full of opportunities to speak up, show up, and do more for people and families living with sickle cell. We are proud of all that's been achieved—and energised for what comes next.



Dr Matthew Sowemimo
Chair



John James OBE
Chief Executive

Leadership news

In late 2024, we heard that the Chair of our Board of Trustees, Michele Salter, would be stepping down from her role in the spring of 2025 after 11 years of dedicated service.

Michele was an excellent leader, offering invaluable guidance and support during her time on the Board. Under her stewardship, the charity has grown, our finances have been transformed, and through effective strategic leadership; our impact in the sickle cell community has increased. Her contributions have left a lasting legacy that will continue to benefit the Society and those we serve.

While we were sad to see Michele step down, we focussed on ensuring that the transition would pave the way for new ideas and fresh perspectives to further our mission, and honour the progress that Michele has made.

The Board of The Sickle Cell Society

OUR ROLE AND ORGANISATION

About sickle cell disorder

Sickle Cell Disorder (SCD) is an inherited blood condition that affects red blood cells, which are responsible for carrying oxygen from the lungs throughout the body. In individuals with SCD, the normally round and flexible red blood cells take on a crescent or sickle shape. These abnormally shaped cells are rigid, sticky, and prone to breaking easily, leading to anaemia. They also tend to clump together, blocking blood vessels and causing severe pain known as a "sickle cell crisis." These crises can last from a few hours to several weeks and often require hospitalisation for treatment with potent painkillers, although milder crises can sometimes be managed at home.

Over time, people with SCD may suffer from organ damage, affecting the liver, kidneys, lungs, heart, and spleen. These complications often lead to disabilities. Bone marrow transplants are a curative option, but they come with significant risks and complications and are not a simple cure.

Sickle Cell Disorder is one of the most common genetic conditions both in the UK and globally. In England, 1 in 77 babies tested is found to be a carrier of the sickle cell trait. Despite advances in NHS specialised services and clinical care, there remain significant challenges in service support, awareness, and understanding of the condition. This has been highlighted by peer reviews of NHS Sickle Cell Services and the Sickle Cell and Thalassaemia All-Party Parliamentary Group's report, "No One's Listening" published in November 2021.

England has a national antenatal and newborn screening programme for sickle cell disorder. All pregnant women are offered screening to determine if they carry the gene for SCD, with subsequent screening offered to the baby's father if the mother is a carrier. These screenings can present complex and difficult choices for parents, especially when there is a lack of understanding about the condition among both parents and healthcare professionals. Additionally, all newborn babies are tested for the sickle cell gene to ensure early diagnosis and management.

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.

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

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/Family Retreat 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. 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.

Board development

The Board of 10 Trustees has 2 members with sickle cell disorder and 4 Trustees are also carers for family members with sickle cell. The Board undertook board development training during 2024/2025. 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.

KEY HIGHLIGHTS FROM THE YEAR 2024/2025

Stakeholder relationships

Over the past year, we have partnered and collaborated with a wide range of organisations across the voluntary, statutory, clinical, and commercial sectors to progress sickle cell care, raise awareness and extend the reach of our work.

These partnerships have been central to delivering education, improving care pathways, and influencing health policy. We continued our close work with NHS England, NHS Blood and Transplant, the UK Thalassaemia Society, Genomics England, and the NHS Sickle Cell and Thalassaemia Screening Programme. Our participation in the UK Forum on Haemoglobinopathies and collaborations with the MHRA, and the UK Health Security Agency (UKHSA) allowed us to contribute to delivering information and advice about health and regulatory processes.

We also supported hospital sickle cell service patient reviews, ensuring that patient voice and lived experience remain embedded in service delivery.

We've also forged valuable relationships beyond the clinical sector, including with the NHS Race and Health Observatory (RHO), the National Council for Voluntary Organisations (NCVO), and the Sickle Cell and Thalassaemia Association of Counsellors (STAC). Our media and cultural collaborations included projects with HarperCollins Publishers, Netflix, Theatre Peckham, University of Westminster, Black Minds Matter, and awareness campaigns such as the "*Do with*" campaign, and the "*I Am Number 17*" campaign.

We joined with several organisations across industry, the health and charity sectors to submit a joint response to the NHS 10-Year Plan consultation. We engaged with His Majesty's Prison Service to support people with sickle cell in custody and partnered with the Anthony Nolan Trust on new treatment advocacy work.
In everything we do, we remain committed to working alongside community groups, individuals, and industry stakeholders to ensure that people living with sickle cell are seen, heard, and supported at every level.

Membership & Support Group Base

We have maintained our free membership policy, and as of FY 2024/25, our membership has grown to 2,990 members, up from 2,344 in 2023/24. New members continue to join us through our website, social media, and in-person events.

This year, we began migrating to a new CRM system, Beacon, to help us better organise and manage our data, strengthen compliance, and support more effective engagement with our community. As a result of the data cleaning done during the migration, the figure of 3,005 previously quoted for the financial year 2023-24 has been reviewed and revised to 2,344.

We also began work on a full website refresh, with plans to improve user experience and make a stronger case for joining as a member as part of our wider content review. While the timing of newsletters varied this year, these developments are laying the foundations for more consistent, streamlined communications.

As the national umbrella organisation for over 40 support groups, voluntary organisations, and statutory centres across the UK, we are proud to maintain an active and engaged support base across all our channels.

Media & Communication

We used a range of platforms to raise awareness, amplify lived experience and the patient voice, share information and education, and support the Society's projects and advocacy activities.

At the ASCAT conference in October, we presented on the power of storytelling through our newly launched podcast episode focused on transition from paediatric to adult care. The episode explored how young people, families, and clinicians can better navigate this critical period. Our presentation was well received by the international audience of clinicians, healthcare professionals, and industry leaders, reinforcing the value of patient voice in service development and support.

Building on that momentum, we released a two-part podcast series exploring fertility, family planning, dating, and relationships—topics that are often underrepresented in the sickle cell conversation. The episodes featured insights from a leading consultant obstetrician specialising in sickle cell care, alongside an honest and compelling discussion with a panel of young adults sharing their lived experiences. These conversations tackled sensitive issues with openness and depth, offering valuable perspectives and guidance for both patients and healthcare professionals.

One of our biggest communication challenges remains that of reaching audiences beyond the core sickle cell community. However, this year saw real progress. In January 2025, we were featured in Superdrug's national magazine, with a mother and daughter sharing their story—helping bring sickle cell into mainstream health conversations and widen awareness.

In the spring of 2024, we collaborated with the biggest streaming platform, Netflix, on communications activities for *Supacell*, their new superhero drama which centred around a sickle cell storyline. The show was written by Andrew Onwubolu MBE, better known by his stage name, Rapman, a British rapper, record producer, screenwriter, and film director from South London.

The show went to number one in the Netflix charts worldwide with 7.1 million views in early July. It also hit number one in multiple countries and held a top 10 spot for six weeks. Combined with the intense media interest stemming from the gene therapy approval process, this visibility sparked a major surge in online conversations about sickle cell.

We worked with NHS England on the ACT NOW acronym campaign—a tool for A&E and ambulance staff to respond rapidly to patients in sickle cell crisis. The acronym was developed in response to the *No One's Listening* report, and formed part of NHS England's Sickle Cell Improvement Programme. The national rollout began in the spring of 2024. Initial feedback from patients and clinicians show signs that the acronym is working to support patients while they access non specialist emergency care.

We were pleased to collaborate with HarperCollins Publishers on *The Secret Diary of Joynina K. Jones*—a new book written from the perspective of a 13-year-old girl living with sickle cell. Told in a diary format, the story explores how the main character navigates hospital stays, school life, and relationships with family and friends, offering a relatable and heartfelt window into life with the condition. Published under the Collins Big Cat imprint, the book will be distributed to schools, helping to raise awareness of sickle cell among young readers and educators, and bringing vital insights into classrooms across the UK.

Our social media platforms continue to play a vital role in raising awareness, sharing key information, and connecting with our community. This year, we reviewed our platform strategy in light of changing trends across the digital landscape. With a noticeable decline in the popularity and reliability of X (formerly Twitter), we made the decision to join Bluesky as we monitor developments and assess the best channels for meaningful engagement.

Aside from X, each platform has continued to see steady growth across the year. TikTok has emerged as a growing area of opportunity, particularly for reaching younger audiences. We've seen steady growth on the platform, with strong engagement on posts that highlight lived experience, blood donation, and health information in relatable and creative ways. Instagram and Facebook remain important channels for community conversation, while LinkedIn continues to support our professional visibility, helping us connect with health sector stakeholders and partners.

Our content throughout the year featured campaign collaborations and public health messaging, including work with NHS Blood and Transplant on blood genotyping, with Netflix on *Supacell*, with Theatre Peckham for a special *Young, Gifted and Black* season event, and visibility for the *I Am Number 17* campaign to raise awareness of rare genetic conditions - to name a few. As we move forward, we aim to invest more in creative content development, storytelling, and education pieces — ensuring that our platforms remain a trusted and engaging source of information for people affected by sickle cell.

Our website continues to attract visitors from across the globe, reflecting our strong international presence and reputation as a trusted source of information on sickle cell disorder. Throughout the year, we saw clear spikes in traffic around key moments—including World Sickle Cell Day 2024, the release of the Netflix series *Supacell*, and major developments in access to sickle cell treatments. These peaks demonstrate how our website remains a go-to destination during times of high public interest.

Recognising the importance of accessibility and user experience, we have begun work on a full website refresh. The redesigned site is set to launch in the next reporting period and will strengthen how we engage with the sickle cell community, support professionals, and raise awareness both in the UK and internationally.

Helpline and Information Service

Our advice line remains a vital source of support for people living with sickle cell and their families. Throughout the year, we provided people with tailored advice and advocacy during 279 phone calls and 1,000 emails.

The team responded to a wide range of enquiries covering health, education, social care, housing, welfare benefits, and more. The most common queries were around sickle cell treatments, SCD research, requests for our resources, financial matters, donations, and requests for the charity to attend exhibitions and send speakers to events.

We also offered guidance to professionals in schools, healthcare settings, and other organisations seeking to better support individuals with sickle cell.

The strength of our advice service lies in the depth of knowledge and lived experience held across our staff team, supported by input from our panel of expert medical advisers and trusted partners. This collective expertise not only informs the advice line, but also underpins our online resources, face-to-face community engagement, and consultancy work with larger organisations.

Our advice team continues to be active in the community, regularly attending events, hosting stalls, and sharing accessible information. These in-person opportunities are invaluable for connecting directly with.

people affected by sickle cell, gathering feedback, and helping shape how we deliver support—ensuring that our services remain responsive to the real-world needs of those we serve.

Education/information and awareness

On June 19, 2024, we marked World Sickle Cell Day under the theme "We Are Stronger Together"—a powerful reminder that collective action and community solidarity are essential to improving sickle cell care. Our campaign spotlighted the strength that emerges when patients, families, healthcare professionals, and advocates unite to challenge under-investment, narrow health disparities, and push for better services.

As part of the day's activity, we launched a new podcast, with a compelling transition-focused episode, featuring discussions between young people, clinicians, and a clinical psychologist, about the challenges of moving from paediatric to adult care. The conversation highlighted the power of storytelling and peer support in improving outcomes.

We also shared some powerful spoken word clips from staff members, reflecting on the theme, and what it meant to them personally and professionally. These short, thoughtful pieces brought some additional storytelling to the day, amplifying voices from within the organisation and reinforcing our collective commitment to the sickle cell community.

We saw a clear spike in engagement across our social media channels and website, driven by the day's powerful messaging. Importantly, we were able to carry that momentum into the summer, building on the increased visibility through strategic collaborations and compelling content—ensuring sickle cell remained part of the national conversation well beyond a single awareness day.

Sickle Cell and Thalassaemia Screening Programme

In October 2024, we began the second year of our collaboration with the UK Thalassaemia Society (UKTS), working in partnership with the NHS Sickle Cell and Thalassaemia Screening Programme. This project continues to ensure that the screening pathway is shaped by service user needs and focused on tackling health inequalities. However, the planned third year of this work is now uncertain, given the wider restructuring of NHS England and its potential impact on future programme funding.

A key focus this year was follow-up activity from our landmark report: *It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia*.

This report explores the lived experiences of individuals and families receiving screening results for sickle cell and thalassaemia through the NHS antenatal and newborn screening pathways. It highlights significant gaps in how results are communicated—particularly the lack of empathy, cultural understanding, and clear information provided to families at that crucial time.

The findings were drawn from detailed feedback from service users, revealing that many felt unprepared, unsupported, or confused by the way results were delivered. In response, the report makes several recommendations to improve communication practices, including better staff training, consistent messaging, and more person-centred approaches.

This year our work included a highly successful online learning session, attended by 127 healthcare professionals. Feedback highlighted how impactful it was to hear directly from parents, with one antenatal and postnatal screening midwife noting how it would directly improve their practice.

The *It's in Our Genes* findings were also showcased at two major events through poster presentations—first at the London Maternity and Midwifery Festival in Bath, and then at the international *Academy for Sickle*

Cell and Thalassaemia (ASCAT) conference in London. Each event drew over 300 attendees. A video podcast version of the poster was also produced and shared to extend the reach of the findings further.

Throughout the year, we also delivered eight educational talks, hosted three information stalls, and ran an online webinar—primarily aimed at midwives and health visitors involved in communicating screening results. Combined, these activities are estimated to have reached more than 500 professionals, helping raise awareness and improve understanding of screening and its importance in sickle cell care.

Looking ahead, we are planning a joint podcast with UKTS and the NHS Screening Programme, a national conference on communicating screening results, and the launch of a new preconception testing leaflet—further building on the momentum and learning from this year's achievements.

Family Retreat 2024

In August 2024, we welcomed 27 families to our Family Retreat at Whitemoor Lakes in Staffordshire. With 100 participants - including children with sickle cell, their siblings, and parents - the retreat provided a much-needed break and a space for fun, adventure activities, education, and peer connection in a safe, inclusive setting.

Designed for families with at least one child living with sickle cell, the retreat saw overwhelming demand, with more than 100 families applying for under 30 places. Families were prioritised based on need, enabling us to include several vulnerable households, including some new to the UK or affected by housing insecurity.

The retreat offered a rich mix of activities designed to support the whole family—building confidence, improving understanding of sickle cell, and encouraging new friendships. The programme included high-energy activities like abseiling and ziplining, along with wellbeing workshops, sibling support sessions, and dedicated sickle cell education for children and parents. Separate sessions were also held for parents, siblings, and young people, ensuring tailored support across the group.

We were thrilled to be joined by our long-standing friends at Miffy, the iconic rabbit character from children's storybooks, enjoyed by generations. The Miffy character visit brought an extra touch of magic for the younger children. Miffy's generous contribution of goody bags, along with additional kind support from Pass the Bricks (who provided LEGO), added to the sense of fun and celebration throughout the weekend.

The retreat proved to be a transformative experience. Families told us it was the first time they felt truly understood, and they made meaningful new friendships. They also shared that their children left with renewed energy and confidence—which was particularly important ahead of the new school year. One child described it best: "We were like a big family."

Notably, 100% of families said they'd like to attend again, and children overwhelmingly reported having fun, learning new things about sickle cell—and about themselves.

This was our second Family Retreat and it is very clear that this model works. We made some improvements – including making available some separate activities for children and parents, and providing a professional creche, so that even the youngest attendees could be supported, allowing parents time to connect and participate in focused discussions. These changes provided a better overall experience for families.

The retreat also provided an opportunity for volunteers and professionals to connect and support one another, building a community that extends beyond the weekend.

The retreat offers emotional, educational, and social support that families tell us is otherwise hard to find. We look forward to building on its success and continuing to offer spaces that inform, empower, and bring people together.

Parliamentary & policy work :
The Sickle Cell & Thalassemia APPG

Engaging with parliamentarians remains a vital part of our advocacy work. However, changes introduced in summer 2024 to the rules governing All-Party Parliamentary Groups (APPGs) have made it increasingly difficult and competitive to secure MPs to support new or continuing groups. As a result, we were unable to reconvene the Sickle Cell APPG following the general election. We are actively working to re-establish the group and are in ongoing conversations with potential parliamentary champions, aiming to relaunch the APPG as early as possible in the next parliamentary session.

We have continued to engage with parliamentarians and advocate for policy change through other means. In April, we represented the sickle cell community at a special event in the Houses of Parliament for the *I Am Number 17* campaign—an initiative highlighting the stories of individuals affected by rare genetic conditions, of which sickle cell is one of the most common in the UK. The campaign challenges stigma and promotes greater awareness and equity in care for people with rare conditions.

At the event, we met with MPs to emphasise the ongoing inequalities faced by people living with sickle cell and to explore how they could support change in their constituencies and in Parliament. While we work to re-establish the APPG in the future, this kind of direct engagement ensures that sickle cell remains on the political agenda and that we continue to amplify the voices of our community in policy spaces.

Give Blood, Spread Love, England

Our *Give Blood, Spread Love* campaign continued to make a powerful impact this year, reaching over 30,000 people across 59 events aimed at increasing awareness and participation in blood donation within Black and Brown communities.

This work is vital to improving the supply of well-matched blood for people living with sickle cell, many of whom require regular transfusions to prevent life-threatening complications. Thanks to these efforts, we secured enough new donor sign-ups to potentially save or improve the lives of up to 1,800 adults or 3,600 children with sickle cell—a truly life-changing outcome.

A key part of this outreach included the *Unite for Sickle Cell* student programme, which engaged university communities in cities including Manchester, London, Bristol, and Birmingham. The programme focused on building awareness, creating donor networks, and connecting students with the cause through wellness events, creative sessions exploring lived experiences, and NHSBT-supported donor registration drives.

Activities ranged from yoga and nutrition talks to storytelling and physical fitness sessions—all tied back to the central message of creating a healthier, better-informed donor community.

This grassroots engagement is helping to build a new generation of regular donors, equipped with the knowledge and motivation to support people with sickle cell for years to come.

Children and Young People Peer Mentoring

Our Children and Young People's Peer Mentoring Programme continues to provide essential, structured support for young people living with sickle cell. This year saw significant growth in reach and impact, with over 300 referrals in the London area —a clear reflection of rising demand for peer-led, condition-specific mentoring.

To meet this need, we successfully expanded our mentor pool, improving our capacity to match mentees more quickly and provide timely, high-quality support.

Feedback from participants showed encouraging outcomes, including improved confidence, emotional resilience, and overall wellbeing.

Key highlights included national coverage on ITV News, which raised awareness of the challenges young people with sickle cell face and spotlighted the programme's value. We also launched a dedicated mentoring promotional video, helping to boost visibility and inspire more young people to get involved.

Our Future Focus sessions—designed to support mentees as they explore university, apprenticeships, and life beyond school—offered practical guidance and broadened the scope of support we provide.

Despite increased pressure on services, the programme has continued to deliver powerful, life-changing outcomes. Looking ahead, we aim to grow our mentor recruitment and training offer, strengthen transitions for young people completing the programme, and further embed Patient and Public Involvement and Engagement (PPIE)—ensuring that young voices are not only heard but shape the future of sickle cell support services.

During the year, we also focused on expanding the Peer Mentoring Programme into Liverpool, Manchester, and Sheffield, extending our reach to young people with sickle cell across the North West and South Yorkshire.

We've worked hard to build relationships and gain engagement from clinical teams in these regions—essential groundwork for establishing local pathways into the service. While the expansion has not been without its challenges, we are pleased to report that mentor recruitment has been successful, and referrals have begun to come through. We are committed to building on this early progress, strengthening regional links, and ensuring that young people living with sickle cell in these areas have access to the same high-quality, peer-led support as those in other parts of the country.

Volunteer Programme

This year, we re-launched and strengthened our volunteer programme, with a renewed focus on creating meaningful opportunities that reflect the talents, lived experience, and dedication of our supporters. Volunteer involvement remains vital to our work—helping to extend our reach, raise awareness, and champion the voices of those living with sickle cell.

We recruited 11 new volunteers this year, bringing our total to 53 active volunteers across the organisation. From supporting fundraising events to representing the Society at outreach days, talks, and awareness campaigns, our volunteers continue to play a crucial role in building community connections and delivering impact on the ground.

Our approach this year has centred on aligning volunteering opportunities with individual skills and experience, while ensuring volunteers feel valued and empowered. We've seen inspiring contributions—from organising health and wellbeing events at HMP Send, to supporting awareness activities at the University of Nottingham and A2ndVoice's Autism Cultural Experience Fayre.

As we continue to roll out our refreshed volunteering programme, we remain committed to nurturing this growing network and building a stronger, more inclusive volunteer community.

Sickle Cell Genomics Research Priorities Project

In partnership with Genomics England and the James Lind Alliance, we created a Priority Setting Partnership (PSP) to identify the top unanswered research questions for sickle cell disorder, with a particular focus on the role of genomics.

The Priority Setting Partnership is a vital step in ensuring that research into sickle cell disorder is shaped by the voices of those most affected. For too long, people living with sickle cell have been underrepresented in medical research, with limited influence over the questions being asked or the direction of innovation.

This project puts patients, carers, and clinicians at the centre of the conversation — identifying the research priorities that matter most to them. By focusing on what people actually want to know, and what could genuinely improve care, quality of life, and future treatments, we can help ensure that new developments in genomics are relevant, equitable and impactful.

As the landscape of genetic therapies continues to evolve, it's crucial that sickle cell communities are not left behind. This partnership is one way of making sure that the science reflects the needs, hopes and experiences of the people it's meant to serve.

The process is driven by the voices of those with lived experience, carers, and healthcare professionals. During the reporting period, a UK-wide survey was conducted and received over 440 responses. The team is now analysing this rich dataset and reviewing existing research evidence to ensure that future research addresses the priorities that matter most to the sickle cell community. The next phase will involve refining these themes through a second survey and finalising a top 10 list of research priorities to guide funders and researchers.

Improving Equity in the East of England, through advocacy:
Advocacy Link Worker

In 2024, we appointed our first Advocacy Link Worker—an important new role funded in partnership with the Haemoglobinopathy Coordinating Centre (HCC) for North Central London and East Anglia. This marked the start of a pioneering pilot project aimed at tackling health inequalities and improving access to specialist sickle cell care, particularly in low-prevalence areas where patients often face significant barriers to support.

In just eight months, the Link Worker has supported more than 250 patients across the East of England. This work has included attending patient education events in Norfolk, Cambridge, and Bedford, launching a localised WhatsApp support group, and delivering critical one-to-one advocacy. Interventions have helped to prevent delays in A&E admissions and treatment, resolved issues where patients struggled to access GPs or consultants, and provided vital support in cases involving housing insecurity, debt, and Personal Independence Payment (PIP) applications.

The early results are encouraging. This pilot is already showing the powerful impact of tailored advocacy—enabling people to better navigate the healthcare system, speak up for their needs, and access the care they are entitled to. It's a model we hope to build on in the future to reduce the marginalisation of people living with sickle cell.

This work reflects our wider approach to tackling inequality from all sides—working at a strategic level with partners like the NHS Race and Health Observatory, while also investing in grassroots advocacy that directly supports individuals and delivers meaningful change.

Transition Care Project

In March 2025, just four weeks before the end of the reporting year, we appointed a project manager to lead a significant new project aimed at improving transition care for young people with sickle cell.

'Transition' in sickle cell care relates to the transfer of paediatric patients to adult healthcare services, typically during the teenage years. This takes a young person from care managed by a parent or carer, and delivered in a safe and friendly environment through a familiar team - to taking on full responsibility for their own care, in adult hospital settings, sometimes in new clinical spaces in different locations, with new healthcare teams, and the need to have a voice and advocate for themselves.

Poorly managed transitions are associated with higher rates of A&E visits, hospitalisations, and complications, as well as a decline in care continuity and patient satisfaction. While some hospitals offer well-structured, fully staffed transition pathways, others fall short.

This project follows a successful funding award of £99,886 from the NHS Race and Health Observatory, to lead a piece of action research in partnership with the North-East London and Essex (NEL-E) Haemoglobinopathies Coordinating Centres (HCC). The project will explore what young people need to successfully move from paediatric to adult sickle cell services, with a focus on co-production and equity of access.

Through a series of workshops, peer engagement, and evaluation, the project aims to develop an evidence-based, standardised transition framework—ensuring that mental health support, advocacy, and tailored information are embedded in future care models across the NHS.

Although the work began only weeks before year-end, our first online workshop for 12–14-year-olds in North East London received very positive feedback. Young people appreciated the accessible health information, practical advice on nutrition, and the open space to ask questions. Every participant agreed that the information was useful to them, and said they learned something new.

More workshops and a major in-person co-production event will follow in the new reporting period, and we look forward to sharing the full outcomes and impact of this important project in next year's report.

Fundraising and Support : Grants and donations

This year, we were once again uplifted by the generosity, creativity, and determination of our supporters—individuals, companies, and communities who fundraise, donate, and advocate for better outcomes for people living with sickle cell.

We've continued to build strong relationships with corporate supporters, many of whom connect with our mission through their Diversity & Inclusion or Corporate Social Responsibility initiatives. Black History Month remained a particularly active and successful period, generating not just vital income, but also meaningful awareness and visibility. We were honoured to receive support from a wide range of organisations—from consulting firms and transport bodies to faith groups and schools—all helping to amplify our message of equity and representation in healthcare.

Challenge events were another major highlight, with fundraisers across the UK taking on incredible physical feats to raise funds and awareness. From marathons and ultra challenges to bake sales and mountain climbs, their efforts helped raise essential funds to support our work. We are especially grateful to all those who ran, hiked, baked, and trekked for sickle cell over the course of the year, often in memory of loved ones or to show solidarity with the sickle cell community.

Together, these efforts not only raise funds but remind us of the deep and growing support for our cause. As ever, we are committed to nurturing these relationships, sharing impact, and expanding opportunities for individuals and organisations to get involved.

During the year we made funding applications towards core and restricted projects, and initiated or nurtured relationships to help continue to deliver services. We received income of £123,325 from corporate supporters.

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

Black History Month

October's Black History Month remains one of our most active and important periods for fundraising and awareness raising. In 2024, we saw strong engagement across all areas of our work, with an incredible £37,596 raised to support people living with sickle cell.

Although this represents a decrease compared to 2023, it's a significant achievement in the face of a challenging economic and political climate. We've seen a notable decline in corporate engagement, particularly from the US, as many Diversity, Equity and Inclusion (DEI) budgets have been cut or frozen. Even so, Black History Month continues to show clear potential as a major fundraising moment for us.

Corporate donations were vital to this year's success. We're especially grateful to the Vitol Foundation UK, part of global energy company Vitol, which contributed an outstanding £25,191. Metro Bank staff once again showed fantastic commitment, raising £2,605 through their employee raffle — a brilliant effort during a time of widely reported internal change.

Our message to all our donors was clear and consistent: addressing the deep inequities experienced by people with sickle cell is not optional — it's urgent. Many of the organisations that chose to support us did so as part of their Corporate Social Responsibility and Diversity & Inclusion commitments, showing the value of ongoing partnerships rooted in shared values.

Contracts

During the year, we received a total of £310,663 through contractual service agreements to deliver projects that directly support and empower people living with sickle cell.

A significant part of this came from the Sickle Cell & Thalassaemia Outreach & Engagement Project, funded by NHS England. In partnership with the NHS Sickle Cell and Thalassaemia Screening Programme and the UK Thalassaemia Society, this work enabled us to raise awareness, improve access to services, and engage communities more effectively. Total income from this project was £129,940.
We also received £110,780 from Genomics England to support the Sickle Cell Patient Advisory Group (PAG), alongside community workshops and surveys. These activities ensured the voices of people with lived experience were heard in key areas of genomics and future research studies.

In June 2024, we were awarded a tender funded by the NHS Race and Health Observatory to improve transition services for young people living with sickle cell in North East London. This project focuses on bridging the gap between paediatric and adult care through peer mentoring, co-produced resources, and patient-led insight. Our goal is to empower young people with the tools, confidence, and knowledge to manage their own health as they move into adult services. We received £49,943 for this work.

We received £20,000 from NHS England to further support the Patient Advisory Group (PAG) and a workshop focused on empowering and informing the sickle cell community.

PLANS FOR THE FUTURE

As we look ahead, we remain committed to standing alongside everyone affected by sickle cell, and are dedicated to making a difference at every level — from working at a strategic level, influencing and advising policymakers; to working with grassroots organisations, and providing practical support for individuals and families living with the condition.

The year ahead brings both opportunity and uncertainty. We are navigating a time of major change in the NHS, with new strategies emerging that could shape the way care is delivered. It is vital that the sickle cell community is not left behind, and that any opportunity to improve care and support in the new vision of the NHS is firmly grasped. We will continue to advocate for our community at the highest levels, building on the momentum of the NHS Sickle Cell Improvement Programme, and pushing to ensure that sickle cell remains a national priority.

At the same time, we are seeing increasing demand for support on the ground – particularly in areas of low prevalence where people too often struggle alone. We will continue to develop and evaluate our pilot advocacy model to tackle inequality from all sides – working with national bodies such as the Race and Health Observatory and delivering practical, person-centred help in emergency departments, communities and homes.

Our impact and influence is also growing, so we are seeing more demand for our expertise and expect that to feature strongly in the year ahead. As awareness has widened, we are also seeing more interest in our running events, and we look forward to supporting more of our wonderful fundraisers in events like the London Marathon.

Our trustee board is also entering a period of renewal, bringing fresh perspectives and energy to our strategic direction. This comes at a time when more people are living with sickle cell than ever before – and living longer – which makes long-term planning, inclusive services and sustainable funding even more critical.

Across all of this work, our commitment is to put people affected by sickle cell at the heart of everything we do. Their voices will continue to shape our priorities, partnerships and programmes.

TREASURER'S REPORT

The financial year 2024/2025 was a year of continued progress in delivering services for people who live with Sickle Cell Disorder (SCD) and their families. I am delighted that the Society has continued to make positive progress for the sickle cell community throughout the year. This has been underpinned by sound financial management and governance.

The Society ended the financial year with a surplus of £320,016 which is a great achievement, considering at the start of the year we estimated a deficit of £151,463. Our total income for this financial year is £1,426,839, and a total expenditure of £1,106,823. Congratulations to the leadership team and our dedicated staff for another strong performance.

The outlook for the financial year 2025/26 will continue to be very challenging for the organisation with a combination of cessation of grant funding and economic uncertainties. Nevertheless, based on our consistent stewardship and good governance, we plan to navigate these serious challenges as best we can to ensure continued services for people who live with SCD and their families.

I would like to take this opportunity to thank my colleague trustees, staff, our donors and our volunteers in helping to navigate the challenges we experienced, allowing us to continue to make progress.

J McLarty

Julia McLarty
Treasurer

Date: 20/10/2025

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 £138,161 on 31 March 2025. This policy was met during the financial year to 31 March 2025, with year-end free reserves of £770,760 (2024 - £633,421), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2024/2025 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 £1,426,839, which is £434,340 better than the previous year's results. This has been achieved from restricted grant payments of 453,109 and £973,730 from unrestricted income and contracts. The unrestricted income consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools, training and consultancy, gift aid, communities, bank interest and contract services.

During the year the unrestricted funds incurred a net income of £421,087 (2023/24: net income of £236,084).

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 transfer of £101,071 (2023/24 surplus of £29,270). The total restricted reserves at the end of the year were £385,260 (2023/24: £346,480).

FUNDRAISING STATEMENT

We would like to thank you, our dedicated supporters, for your commitment to our work. Your fundraising endeavours have provided the Sickle Cell Society with invaluable resources that enabled us to reach out to more and more people living with sickle cell. Without your help, we could not carry out with the crucial work we do. Thanks to you, we have been able to roll out new initiatives and expand existing ones that meet the daily changes and challenges experienced by people living with sickle cell.

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

We are acutely aware that fundraising is one of the key ways in which we interact with our supporters, donors and the general public. Therefore, our approach ensures that our fundraising practices and reputation are maintained at the highest level. We strive to be an approachable and professional organisation and thus, free membership to the Society includes opt-ins for contact with us and withdrawal from such consent can be easily requested by contacting us at info@sicklecellsociety.org.

We have a Fundraising Working Group that includes Trustee representation and reports on fundraising performance, policy and practice matters to the Board of Trustees. We believe this level of governance allows us to oversee compliance with the regulatory standards. We monitor our fundraising practices closely and can report that we have not received complaints in this regard during the last financial year. As a charity, we are committed to outstanding fundraising conduct and, we have amply achieved this aim.

Thank you from the bottom of our hearts for your committed support.

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.

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

Dr Matthew Sowemimo
Chair

Date: 20/10/2025

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 2025 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 2025 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.

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 strategic report 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:

- 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 legal expenses and review of Trustee meeting minutes.
- 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

23 October 2025

15 Westferry Circus
Canary Wharf
London E14 4HD

STATEMENT OF FINANCIAL ACTIVITIES
for the year ended 31 March 2025
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2025 £	Total Funds 2024 £
Income:					
Voluntary Income	3	950,437	453,109	1,403,546	976,153
Investment income	4	23,293	-	23,293	16,346
Total income		973,730	453,109	1,426,839	992,499
Expenditure					
Costs of raising funds					
Fundraising costs	5	156,015	9,648	165,663	157,047
Charitable activities	5				
Campaign		173,855	165,091	338,946	240,481
Direct services group		150,526	296,122	446,648	186,235
Provision of information and advice		62,333	57,178	119,511	107,037
Family Retreat / Children's Holiday		9,914	26,142	36,056	36,345
Total expenditure	5	552,643	554,181	1,106,824	727,145
Net income for the year before transfers		421,087	(101,072)	320,015	265,354
Transfer between funds		(139,851)	139,851	-	-
Net movement of funds in year		281,236	38,779	320,015	265,354
Reconciliation of funds					
Total funds brought forward	14	797,348	346,480	1,143,828	878,474
Total funds carried forward	14	1,078,584	385,259	1,463,843	1,143,828

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.

Balance sheet
at 31 March 2025

Company number 2840865	Note	2025 £	2025 £	2024 £	2024 £
Tangible fixed assets					
Tangible assets	9		128,791		154,894
Current assets					
Debtors and prepayments	10	253,706		176,913	
Cash and cash equivalents	12	1,746,829		1,028,962	
		2,000,535		1,205,875	
Creditors - amounts falling due within one year					
Creditors	13	665,483		216,941	
Net current assets			1,335,052		988,934
Total assets less current liabilities			1,463,843		1,143,828
Represented by:					
Unrestricted funds	14		899,551		788,315
Designated Funds			179,033		9,033
Restricted funds	14		385,259		346,480
			1,463,843		1,143,828

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 20/10/2025 and signed on its behalf by:

Trustee

Dr Matthew Sowemimo

Trustee

Julia McLarty

STATEMENT OF CASH FLOWS
for the year ended 31 March 2025

	Note	2025 £	2025 £	2024 £	2024 £
Cash generated in operating activities	19		704,644		315,508
Cash flows from investing activities					
Interest income		23,293		16,346	
Payments to acquire tangible fixed assets		(10,070)		(9,356)	
Net cash from investing activities			13,223		6,990
Increase in cash and cash equivalents in the year			717,867		322,498
Cash and cash equivalents at the beginning of the year	12		1,028,962		706,464
Cash and cash equivalents at the end of the year	12		1,746,829		1,028,962

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

NOTES FORMING PART OF THE FINANCIAL STATEMENTS
for the year ended 31 March 2025

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).

Going Concern

The Board of Trustees have produced a forecast for the next 12 months from the date of the financial statement was authorised. 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.

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.

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 residential 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.

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 Vountary Income

	Unrestricted	Restricted	Total 2025	Unrestricted	Restricted	Total 2024
	£	£	£	£	£	£
Donations and legacies	639,774	-	639,774	493,768	-	493,768
Grants	-	453,109	453,109	-	301,527	301,527
Contract Income	310,663	-	310,663	180,858	-	180,858
	950,437	453,109	1,403,546	674,626	301,527	976,153

4 Investment income

	Unrestricted 2025	Unrestricted 2024
	£	£
Bank and COIF deposit interest	23,293	16,346

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2025 £	Total 2024 £
Costs of raising funds					
Fundraising costs	57,384	64,304	43,975	165,663	157,047
Charitable activities					
Campaign	119,190	129,782	89,974	338,946	240,481
Direct services group	220,564	107,520	118,564	446,648	186,235
Provision of information and advice	23,678	64,108	31,725	119,511	107,037
Children's Activities & Family Retreat	26,485	-	9,571	36,056	36,345
Total expenditure	447,301	365,714	293,809	1,106,824	727,145

Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2025 £	Total 2024 £
Charitable activities						
Fundraising costs	11,365	13,178	15,282	4,150	43,975	57,432
Campaign	23,252	26,963	31,268	8,491	89,974	87,943
Direct services group	30,640	35,530	41,204	11,190	118,564	68,105
Provision of information and advice	8,199	9,507	11,025	2,994	31,725	39,143
Children's Activities & Holiday	2,474	2,868	3,326	903	9,571	13,291
Total support costs	75,930	88,046	102,105	27,728	293,809	265,914

Total expenditure in the year to 31 March 2025 was £1,106,823 (2024: £727,145) of which £552,643 (2024: £454,888) was unrestricted and £554,180 (2024: £272,257) was restricted.

6 Staff cost and numbers

	2025 £	2024 £
Wages and salaries	414,610	311,664
Social security	35,940	27,103
Pension	17,270	17,839
	467,820	356,606

The average number of employees during the year was 15 (2024:13).

No employee earned more than £60,000 per annum (2024: None).

Remuneration of £1,494 was paid to Lanre Ogundimu for professional services carried out with the South East London Mentoring Project, offering mentoring services to Children and Young people in the region. Her position as a Mentor was discussed with the Board of Trustees, including checking that there was no conflict of interest.

£4,935 was paid to Zainab Garba-Sani. This amount relates to remuneration from Genomics £4,485 (Co-chair Patient Advisory and attending Sickle working group) and remuneration from NHS £450 (Chairing the Sickle Cell Patient Advisory Group).

Reimbursement of for travel and accommodation to 3 trustees (£894), membership cost to Association of Chairs membership (£60), and Refreshment for meetings (£73) totalling £1,027 (2024: £1,326).

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 £55,176 salary and £6,405 NI, total - £61,582 (2024: £61,082).

7 Net Income for the year

	2025 £	2024 £
Is stated after charging:		
Depreciation on owned assets	36,172	35,262
Auditors' remuneration (including VAT):		
- Audit fees	12,390	11,970
Equipment rental	5,041	-
Property Lease/Rent – 56 Station Road	9,600	9,600

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.

9 Tangible Fixed Assets

	Leasehold Improvements	Furniture & Equipment	Total
	£	£	£
Cost			
At beginning of year	200,772	58,467	259,239
Additions	-	10,070	10,070
Disposals	-	-	-
At end of the year	200,772	68,537	269,309
At beginning of year	63,651	40,694	104,345
Charge for the year	27,280	8,893	36,173
Disposal	-	-	-
At end of the year	90,931	49,587	140,518
Net Book Value			
As at 31 March 2025	109,841	18,950	128,791
As at 31 March 2024	137,121	17,773	154,894

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

10 Debtors

	2025 £	2024 £
Grants and Legacies receivable (note 11)	244,233	164,689
Prepayments	9,473	12,224
	253,706	176,913

11 Grants & Legacies receivable

	2025 £	2024 £
Barts Healthcare Trust	62,113	-
UCLH NHS Foundation Trust	2,363	-
Genomics England	26,745	-
Legacies	153,012	107,740
Mentoring Project (London)	-	56,949
	244,233	164,689

12 Cash and cash equivalents

	2025 £	2024 £
Cash in hand	206	15
NatWest Reserve Account	1,574,752	867,363
NatWest Current Account	100	100
COIF Charities Deposit Fund	168,608	160,650
Paypal	3,163	834
	1,746,829	1,028,962

13a Creditors - amounts falling due within one year

	2025 £	2024 £
Trade creditors	168,560	74,074
Accruals and deferred income	496,923	142,867
	665,483	216,941

13b Deferred Income Reconciliation

	2025 £	2024 £
Balance as at 1 April	92,249	27,995
Amount Released to Income	(54,749)	(27,995)
Amount deferred in the year	351,340	92,249
Balance as at 31 March	388,840	92,249

14 Analysis of charitable funds

	Balance 1 April	Movement in funds			Balance 31 March
	2024	Income	Expenditure	Transfers	2025
	£	£	£	£	£
Restricted funds					
Family Retreat / Children's Holiday scheme	887	26,456	26,485	-	858
Volunteer Project	-	-	7,417	7,417	-
Research	46,227	-	-	-	46,227
Helpline Worker	-		58,437	58,437	-
CLAHRC	2,995	-	-	-	2,995
APPG for Sickle Cell & Thalassaemia	-	31,540	39,156	7,616	-
Refurbishment Income	23,365	-	-	-	23,365
NHS England	2,500	-	2,500	-	-
Mentoring Programme	65,469	279,992	190,310	-	155,151
Give Blood Spread Love	-	15,220	81,601	66,381	-
Public Awareness Campaign – Priapism	68,404	-	-	-	68,404
Genomics England	56,593	-	40,831	-	15,762
Northwest England Children & Young People Peer Mentoring Project	80,040	-	37,611	-	42,429
UCLH NHS Foundation – Advocacy	-	18,901	18,901	-	-
Barts NHS Trust – NEL Community Projects	-	81,000	50,932	-	30,068
Restricted funds	346,480	453,109	554,181	139,851	385,259
Unrestricted funds					
General fund	788,315	973,730	552,643	(309,851)	899,551
Designated Funds	9,033	-	-	170,000	179,033
Total funds	1,143,828	1,426,839	1,106,824	-	1,463,843

Analysis of charitable funds – previous year

	Balance 1 April 2023	Movement in funds			Balance 31 March 2024
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Family Retreat / Children Holiday scheme	-	23,941	23,054	-	887
Jeans for Genes	-	3,000	15,287	12,287	-
Research	45,227	1,000	-	-	46,227
Helpline Worker	-	-	48,111	48,111	-
CLAHRC	2,995	-	-	-	2,995
APPG for Sickle Cell & Thalassaemia	-	14,000	27,224	13,224	-
Refurbishment Income	23,365	-	4,348	4,348	23,365
NHS England	2,500				2,500
Mentoring Programme	-	137,697	72,228	-	65,469
Give Blood Spread Love	-	21,849	44,298	22,449	-
Nursing Workforce	-	20,000	20,000	-	-
Public Awareness Campaign – Priapism	68,704	-	300	-	68,404
Genomics England	74,000	-	17,407	-	56,593
Northwest England Children & Young People Peer Mentoring Project	-	80,040	-	-	80,040
Restricted funds	216,791	301,527	272,257	100,419	346,480
Unrestricted funds					
General fund	652,650	690,972	454,888	(100,419)	788,315
Designated Funds	9,033	-	-	-	9,033
Total funds	878,474	992,499	727,145	-	1,143,828

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

Annual Children's Holiday scheme/Family Retreat
Each year, we run a Children's holiday for young people with sickle cell. For the three years during the COVID-19 pandemic, the holiday was held virtually. The virtual holiday offered additional value by including parents and siblings in the experience. As a result, in 2023 the Sickle Cell Family Retreat was born. We held the second Family Retreat during 2024, with a group of families with at least 1 child with sickle cell. The Retreat was held at the Pioneer Centre in Shropshire. £26,456 was received in 2024/25 towards this project.

Volunteer Programme – no funding was received towards the Volunteer Project in 2024/25. £7,417 was transferred from the unrestricted funds to support this work during this year.

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.

Helpline Worker
To provide telephone and email advice, information and support for people, living with sickle cell, their families and carers. A transfer of £58,437 was made from the unrestricted funds in 2024/25 to carry out this service.

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.

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)
We continued to provide the secretariat of the SCTAPPG. Three restricted grants were received total of £31,540, £16,540 from Vertex Pharmaceuticals, £10,000 from Pfizer and £5,000 from Terumo BCT. £7,616 was transferred from the unrestricted fund to help carry out this service.

Office Refurbishment
Phase 1 of the Sickle Cell Society Headquarters refurbishment has now been completed. We are currently seeking funding towards Phase 2 work.

Mentoring Project
The Young Person's Mentoring Scheme aims to improve the health and wellbeing of young people living with sickle disorder. The programme began in North East London ICB (NEL). We're pleased to now have rolled the service out to the other 4 London regions ; North West London (NWL), North Central London (NCL), South West London (SWL) and South East London. A total of £279,992 was received during 2024/25 to carry out this service.

***Give Blood, Spread Love, England* and Digital Marketing – Blood Donation**
Digital Marketing for the *Give Blood, Spread Love, England* programme, which aims to increase the number of people from black heritage communities who donate 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
This Campaign raised awareness about priapism, which can affect males who live with sickle cell. The campaign targeted Healthcare professionals, men and young boys, and parents. Funding for the project was provided by Boston Scientific International.

Genomics England
We secured funding from Genomics England to appoint a new SCS/Genomics England Partnership role for 18 months, six months of which have been completed. We plan to deliver a priority setting exercise for future genomics research into Sickle Cell Disorder.

North West and South Yorkshire Mentoring Project
This is a pilot scheme aimed at improving the health and wellbeing of children and young people in North West England and South Yorkshire, focussing on Manchester, Liverpool and Sheffield. £80,040 was received during 2023/24, and the new project began in July 2024.

UCLH NHS Foundation Trust (Red Cell Network) – Advocacy
Our Link Advocacy worker for North East London seeks to reduce the marginalisation of people by addressing inequalities they face in living with sickle cell disorder. The postholder provides advice, information and support to patients, carers and professional staff, across the East of England.

Barts NHS Trust – North East London(NEL) Community Projects
With support from the NEL Community Fund, we are now in the early stages of delivering a wide-ranging programme of work to support individuals and families affected by sickle cell across North East London. This funding will enable us to roll out several new initiatives that respond directly to the needs of the SCD community.

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

Legacy of late Evanie Andrews	110,000
Community and challenge events fundraising (Just Giving)	87,827
Garfield Weston Foundation	30,000
Vitol Foundation	25,191
Bloomberg LP	11,800
Lewisham Cemetery and Crematorium	11,600
Legacy of late Ms Sheila Ryan	9,994
Community Event Fundraising (CAF - ONLINE)	6,407
C.E.X Limited	7,183
Facebook	7,142
Atkins Realis Group Inc	5,000
Melissa Thompson and Bleecker Street Burgers Ltd	5,000
Russell Gundry (Gift in kind)	4,635
Anonymous in lieu of fees	3,000
Bola Owolabi	3,000
Eugene Oteng - Ntim	3,000
Sonia Wolf	3,000
John Bradley	3,000
Nathalie Kingston	3,000
Metro Bank	2,605
FundApps	2,600
Lloyds Bank	2,395
Zscaler	1,808
Transport for London	1,750
Bexley Grammar School	1,737
Edgar Cornelius (EMC Promotions)	1,650
Pearson Aigbogun	1,500
Generation Foundation	1,500

Leicestershire Law Society	1,361
London Ambulance - Shurelle Elevique	1,353
Bianca Okoye	1,316
Citi Bank	1,257
Becket Keys School	1,250
Belinda Walkingshaw and Jury O'Shea LLP (Gift in kind)	1,080
Solar Radio (Clive Richardson)	1,000
Tesco Mobile	1,000
Lewis Communications Ltd	1,000
Scottish and Southern Energy PLC	1,000
Aviva UK	1,000
Arriva UK Bus Limited	1,000
Bio Products Laboratory Ltd	1,000
Gloria Antwi-Ahima	1,000
Karen Pritchard	1,000
Ann Styles	1,000
Anonymous	1,000
Elizabeth Williams	1,000
Amicus Therapeutic	970
Tieran Dubique	958
Pollards Hill Baptist Church	911
Ark Academy	906
The Helio Lodge	880
The Pyramid School	858
Monzo Bank	855
Vibes Music Lounge	800
The Tabernacle Global Ministries	800
Christmas Carol service (Shell)	789
Depop Limited	724
Samuel Chuku	700
Boguslawa Paszel	692
Hogan Lovell International LLP	658
Addison Lee Ltd	642
Charter North School	641
Jo Rooney	630
St Augustine Church	600
Jennifer Swimley	511
T K Maxx and Home	500
Balham and Tooting Community Association	500
The Goodwill Lodge L5397	500
BNP Paribas London branch	500
Lloyds Bank Foundation	500
M&G Investments	500
Obinna Udekwereze	500
Osa Pretoru	500
Jo Drummond (Mace Group)	500

Daniel Poser	500
Adetola Oyegbite (Varo Partners)	500

16 Analysis of net assets between funds

	Unrestricted £	Restricted £	2025 Total Funds £
Tangible assets	128,791	-	128,791
Current assets	1,615,275	385,260	2,000,535
Current liabilities	(665,483)		(665,483)
Net assets	1,078,583	385,260	1,463,843

Analysis of net assets between funds – previous year

	Unrestricted £	Restricted £	2024 Total Funds £
Tangible assets	154,894	-	154,894
Current assets	859,395	346,480	1,205,875
Current liabilities	(216,941)	-	(216,941)
Net assets	797,348	346,480	1,143,828

17 Transfer between funds

During the year the Trustees agreed transfers of £139,851 (2024: £95,171) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding. Transfers were made to Volunteer Project, Helpline Services, APPG for Sickle Cell & Thalassaemia Project, and Give Blood Spread Love Project.

£170,000 was designated from the unrestricted funds to support 4 projects in 2025-2026. As at 31 March 2025 the designated funds currently stand at £179,033. No transfer was made from the designated funds in 2024-25 financial year. See note 14 for further breakdown.

18 Leasing commitments

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

Commitments expiring:	2025 £	2024 £
Within 1 year	13,597	15,152
Within 2 to 5 years	32,384	16,096
	45,981	31,248

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

	2025 £	2024 £
Net Movements in Funds	320,015	265,354
Depreciation	36,173	35,262
Interest income	(23,293)	(16,346)
(Increase)/Decrease in debtors	(76,793)	(18,507)
(Increase)/Decrease in creditors	448,542	49,745
Net cash generated from operating activities	704,644	315,508

20 Related party transactions

There are 2 related party transactions during 2024-25 financial year. Please refer to note 6 for details of transactions.

THE SICKLE CELL SOCIETY

England & Wales - Charity number 1046631

Accounts



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 2024

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2024

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The Sickle Cell Society

Company information
for the year ended 31 March 2024

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
	Ms Julia McLarty	Treasurer - From 01 April 2023
	Ms Carol Burt	
	Mr Ganesh Sathyamoorthy	
	Mr Shubby Osoba	To 30 September 2023
	Mr Nathan Fordwor-Hepburn	
	Ms Lisett Brown	
	Ms Zainab Garba-Sani	
	R Kilali Ominu- Evbota	
	Ms Claudette Allerdyce	
	Ms Lanre Ogundimu	From 01 December 2023
Staff	Mr John James OBE	Chief Executive
	Ms Iyamide Thomas	NHS Engagement Lead
	Ms Miriam Williams	Finance & Administrative Manager
	Mrs Clare Rudd	Interim Communications and Social Media Officer – To October 2023
	Ms Tracy Williams	Give Blood Spread Love Project Manager – To November 2023
	Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation
	Ms Michelle McFarlane	Helpline & Information Officer
	Miss Keyah Miller	Helpline & Information Office
	Ms Oluwaseyi Afolabi	Parliamentary Officer for SCTAPPG
	Ms Sandra Reyes-Hayduk	Fundraising Manager
	Ms Addassa Follet	Sickle Cell C&YP Mentoring Programme Manager- From July 2023
	Ms Emma Piper	Mentor Administrator – From September 2023
	Ms Sarah Babalola	Give Blood Spread Love Manager – From March 2024
	Ms Paula Shutt	Communications Manager – From June 2023
	Ms Rachel Simpson	Communication Officer – From October 2023

The Sickle Cell Society

Company information
for the year ended 31 March 2024

Ms Rashae Peart	Sickle Cell & Genomics England Partnership Manager – From November 2023
Ms Lorraine Owusu	Volunteer Co-ordinator – From October 23 - January 2024

The Sickle Cell Society

Company information
for the year ended 31 March 2024 ***(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	Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust Professor Dame Sally Davies Rector Cambridge University Cambridge Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London Professor Bernadette Modell Emeritus Professor, UCL, London Professor David Rees Consultant Haematologist Kings College Hospital, London Dr Allison Streetly Consultant in Public Health Public Health England Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital

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 Division 3 - Childrens Acute Services The Royal Wolverhampton Hospitals NHS Trust

The Sickle Cell Society

Trustees' report
for the year ended 31 March 2024

The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2024 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 (SCD) is an inherited blood condition that affects red blood cells, which are responsible for carrying oxygen from the lungs throughout the body. In individuals with SCD, the normally round and flexible red blood cells take on a crescent or sickle shape. These abnormally shaped cells are rigid, sticky, and prone to breaking easily, leading to anaemia. They also tend to clump together, blocking blood vessels and causing severe pain known as a "sickle cell crisis." These crises can last from a few hours to several weeks and often require hospitalisation for treatment with potent painkillers, although milder crises can sometimes be managed at home.

Over time, people with SCD may suffer from organ damage, affecting the liver, kidneys, lungs, heart, and spleen. These complications often lead to disabilities. While bone marrow transplants have shown promise as a treatment, they come with significant risks and complications and are not a simple cure.

Sickle Cell Disorder is one of the most common genetic conditions both in the UK and globally. In England, 1 in 77 babies tested is found to be a carrier of the sickle cell trait. Despite advances in NHS specialised services and clinical care, there remain significant challenges in service support, awareness, and understanding of the condition. This has been highlighted by recent peer reviews of NHS Sickle Cell Services and the Sickle Cell and Thalassaemia All-Party Parliamentary Group's report, "No One's Listening" published in November 2021.

England has a national antenatal and newborn screening program for sickle cell disorder. All pregnant women are offered screening to determine if they carry the gene for SCD, with subsequent screening offered to the baby's father if the mother is a carrier. These screenings can present complex and difficult choices for parents, especially when there is a lack of understanding about the condition among both parents and healthcare professionals. Additionally, all newborn babies are tested for the sickle cell gene to ensure early diagnosis and management.

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.

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/Family Retreat 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. 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.

Board development

The Board of 10 Trustees has 2 members with sickle cell disorder and 4 Trustees are also carers for family members with sickle cell. The Board undertook board development training during

Board development (continued)

2023/2024. 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 2023/24

This year has been another positive and transformative one for our charity, as we continue to make significant impacts for the sickle cell community. We're especially proud of this achievement given that the charity sector is still recovering from recent challenges, with fierce competition for attention and funds. We extend our heartfelt thanks to our staff, volunteers, Trustees, Patrons, donors, and supporters for their unwavering support.

A major highlight of the year was expanding the Children and Young Person's mentoring scheme across London and in the north of England. This expansion allows us to support more young people with sickle cell disorder (SCD). The guidance our mentors provide is crucial, helping each young person build a better quality of life for themselves, more equipped to manage their physical and mental health, and to find their place in the world.

We faced a setback with the revocation of Crizanlizumab, the first drug approved for sickle cell in 20 years. In January 2024, we learned the marketing authorisation had been revoked by the Medicines and Healthcare products Regulatory Agency (MHRA). Despite this, we remain hopeful that new treatments being assessed by NICE will offer more options for the sickle cell community in the coming year.

Our commitment to ensuring the best possible care and support for everyone with sickle cell disorder from birth onwards continued strong. Our blood donation program significantly contributed to the ethnically matched blood stocks needed for people living with sickle cell disorder. More Black donors are needed because of a rise in demand for some rare blood subtypes that are more common in people of Black heritage. Closely matching the blood for people receiving multiple blood transfusions to manage their sickle cell disorder gives these patients the best possible treatment.

Our screening program supported families from the preconception stage, and worked with the NHS to ensure sickle cell screening test results are delivered sensitively and effectively.

In August 2023 we held our first in- person Family Retreat - for children with SCD and their families. This is an evolution of the Children's Holiday that we held in previous years, and a pilot to see if we could deliver more value to children with sickle cell if they came in their supportive family unit. The retreat was a tremendous success, and delivered a far larger and longer lasting impact than taking just the children away for a break. 29 families joined us from across the UK to a venue in Shropshire. Parents reported that the sense of support and belonging was incredibly positive. It was heartening to hear that the retreat boosted children's self-confidence and provided families with the strength to face the condition's challenges.

We remain dedicated to ensuring that people with sickle cell have access to the best care and support, and holding those in decision making positions to account. In November 2023, following on from the care failures highlighted in our 2021 report, 'No One's Listening', we took a deeper look at sickle cell nursing care in a new report called 'The difference between life and death'. Our findings showed the need for vastly more resources, training and support in this critical area of care, and highlighted that not only was no-one

SUMMARY REVIEW OF 2023/24 (continued)

listening, but that lives were still being put at risk. We will continue to campaign for and implement the recommendations from these reports in the coming year.

We saw the benefits of the conversations around sickle cell disorder. We have continued to raise discussions with the sickle cell community and other stakeholders primarily to enable more awareness of the condition and funding towards improved services. It is clear that more people are talking about sickle cell, and seeking ways to get involved in action and in finding solutions. We have seen a huge sickle cell transformation programme take place in the NHS as a result, and more opportunities opening up.

We are proud of the progress we have made so far, and excited to see the impact of our ongoing efforts. Our dedication to transforming care and outcomes for individuals and families living with sickle cell disorder drives us to continually strive for excellence. We aim to make a lasting, positive difference in their lives.

Michele Salter
Chair

John James OBE
Chief Executive

KEY HIGHLIGHTS FROM THE YEAR 2023/2024

STAKEHOLDER RELATIONSHIPS

Collaborations are essential for our success, and by working with researchers, clinical experts, people with lived experience, and other key decision-makers, we can make significant impacts. Building strong relationships with stakeholders is crucial for connecting our work with partners globally.

Our most important stakeholders are the growing number of patients we represent. Sickle cell disorder is the UK's fastest-growing genetic condition, yet advancements in care and treatments have been slow. We collaborate with individuals living with the condition, their families, and patient groups to ensure their needs are central to our work.

We continued partnerships with organisations like Rare Disease UK, Genetic Alliance, the Anthony Nolan Trust, and the Specialised Healthcare Alliance. Our board members and staff serve on their committees, influencing their strategic directions.

Our collaboration with the NHS Sickle Cell and Thalassaemia Screening Programme advanced, as we worked alongside the UK Thalassaemia Society on joint initiatives. We are incredibly proud of the work we have done over the years in this area, and whereas screening for sickle cell is widely available, there is still much work to do. Our work during the year centred around what the results mean to the people who receive them, how they receive results and obtain information and support, and increasing awareness amongst both clinicians, and the people who may carry the gene for sickle cell, and are planning to start a family.

We also partnered with numerous organisations, including the 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 related voluntary and statutory bodies.

STAKEHOLDER RELATIONSHIPS (continued)

Additionally, we collaborated with various research and improvement organisations to enhance understanding of sickle cell. These collaborations included the National Haemoglobinopathies Panel (NHP) and their Health Coordinating Centres (HCCs), the National Institute for Health Research (NIHR), NHS Boards, European Medicines Agency (EMA), NHS Blood and Transplant Clinical Trials Unit, University College London (UCL), Genomics England, and others.

As the secretariat for the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG), we continued to highlight key issues and advocate for change. The SCTAPPG works to raise awareness and prioritise sickle cell disorder and other haemoglobin disorders in political discussions.

Membership & Support Group Base

We have continued our free membership policy, and as of FY 23/24, our membership has grown to 3,005 members, from 2,891 in 2022/23.

We encourage people to join through our website, social media, and events. Members receive newsletters in print or electronic formats, along with regular e-news updates. Due to staff changes in our communications team, the timing of these mailings varied this year, and we aim to get back to a regular routine in the coming year.

We serve as the national umbrella organisation for over 40 independent support groups, voluntary organisations, and statutory centres across the UK. Our support base is also active on our social media channels.

Media & Communication

Our social media platforms saw continued growth in followers, fostering conversations and engagement around sickle cell news, campaigns and information. To better connect with young people, we launched on TikTok, in addition to our existing presence on Instagram, Facebook, X, and LinkedIn.

Our social media content included collaborations with partners and campaigns such as Jeans for Genes, NHSBT for blood genotyping, and the "I Am Number 17" campaign to highlight sickle cell as a rare genetic disorder.

We also worked with NHS England on a campaign to raise awareness of pre-payment certificates for prescriptions – to lower the cost of medication for people with sickle cell.

Our website attracted visitors from 208 countries and territories, all seeking information about sickle cell disorder. This highlights our global reach and solid reputation as a trusted source for sickle cell information.

Press and media coverage was strong, with new therapies capturing the attention of major national news outlets. This increased awareness of sickle cell, making it a topic more journalists and the general public are familiar with. We plan to build on this momentum in the coming year to further raise awareness.

Helpline and Information Service

We offered crucial support and advocacy to people with sickle cell and their families by phone and email. Our team also gave advice to educational and healthcare professionals and other stakeholders.

The knowledge, commitment, expertise and lived experience of sickle cell disorder across our full charity staff team supports the delivery of the advice and information we provide, and we obtain specialist advice from our panel of medical advisers, and other partners. This enables us to offer advice to people living with sickle cell on health, school/education, social care, housing, financial assistance, and more. This expertise supports not only

Helpline and Information Service (continued)

our helpline, but also the website, and our attendance at face-to-face events; and informs the consultancy services we offer to larger organisations.

The advice line team regularly attend and have stalls with literature at community and organisational events, allowing us to engage directly with people living with sickle cell and gather feedback from people in the community, as well as large employers, on how we can best provide support to the community.

EDUCATION / INFORMATION AND AWARENESS

We observed the United Nations' nominated World Sickle Cell Day on June 19th with the theme "Celebrating Success." We highlighted progress in medical advances for individuals living with sickle cell, the improved standards of care since the "No One's Listening" report, and the event gave us a platform for our ongoing efforts to raise awareness about the condition.

On the day, we placed the spotlight on Priapism and launched an animated awareness video we developed in collaboration with experts at Guy's and St Thomas' Hospital, with the support of Boston Scientific. The video featured a young boy's story of his experience of priapism, an unwanted and painful penile erection, which is a medical emergency. The video addressed how teenagers might deal with this challenging situation. The campaign achieved widespread coverage, and won 3 Association of Medical Illustrators awards.

We also encouraged people to 'Wear Red for Sickle Cell' to get involved in a fun way, and crucially, to start conversations around sickle cell.

The day was an opportunity to take part in sickle cell events and reach people face to face. We also achieved widespread media coverage, with our Chief Executive appearing on BBC TV news on the day amongst the highlights.

We achieved broadcast coverage across the UK, working with Vertex, who organised a 'Radio Day' as a tool to generate coverage. The aim was to make listeners aware of sickle cell disorder and the findings of the "No One's Listening" Report.

We had a phenomenal result, with the many highlights including:

- Over 19 hours of airtime across 124 stations.
- The content reached 42,550,000 Prime Time listeners.
- Coverage on the Radio News Hub, who reach 117 member stations, including Jazz FM, Nation Radio Group and News Radio UK. They have a combined reach of 8,086,000 listeners.
- SKY News, who broadcast to 34,000,000 listeners.

Sickle Cell and Thalassaemia Screening Programme

In October 2023, we secured ongoing funding for the Screening Programme Project, jointly with the UK Thalassaemia Society (UKTS). We continue to work collaboratively to help ensure the screening service is underpinned by service user needs and addresses any inequalities that arise.

Key Project Achievements:

- A consultation with users of the screening pathway which culminated in the launch of a report *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'* at a national conference on 18 April 2023 attended by 168 stakeholders
- Recording and dissemination of a 6-minute overview video of how the Sickle Cell Society / UKTS work with the Screening Programme to provide the service user voice

Sickle Cell and Thalassaemia Screening Programme (continues)

- Successful submission of two abstracts on the *'It's in Our Genes'* report, resulting in workshop and poster presentations respectively at the London Maternity and Midwifery Festival 2024 and Brighton and Sussex Medical School's Anti-racism in Healthcare conference

- Contributing service user feedback and experiences to the NHS SCT Screening Programme review of their *'Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'* targeted at health professionals
- Contribution to the revised Sickle Cell Society leaflet *'Sickle Cell Disorder and Sickle Cell Trait'* to now include a separate a page on screening and preconception testing
- Raised awareness of sickle cell and screening in the media, at public talks and stalls, webinars and conferences.

Family Retreat 2023

From Friday 11th August to Sunday 13th August, 29 families from across the UK (everywhere from Newcastle to Bristol) who had one or more children with Sickle Cell, joined us for a family retreat at the Pioneer Centre in Shropshire for a busy weekend of sickle cell education, adventure activities, networking and fun.

We welcomed:
- 37 young people with Sickle Cell
- 19 siblings of young people with Sickle Cell
- 48 parents

This retreat was a pilot, and a departure from the previous 'children's holiday' format of taking only the children with sickle cell away for a break and some respite. This new format of taking the whole family unit away was a resounding success, which delivered a greater impact on the participants.

The families had a wonderful time and in feedback:

- Families told us that the best part was the children all meeting each other and playing together, and not feeling like their family was the odd one out.
- Some of them told us that this is the first time they'd felt like they had a true support network that they were able to call on.
- Some commented that this marked a real turning point for their child.
- Most importantly perhaps, many of the families reported that they no longer felt alone.

During the retreat, the families took part in the following activities:

Activity Blitz: Inflatable Challenge, Abseiling, Zip Trek, Archery, Challenge Course
Campfire
Yoga
Mindful Doodling
Fencing
Caving
Hand Massage and Relaxation
Sickle Cell Education
Mindfulness
Sickle Cell Q&A
Arts and Crafts
Team Challenge
Drama
Healthy Living
Sibling Mental Health and Wellbeing

The Family Retreat 2023 (continued)

Disco
Family Mental Wellbeing
Parent Session with a Nurse Counsellor
Under 8's Play Sessions
Board Games

The highlight of the Retreat 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:

"My daughter .... really came out of her shell, she was a totally different child. She had such a lovely time and made some wonderful new friends who she has kept in contact with. She doesn't like talking about her condition but she was happy to talk to her new friends. For once she wasn't being pulled away from her friends to take medication as they all had to take their medication, so for the first time in 11 years she didn't feel like the odd one out."

"I am a single parent and don't have much of a support network, so it was so nice to be around other parents who I could get advice from and understand what it's like to have a child with sickle cell, I have met new friends and feel like I also now have a support network."

"The best bit was meeting other families just like us. It can often feel isolating as a parent but the retreat showed us we are not alone. "

"We have learnt a lot and met some wonderful people. We leave with more knowledge about sickle cell and also how to access support we didn't know was available."

"She doesn't like talking about sickle cell and finds it difficult to tell anyone she's in pain, she never says the words 'sickle cell' and doesn't even like me talking about it, but when we came home we had a very long talk and she really opened up about having sickle cell. She was so much more confident ... that's such a positive thing because I have been trying to get her to talk about sickle cell for years and she would just say she doesn't want to talk about it, but since the retreat and meeting so many other people who also have sickle cell she has opened up so much more."

PARLIAMENTARY & POLICY WORK

The Sickle Cell & Thalassemia APPG

We are incredibly proud of the progress in improving care for people living with sickle cell disorder, since we released the 'No One's Listening' APPG report in November 2021. The Sickle Cell & Thalassemia All-Party Parliamentary Group (SCTAPPG) aims to raise awareness and promote sickle cell disorder and other haemoglobin disorders on the political agenda. Accountability is achieved through the Group's Chair, Janet Daby MP. We work closely with the SCTAPPG through our work as secretariat, and with our Parliamentary & Policy Officer.

The Group's AGM was held on 12th June 2023 and attendees heard from Dr Dianne Addei, Senior Public Health Advisor for the National Healthcare Inequalities Improvement Programme.

Dr Addei's presentation provided a summary of the National Sickle Cell Healthcare Pathway Review, highlights included :

- The quality improvement programme created a timely opportunity to review the entire sickle cell pathway after the publishing of the 'No One's Listening' report.

PARLIAMENTARY & POLICY WORK (continued)

- Sickle cell care extends beyond when patients present in A&E with a crisis – and includes multiple specialisms including screening, pregnancy, delivery, primary care, community services and end of life care.
- Conducting the pathway review included the involvement of lead clinicians, head of departments and the establishment of a Patient Advisory Group for co-production.
- The pathway review was finalised with 77 recommendations, grouped into 10 themes, and presented to the Executive of the NHS.
- Rapid attention was given to urgent care when patients present with a crisis. The focus recommendation was the ability of patients to access specialist care at these moments. This included;
    - Not only being seen by a haematologist but those who have knowledge of sickle cell.
    - Efficiency of pain relief.
    - Patient follow up after discharge.
- The pathway review data also highlighted that a large percentage of patients presented in hospital outside of standard working hours. The review would therefore look into providing 24/7 services.
- Nottingham University Hospitals Trust was presented as a case study for excellent care provision. The Trust utilised 'A&E Bypass' so that sickle cell patients went straight to specialist care when attending hospital.
- The pathway review would be running model pilots in London Metropolitan areas from September 2023. The vision for sickle cell hyper acute units would include one 24/7 unit per geographical area.
- The pathway review also analysed care plans and creating wider access to the documents. The proposal is to make patients' care plans digital, with a roll out scheduled over a few years. In the interim, the London area trials hope to fast-track sickle cell patients' care plans for digital transformation.
- An interim physical wallet card had been developed to flag sickle cell patients as a medical emergency with the NICE guidelines on the back. These cards would be sent to the Haemoglobinopathy Co-ordinating Centres.
- A long-term piece of work would be undertaken to review medication and prescription charges. This would include;
    - Pre-payment prescription certificate campaign.
    - NHS low income scheme.
- There would be efforts to flag genetic counselling for sickle cell patients and to educate healthcare practitioners.
- The team were working with NICE to review the sickle cell guidelines.
- There would be a stream of work to create care auditing processes to ensure accountability.
- London and Birmingham had prioritised the sickle cell pathway, so funding would be provided for the improvement of community services. This was also being rolled out in other regions.
- There were also efforts to prioritise sickle cell research.

Going forward, the SCT APPG is focused on ensuring the 'No One's Listening' report recommendations are progressed. Alongside this, the APPG will address longstanding policy issues beyond healthcare, such as housing, prescription charges, benefits, and employment.

We're pleased with the progress in various Trusts across the UK, particularly the National Sickle Cell Healthcare Pathway Review, which aims to reduce healthcare inequalities for sickle cell patients. As the report reaches more Trusts, we are receiving increasing requests to discuss its recommendations with hospital teams.

GIVE BLOOD, SPREAD LOVE, ENGLAND

Give Blood, Spread Love (GBSL) works with Black African and Caribbean communities to raise awareness about sickle cell disorder. We explain why people with sickle cell need blood from donors of similar ethnic backgrounds and encourage people from these communities to become regular blood donors. We do this by hosting events with corporate organisations, community groups, sports and leisure agencies, and faith groups, where we share our key messages and calls to action.

Social media and online engagement are crucial for GBSL, helping us reach younger audiences and connect with thousands of people through accessible information on sickle cell, blood donation, and related topics.

Our volunteer team, the 'Give Blood Squad', includes blood donors, recipients, and those with personal connections to sickle cell. Their lived experiences bring authenticity to our campaigns.

Our social media presence continues to grow, with 1,699 followers on our Instagram account, @givebloodspreadlove. The account features educational content on sickle cell and blood donation, personal stories from our volunteers, and various messages and videos featuring influential community figures.

In October we were hosted by Amazon's Black Employee Network for their Black History Month event, where we shared our expertise and experiences of sickle cell and blood donation. We also registered new blood donors alongside NHSBT's Know Your Type Team.

In November, we launched a partnership with Saracens Rugby Club and Stone X Stadium. We were delighted to have their support, and for their commitment to raising awareness of sickle cell and the need for more black and mixed race donors. 10,000 fans got to see films about our work, read about us in the match day programme, and heard from our team who were interviewed at halftime on the pitch. They also pledged to donate £2k for every try scored at their match with Leicester Tigers: 4 tries were scored thanks to Maro Itoje and teammates.

Children and Young People Peer Mentoring

Our peer mentoring programme supports youths aged between 10 and 24. It enables them to meet with a 'peer' or other young person who like them live with sickle cell, and are also trained in mentoring. The programme aims to support young people to improve their understanding of their condition, and improve their emotional and social wellbeing. It provides support for young people going through the process of transition from paediatric to adult services, as well as support with navigating education and employment.

In previous years, the programme was only available in the City and Hackney areas of London. In March 2023, we received confirmation from North East London (NEL ICB) that they would fund the programme for another 12 months. A month later we also learned that we would receive two years of funding from all other London ICBs. So far, we have begun recruitment of Lead Mentors, Clinical Leads, and new mentors, as well as a Clinical Director for the programme.

Children and Young People Peer Mentoring (continued)

In January 2024 we received the official news that we are one of only two winners for the Health Inequalities Targeted Call, a competitive process by NHS England, NHS Race and Health Observatory, supported by NHS Innovation Accelerator.

We won for our role as catalysts for transformative change in healthcare, and our innovative work in tackling health inequalities, and the Children and Young People's Peer Mentoring Programme was cited as an example of our work in this area. The accolade allowed us some funding to roll the peer mentoring programme out into the North West and Sheffield. We are excited by the promise this holds for young people living with sickle cell.

This is what some of our mentees said about the programme :

"Emotionally it has helped me gain confidence in myself-which in turn has helped me put myself out there."

"The programme has inspired me to learn more about SCD to create awareness in my university and hopefully the world soon."

"My mentor has been so helpful to me, through working together and talking regularly with my mentor I have gained a better understanding of my condition. Working with my mentor has enabled me to ask questions about my condition and question how to deal with the impact on my life."

Volunteer Coordinator - Sickle Cell Society

During the last financial year, good progress was made in relation to our volunteer programme following the recruitment of the volunteer coordination role which took place in June 2023. Headway was made in key areas such as helpline and information support, volunteer engagement, recruitment strategies, social media initiatives and collaborations with educational establishments and other charities. There were some challenges but overall, the direction of travel is positive. We received 30 new applicants and just under half of these were successfully onboarded and inducted as SCS volunteers.

Although the volunteer coordinator was in post for only seven months, there were significant achievements in volunteer coordination, successful recruitment, engagement, and collaborations. The ongoing commitment to improvement, collaboration, and community outreach remains unchanged and a new coordinator is being actively recruited.

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 £127,262 from corporate supporters.

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

Black History Month

Black History Month is one of the most active and important months for the Sickle Cell Society. This is the time we see increased engagement across all areas of business.

During Black History Month (BHM) 2023, a remarkable £51,997 was raised in support the work of the SCS. This is an incredible achievement and a substantial increase from the £20,000 we received during BHM 2022 and the over £5,000 in BHM 2021.

Again, corporate donations have proved vital in ensuring that BHM is a success for the Sickle Cell Society, and continues to show great evidence that income during this special month can keep on increasing.

Contributing an amazing £19,708 was C. Hoare & Co, the UK's oldest privately-owned bank and once again Metro Bank employee raffle raised £5,500, a tremendous increase from the £2,976 they supported us with during BHM 2022.

It is worth noting that the key message delivered by the SCS to these donors was that of addressing inequities. In addition to this, most of the corporate donors that approached us in the first place, did so on the basis of being part of their Corporate Social Responsibility (CSR) and Diversity and Inclusion (D&I) initiatives.

CONTRACTS

During the year the Society received a total of £180,858 for contractual services:

The Sickle Cell & Thalassaemia Outreach & Engagement Project is an NHS England formerly known as 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 income for this financial year is £137,858.

Vertex Pharmaceuticals (Europe) Ltd, Sponsorship of Patient Education – All You Need to know about Gene Therapy and Transplantation of Sickle Cell. Total income of £15,000.

The Sickle Cell Society is collaborating with the London Ambulance Service NHS Trust to undertake a research project to find out more about sickle cell patients' experiences of using the ambulance services, including ambulance care, 999 and 111 calls. Total income received £10,000.

£10,000 from NHS England to support Sickle Cell Patient Advisory Group.

Terumo BCT contributed £8,000 during the year to support the Sickle Cell Society's Podast.

PLANS FOR THE FUTURE

The trustees and staff will continue to work together. We have successfully delivered our charity strategy for the three years up to 31 March 2024.

Our five strategic commitments for the next year 2024/2025 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

During 2024/2025 we will embark on an inclusive approach to revisit and refresh a new 3 year strategy, building on the good progress we have made as an organisation, remaining focussed on making a positive difference to the lives of those who live with sickle cell disorder and their families.

TREASURER'S REPORT

I am pleased to present the 2023/2024 Annual Report and Accounts, my first report since taking up my trustee Treasurer role in April 2023. It has been great to witness at first hand, the excellent work of the charity. I am delighted that the Society has continued to make positive progress for the sickle cell community throughout 2023/24. This has been underpinned by sound financial management and governance.

It is a significant achievement that the financial year 2023/2024 is now the fourth consecutive year the Society has achieved a surplus.

We started the financial year with a deficit budget of £59,665, however, the Society ends the financial year with a surplus of £265,354 which is £325,019 better than planned. This was achieved through receipt of restricted funds of £301,527 and unrestricted income of £690,972. Our total income for 2023/24 is £992,499 with total expenditure of £727,145. I congratulate the Society's leadership team and our dedicated staff for this consistent and strong performance.

I would also like to take this opportunity to thank our many generous donors, supporters and volunteers for their tremendous support throughout the year.

Our good performance financially has been matched by the progressive development of services. Many examples of service delivery for people and families are set out in this Annual report.

We look forward to 2024/25 with new aspirations to support the Sickle Cell Community. We hope we can count on you for your continued support.

JMcLarty

Julia McLarty
Treasurer

Date: 30/09/24

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 £113,722 on 31 March 2024. This policy was met during the financial year to 31 March 2024, with year-end free reserves of £633,421 (2023 - £471,852), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2023/2024 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 £992,499 which is £218,902 better than the previous year's results. This has been achieved from restricted grant payments of £301,527 and £690,972 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools, training and consultancy, gift aid and communities, bank interest and contract services.

During the year the unrestricted funds incurred a net income of £236,084 (2022/23: net income of £156,042).

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 surplus before transfers of £29,270 (2022/23: deficit of £26,633). The total restricted reserves at the end of the year were £346,480 (2022/23: £216,791).

FUNDRAISING STATEMENT

We would like to thank you, our dedicated supporters, for your commitment to our work. Your fundraising endeavours have provided the Sickle Cell Society with invaluable resources that enabled us to reach out to more and more people living with sickle cell. Without your help, we could not carry out with the crucial work we do. Thanks to you, we have been able to roll out new initiatives and expand existing ones that meet the daily changes and challenges experienced by people living with sickle cell.

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

We are acutely aware that fundraising is one of the key ways in which we interact with our supporters, donors and the general public. Therefore, our approach ensures that our fundraising practices and reputation are maintained at the highest level. We strive to be an approachable and professional organisation and thus, free membership to the Society includes opt-ins for contact with us and withdrawal from such consent can be easily requested by contacting us at info@sicklecellsociety.org.

We have a Fundraising Working Group that includes Trustee representation and reports on fundraising performance, policy and practice matters to the Board of Trustees. We believe this level of governance allows us to oversee compliance with the regulatory standards. We monitor our fundraising practices closely and can report that we have not received complaints in this regard during the last financial year. As a charity, we are committed to outstanding fundraising conduct and, we have amply achieved this aim.

Thank you from the bottom of our hearts for your committed support.

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.

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: 30/09/24

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 2024 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 2024 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.

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:

- 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

17 October 2024

15 Westferry Circus
Canary Wharf
London E14 4HD

The Sickle Cell Society
Statement of financial activities

for the year ended 31 March 2024
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2024 £	Total Funds 2023 £
Income:					
Voluntary Income	3	674,626	301,527	976,153	768,635
Investment income	4	16,346	-	16,346	4,962
Total income		690,972	301,527	992,499	773,597
Expenditure					
Costs of raising funds					
Fundraising costs	5	145,562	11,485	157,047	202,782
Charitable activities	5				
Campaign		138,101	102,380	240,481	201,403
Direct services group		114,295	71,940	186,235	114,128
Provision of information and advice		43,639	63,398	107,037	81,314
Children's Activities & Holiday		13,291	23,054	36,345	44,561
Total expenditure	5	454,888	272,257	727,145	644,188
Net income for the year before transfers		236,084	29,270	265,354	129,409
Transfer between funds		(100,419)	100,419	-	-
Net movement of funds in year		135,665	129,689	265,354	129,409
Reconciliation of funds					
Total funds brought forward	14	661,683	216,791	878,474	749,065
Total funds carried forward	14	797,348	346,480	1,143,828	878,474

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 27 to 40 form part of these financial statements.

The Sickle Cell Society

Balance sheet
at 31 March 2024

Company number 2840865	Note	2024 £	2024 £	2023 £	2023 £
Tangible fixed assets					
Tangible assets	9		154,894		180,800
Current assets					
Debtors and prepayments	10	176,913		158,406	
Cash and cash equivalents	12	1,028,962		706,464	
		1,205,875		864,870	
Creditors - amounts falling due within one year					
Creditors	13	216,941		167,196	
Net current assets			988,934		697,674
Total assets less current liabilities			1,143,828		878,474
Represented by:					
Unrestricted funds	14		788,315		652,650
Designated Funds			9,033		9,033
Restricted funds	14		346,480		216,791
			1,143,828		878,474

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 30/09/24 and signed on its behalf by:

Trustee

Michele Salter

Trustee

Julia McLarty

The notes on pages 27 to 40 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows
for the year ended 31 March 2024

	Note	2024 £	2024 £	2023 £	2023 £
Cash generated in operating activities	19		315,508		11,545
Cash flows from investing activities					
Interest income		16,346		4,962	
Payments to acquire tangible fixed assets		(9,356)		(740)	
Net cash from investing activities			6,990		4,222
Increase in cash and cash equivalents in the year			322,498		15,767
Cash and cash equivalents at the beginning of the year	12		706,464		690,697
Cash and cash equivalents at the end of the year	12		1,028,962		706,464

The notes on pages 27 to 40 form part of these financial statements.

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. 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.

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 residential 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.

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 2024 £	Unrestricted £	Restricted £	Total 2023 £
Donations and legacies	493,768	-	493,768	482,791	-	482,791
Grants	-	301,527	301,527	-	136,963	136,963
Capital Income						
NCIL – Brent	-	-	-	-	23,965	23,965
Contract Income	180,858	-	180,858	124,916	-	124,916
	674,626	301,527	976,153	607,707	160,928	768,635

4 Investment income

	Unrestricted 2024 £	Unrestricted 2023 £
Bank and COIF deposit interest	16,346	4,962

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2024 £	Total 2023 £
Costs of raising funds					
Fundraising costs	57,786	41,829	57,432	157,047	202,782
Charitable activities					
Campaign	32,840	119,698	87,943	240,481	201,403
Direct services group	78,833	39,297	68,105	186,235	114,128
Provision of information and advice	14,011	53,883	39,143	107,037	81,314
Children's Activities & Family Retreat	23,054	-	13,291	36,345	44,561
Total expenditure	206,524	254,707	265,914	727,145	644,188

Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2024 £	Total 2023 £
Charitable activities						
Fundraising costs	14,092	17,961	22,008	3,371	57,432	80,947
Campaign	21,578	27,503	33,700	5,162	87,943	80,397
Direct services group	16,711	21,299	26,098	3,997	68,105	45,558
Provision of information and advice	9,604	12,242	15,000	2,297	39,143	32,459
Children's Activities & Holiday	3,261	4,157	5,093	780	13,291	17,788
Total support costs	65,246	83,162	101,899	15,607	265,914	257,150

Total expenditure in the year to 31 March 2024 was £727,145 (2023: £644,188) of which £454,888 (2023: £456,627) was unrestricted and £272,257 (2023: £187,561) was restricted.

6 Staff cost and numbers

	2024 £	2023 £
Wages and salaries	311,664	260,334
Social security	27,103	24,022
Pension	17,839	16,765
	356,606	301,121

The average number of employees during the year was 13 (2023:11).

No employee earned more than £60,000 per annum (2023: None).

No remuneration has been paid to the Trustees other than reimbursement for travel and accommodation to 3 trustees (£1,099), membership cost to Association of Chairs membership (£60), and DBS check and Refreshment for meetings (£167) totalling £1,326 (2023: £1,853).

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 £55,283 salary and £5,799 NI, total - £61,082 (2023: £50,592).

7 Net Income for the year

	2024 £	2023 £
Is stated after charging:		
Depreciation on owned assets	35,262	35,054
Auditors' remuneration (including VAT):		
- Audit fees	11,970	11,231
Equipment rental	-	5,637
Property Lease/Rent – 56 Station Road	9,600	9,600

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.

9 Tangible Fixed Assets

	Leasehold Improvements	Furniture & Equipment	Total
	£	£	£
Cost			
At beginning of year	200,772	68,991	269,763
Additions	-	9,356	9,356
Disposals		(19,880)	(19,880)
At end of the year	200,772	58,467	259,239
At beginning of year	36,372	52,591	88,963
Charge for the year	27,279	7,983	35,262
Disposal	-	(19,880)	(19,880)
At end of the year	63,651	40,694	104,345
Net Book Value			
As at 31 March 2024	137,121	17,773	154,894
As at 31 March 2023	164,400	16,400	180,800

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

10 Debtors

	2024 £	2023 £
Grants and Legacies receivable (note 11)	164,689	144,819
Prepayments	12,224	13,587
	176,913	158,406

11 Grants & Legacies receivable

	2024 £	2023 £
Mentoring Project	56,949	-
Public Health England (PHE)	-	20,819
Genomics England	-	74,000
Legacies	107,740	50,000
	164,689	144,819

12 Cash and cash equivalents

	2024 £	2023 £
Cash in hand	15	338
NatWest Reserve Account	867,363	548,922
NatWest Current Account	100	100
COIF Charities Deposit Fund	160,650	153,202
Paypal	834	3,902
	1,028,962	706,464

13a Creditors - amounts falling due within one year

	2024 £	2023 £
Trade creditors	74,074	70,262
Accruals and deferred income	142,867	96,934
	216,941	167,196

13b Deferred Income Reconciliation

	2024 £	2023 £
Balance as at 1 April	27,995	53,952
Amount Released to Income	(27,995)	(53,952)
Amount Deferred in the year	92,249	27,995
Balance as at 31 March	92,249	27,995

14 Analysis of charitable funds

	Balance 1 April 2023	Movement in funds			Balance 31 March 2024
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Family Retreat / Children Holiday scheme	-	23,941	23,054	-	887
Jeans for Genes	-	3,000	15,287	12,287	-
Research	45,227	1,000	-	-	46,227
Helpline Worker	-	-	48,111	48,111	-
CLAHRC	2,995	-	-	-	2,995
APPG for Sickle Cell & Thalassaemia	-	14,000	27,224	13,224	-
Refurbishment Income	23,365	-	4,348	4,348	23,365
NHS England	2,500	-	-	-	2,500
Mentoring Programme	-	137,697	72,228	-	65,469
Give Blood Spread Love	-	21,849	44,298	22,449	-
Nursing Workforce	-	20,000	20,000	-	-
Public Awareness Campaign – Priapism	68,704	-	300	-	68,404
Genomics England	74,000	-	17,407	-	56,593
Northwest England Children & Young People Peer Mentoring Project	-	80,040	-	-	80,040
Restricted funds	216,791	301,527	272,257	100,419	346,480
Unrestricted funds	652,650	690,972	454,888	(100,419)	788,315
General fund					
Designated Funds	9,033	-	-	-	9,033
Total funds	878,474	992,499	727,145	-	1,143,828

Designated funds currently stand at £9,033 no fund was released in 2023-24 financial year.

14 Analysis of charitable funds *(continued)*

Analysis of charitable funds – previous year

	Balance 1 April 2022	Movement in funds			Balance 31 March 2023
		Income	Expenditure	Transfers	
	£	£	£	£	£
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
Heritage Lottery fund	-		-	-	2,500
NHS England	2,500	-	-	-	-
Digital Marketing – Blood Donation	-	-	-	-	-
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

14 Analysis of charitable funds *(continued)*

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

Annual Children's Holiday scheme/Family Retreat
On a yearly basis The Sickle Cell Society carried out a Children's holiday for young people with Sickle Cell, for the three years over the pandemic the holiday was held virtually. During the virtual holiday there was immense value in including parents and siblings in the experience. In 2023 the Sickle Cell Family Retreat was born. The Society carried out the first Family Retreat with a group of families with at least 1 child with Sickle Cell at the Pioneer Centre. £23,941 was received in 2023/24 towards this project.

Jeans for Genes Campaign
£3,000 received during 2023-24 financial to support the Volunteering Programme.

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.

Helpline Worker
To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families. A transfer of £48,111 was made from the unrestricted funds in 2023/234 to carry out this service.

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.

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)
The SCTAPPG Project has continued to provide the secretariat of the SCTAPPG. Two restricted grants of £14,000 were awarded by Novartis - £8,000 and Vertex - £6,000 respectively. £13,224 was transferred from the unrestricted to help carry out this service.

Office Refurbishment
Phase 1 of the Sickle Cell Society Headquarters refurbishment has now been completed. We are currently seeking funding towards Phase 2 work.

Mentoring Project
Young Person's Mentoring Scheme aims to improve the health and wellbeing of young people living With sickle disorder which started with North East London ICB (NEL). The Society is pleased that we now have all the other 4 regions on board North West London (NWL), North Central London (NCL), South West London (SWL) and South East London a total of £137,697 was received during 2023/24 to carry out this service.

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.

14 Analysis of charitable funds *(continued)*

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.

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.

Genomics England
We have secured funding from Genomics England to appoint a new SCS/Genomics England Partnership role for 18 months, six months of which has already been completed. We plan to deliver a priority setting exercise for future genomics research into Sickle Cell Disorder.

Nursing Workforce
Sickle cell services have faced decades of underfunding and under-prioritisation, as outlined in the No One's Listening report published by the Sickle Cell Society and the All-Party Parliamentary Group on Sickle Cell and Thalassaemia in 2021. This is reflected in the challenges facing the specialist sickle cell nursing workforce. This research project set out to capture the wide ranging role specialist sickle cell nurses perform, gain a more detailed understanding of the current level of specialist sickle cell nurse staffing, the impact this has on patients and clinicians, the reasons behind the workforce shortage, and what needs to happen to ensure there are sufficient numbers of specialist nurses to deliver a good standard of care to people with sickle cell disorder.

Children and Young Person Peer Mentoring Team
Children and Young People Peer Mentoring Scheme is a pilot scheme aim to improve health and wellbeing of children and young people in Northwest England - Manchester, Liverpool and Sheffield. £80,040 was received during 2023/24, however, we estimate the start date of this new project in the first quarter of next financial year.

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

Community & Challenge Event Fundraising (Just Giving)	55,827
Community & Challenge Event Fundraising (Blackbaud)	37,245
Imst.Cem.Crem.MGNT	26,000
Hoare & Co Bank	19,708
Leicester City Council - Lord Mayor	12,124
Bloomberg LP	12,008
Vitol Foundation	11,815
Capital Group Comp	9,500
Community Event Fundraising (CAF - ONLINE)	8,945
Enthuse.com	8,391
Cooley UK LLP	7,828
C.E.X Limited	7,598
Charitable Giving (inc Amazon Grant)	7,461
Facebook	6,161
Paypal	5,595
Metro Bank PLC	5,500
EMIL KUMAR EMIL KUMAR	5,202
Trees Cazenove Charitable Trust	5,000
Legacy of Ms Mavis Mills	5,000
UK Online Giving	4,178
The Oyster PTSHPL	3,354
West Cliff High School	3,221
HMP Frankland and Prison Services Charity Fund	2,000
Charities Trust	1,728
Citi Bank RE FIN UK Online Giving F	1,722
Amazon Core	1,595
Saracen's event - Tracy Collection	1,538
Lodge (The Grand Charity)	1,500
Mrs F B Laurence Charitable Trust	1,500
Event in memory of MC Skibadee	1,500
Beths Grammar School	1,411
E Cornelius EMC - Fundraising Event	1,240
Hurtwood House School	1,200
Memorial Tribute Fundraising (Much Loved)	1,198
Siemens Finance Ltd	1,064
Windrush Foundation - Aurthur Torrington (Colin Graham)	1,000
Toronto Dominion	1,000
Reynolds Porter	1,000
Tinu Williamson-Taylor	1,000
The Dewan Foundation Limited	1,000
First Give the Quest Academy	1,000
New Church of God	1,000
Veolia ES Southw ARK	812
Terumo BCT	667

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

Valero Energy Ltd	600
B A Leslie	600
In Memory of Lucreta La Pierre	550
The GDST-Bromley High School	539
Norbury School & Nursery	538
HMP Whitemoor	525
Elthorne Park High School	514
Winchmore School	509
Hartley Taylor - Dr R Kesse-Adu	500
Elite Golden Ladies Women UK	500
All Saints Catholic School	500
The Nile Valley Lodge NO 6306	500
Najeebullah Habibi	500

16 Analysis of net assets between funds

	Unrestricted	Restricted	2024 Total Funds
	£	£	£
Tangible assets	154,894	-	154,894
Current assets	859,395	346,480	1,205,875
Current liabilities	(216,941)	-	(216,941)
Net assets	797,348	346,480	1,143,828

Analysis of net assets between funds – previous year

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

17 Transfer between funds

During the year the Trustees agreed transfers of £100,419 (2023: £95,171) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding. Transfers were Jeans for Genes – Volunteer Project, Helpline Services, APPG for Sickle Cell & Thalassaemia Project, Refurbishment Project and Give Blood Spread Love & Digital Marketing Projects. See note 14 for further breakdown.

18 Leasing commitments

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

	2024 £	2023 £
Commitments expiring:		
Within 1 year	15,152	14,268
Within 2 to 5 years	16,096	42,583
	31,248	57,051

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

	2024 £	2023 £
Net Movements in Funds	265,354	129,409
Depreciation	35,262	35,054
Interest income	(16,346)	(4,962)
(Increase)/Decrease in debtors	(18,507)	(113,500)
(Increase)/Decrease in creditors	49,745	(34,456)
Net cash generated from operating activities	315,508	11,545

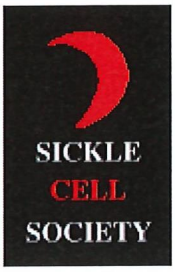
20 Related party transactions

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

THE SICKLE CELL SOCIETY

England & Wales - Charity number 1046631

Accounts



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 – From 01 April 2022
	Ms Michele Salter	Treasurer
	Ms Carol Burt	
	Dr Josephine Ruwende	To 10 September 2022
	Ms Sheree Hall	To 10 September 2022
	Mr Ganesh Sathyamoorthy	
	Mr Shubby Osoba	
	Mr Nathan Fordwor-Hepburn	
	Ms Lisett Brown	From 10 September 2022
	Ms Zainab Garba-Sani	From 10 September 2022
	R Kilali Ominu- Evbota	From 10 September 2022
	Ms Claudette Allerdyce	From 10 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	Animation Project Co-ordinator – To April 2022
Mr Juan Carlos Valero	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	Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust Professor Dame Sally Davies Rector Cambridge University Cambridge Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London Professor Bernadette Modell Emeritus Professor, UCL, London Professor David Rees Consultant Haematologist Kings College Hospital, London Dr Allison Streetley Consultant in Public Health Public Health England Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital

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 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

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-mailnewsletters, social media and communication activities
   - Patient and carer dducation 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. 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.

Board development

The Board of 9 Trustees, excluding vacant positions, has 3 members with sickle cell disorder and 5 Trustees are also carers for family members with sickle cell. The Board undertook board development training during

Board development (continued)

2022/2023, jointly with the staff team of the Society. 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.

This year we witnessed significant changes in leadership on the Board of Trustees. We bid farewell to our outgoing Chair, who has been an invaluable asset to our team, contributing greatly to our progress and success. We extend our gratitude for the dedicated service and the incredible impact Kye Gbangbola made.

At the same time, 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, we were able to roll it 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 person with SCD who underwent a successful stem cell transplant. 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.

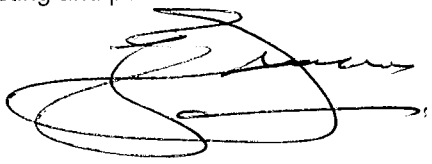
Looking ahead to the next year, we remain committed to our strategic ambitions for the sickle cell community. Our work is driven by our dedication to you and our shared vision of progress and support. While we anticipate challenges stemming from the cost of living crisis, we also embrace the positive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

SUMMARY REVIEW OF 2022/23 (continued)

(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 Disease 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 BT (NHS Blood and Transplant Clinical Trials Unit), UCL (University College London), 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.

MEMBERSHIP & SUPPORT GROUP BASE

The Sickle Cell Society has maintained its free membership policy and the membership gained in FY 22/23 stands at 413 for a total of 2932.

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 Officer 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 1444 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 ickle 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.

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 video 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 conversation 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 majority of these have been done virtually, to adhere to government guidelines.

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.

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).

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.

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

CHILDREN'S HOLIDAY (Continued)

"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

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.

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, will be 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.

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
- 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.

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 2640 people. These events included successful partnerships with Leicestershire Police, Morrisons, 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.

GIVE BLOOD SPREAD LOVE (Continued)

featuring influential community figures. 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 education materials that can be used by parents and adult men as well as healthcare professionals during the new financial year 2023/2024.

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 support the work of the SCS. This is an incredible achievement and a substantial increase from the over £5000 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 income for this financial year is £124,916.

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

During the process of creating our strategy we experienced a global pandemic in the form of Covid-19. We will therefore be revisiting our new three-year strategy having regard to the global impact of the 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
13/11/2023

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).

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.

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: 13/11/2023

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 2023which 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.

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:

- 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

12 December 2023

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	5				
Campaign		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 13/11/2023 and signed on its behalf by:

Trustee

Michele Salter

Trustee

Ganesh Sathyamoorthy

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 pages30 to 44 form part of these financial statements.

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.

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 residential 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.

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	-	-	-	-	-	-
	607,707	160,928	768,635	576,399	295,228	871,627

4 Investment income

	Unrestricted 2023 £	Unrestricted 2022 £
Bank and COIF deposit interest	4,962	115

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.

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
	301,121	351,701

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

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.

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)
At end of the year	200,772	68,991	269,763
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)
At end of the year	36,372	52,591	88,963
Net Book Value			
AS at 31 March 2023	**164,400**	**16,400**	**180,800**
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
	158,406	44,906

11 Grants & Legacy receivable

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

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
	706,464	690,697

13a Creditors - amounts falling due within one year

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

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
Balance as at 31 March	27,995	53,952

14 Analysis of charitable funds

	Balance 1 April 2022	Movement in funds			Balance 31 March 2023
		Income	Expenditure	Transfers	
	£	£	£	£	£
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.

14 Analysis of charitable funds *(continued)*

Analysis of charitable funds – previous year

	Balance 1 April 2021	Movement in funds				Balance 31 March 2022
		Income	Expenditure	Transfers	Fixed Asset Funding Transfer	
	£	£	£	£	£	£
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	-	51,057	49,330	-	-	1,727
Public Awareness Campaign – Priapism	-	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

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.

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.

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

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)
Net assets	661,683	216,791	878,474

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)
Net assets	600,812	148,253	749,065

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.

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
	57,051	35,458

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)
Net cash generated from operating activities	11,545	276,462

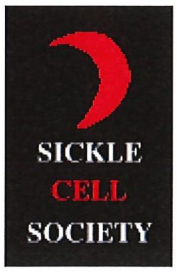
20 Related party transactions

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

THE SICKLE CELL SOCIETY

England & Wales - Charity number 1046631

Accounts



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 2022

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2022

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The Sickle Cell Society

Company information
for the year ended 31 March 2022

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	Mr Kye Gbangbola	Chair
	Ms Michele Salter	Vice Chair and Treasurer
	Ms Joy Adeyemo	To September 2021
	Ms Carol Burt	
	Dr Josephine Ruwende	
	Ms Sheree Hall	
	Mr Philip Udeh	To September 2021
	Mr Ganesh Sathyamoorthy	
	Mr Shubby Osoba	From September 2021
	Mr Nathan Fordwor-Hepburn	From September 2021
Staff	Mr John James OBE	Chief Executive
	Ms Iyamide Thomas	NHS Engagement Lead
	Ms Miriam Williams	Finance & administrative Manager
	Ms Ainhoa Munoz	Fundraising Officer – To August 2021
	Mr Matthew Neal	Communications and Social Media Officer
	Mr Adam Lloyd	Parliamentary Officer for SCTAPPG – To April 2021
	Ms Tracy Williams	Give Blood Spread Love Project Officer
	Ms Alinta Sara	Research & Education Co-ordinator - To July 2021
	Ms Valerie Oldfield	Helpline & Information Officer – To March 2022
	Ms Taja Morgan	Children's Activities Leader
	Ms Layla Lawson	Hackney Engagement Project Officer - To April 2021
	Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation
	Ms Sheri Ponle	Helpline & Information Office
	Ms Micaela Valero	Fundraising Data Processor / Administrator – To October 2021
	Oluwaseyi Afolabi	Parliamentary Officer for SCTAPPG – From July 2021
	Sandra Reyes-Hayduk	Fundraising Manager – From October 2021

Deborah Armantrading	Fundraising & Volunteer Development Lead – From November 2021
Charles Agbede	Animation Project Co-ordinator – From December 2021

The Sickle Cell Society

Company information
for the year ended 31 March 2022 *(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	Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust Professor Dame Sally Davies Rector Cambridge University Cambridge Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London Professor Bernadette Modell Emeritus Professor, UCL, London Professor David Rees Consultant Haematologist Kings College Hospital, London Dr Allison Streetley Consultant in Public Health Public Health England Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital

Scientific advisors	Dr Mary Petrou Director, Perinatal Centre University London Hospital, London Professor Simon Dyson (Retired) De Montfort University, Leicester 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 Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2022 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 is an inherited blood disorder, 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. For an individual with a sickle cell disorder when the red blood cell gives up too much oxygen it loses its flexibility and uniform roundness adopting a sickle shape (sickling). This makes the cell difficult to pass through the blood vessels and creates blockages.

When these blockages occur, they cause a great deal of pain, 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. Anaemia occurs due to excessive breakdown of red blood cells from frequent sickling. Management of painful crisis can range from home treatment with mild pain killers to hospital attendance for the administration of powerful drugs.

Over time, people living with sickle cell 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 this client group experience disability. There is no easy cure, and despite the progress made with bone marrow transplants for children, death is sometimes a further consequence of these complications.

Sickle cell 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) - source: NHS Sickle Cell and Thalassaemia (SCT) Screening Programme Data Report 2019 to 2020. Despite improvements in NHS specialised services and clinical care, poor service support, awareness and understanding of sickle cell remain long standing issues which have 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 new born 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 new born 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. The Society was later established under a Memorandum of Association with the objects and powers of a charitable company and is governed under its 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.

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 and DVDs and CDs Conferences, seminars, workshops and partnership networking
   - Website, e-mail services, 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. 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.

Board development

The Board of 8 Trustees, excluding vacant positions, has 4 members with sickle cell disorder and 2 Trustees are also carers for family members with sickle cell. The Board undertook board development training during

Board development (continued)

2021/2022, jointly with the staff team of the Society. 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 2021/22

We were very pleased and somewhat relieved that we successfully navigated through the unprecedented challenges of the financial year 2021/2022. The impact of the Covid19 pandemic has affected all of our lives. It has also affected our charity, the charity sector as a whole in addition to its global impacts. We take this opportunity to express our sadness at the dreadful loss of life of family and friends in the sickle cell community and more generally, worldwide.

We know the government's strategy is one of learning to live with Covid19 but we urge caution and care as we move towards a new normal because Covid19 remains with us.

As ever, despite the challenges, we have continued throughout the year to work hard as an organisation to continue to support the sickle cell community. We hope this annual report will show you the wide range of achievements and initiatives we have secured towards making a positive difference to the lives of sickle cell warriors and their families.

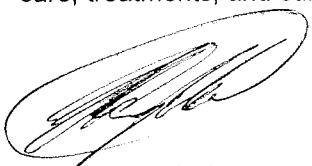
There are many good examples of positive work such as our Give Love Spread Love blood donation campaign, our collaboration with Public Health England on the national sickle cell and thalassaemia screening programme, our exciting programme of activities for young people with sickle cell and of course our annual children's holiday. These are covered in more depth in this report.

However, we wanted to particularly highlight the important work and Inquiry of the Sickle Cell and Thalassaemia All Party Parliamentary Group and its excellent report 'No One's Listening', which was published in November 2021. In our 2020/2021 summary we mentioned the untimely deaths of Nathan Evan Smith and Richard Okorogheye. The All Party Parliamentary Group's report was in part to address the cycle of avoidable deaths and secure improvements in health experience and outcomes at a national level.

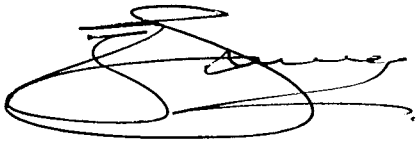
We thank the sickle cell warriors from every part of the country and their families, health care professionals and our stakeholder partners who gave compelling evidence to the Inquiry.

The All Party Parliamentary Group's report and recommendations are already making an impact for long needed change across the NHS, but there is still plenty to do

Finally, as Chair (Kye Gbangbola) of the Sickle Cell Society for the last 9 years, I have stepped down from 31 March 2022. This will therefore be my last Annual report summary. I would like to take this opportunity to say 'It has been both an honour and a pleasure to serve my fellow sickle cell warriors. Great things are never done by one person but by a team, I am proud to be leaving the Society in much better shape than I found it. May I take this opportunity to wish our volunteers, staff, and trustees all strength to keep punching above their weight. God willing, I shall continue to walk alongside the Society, securing better quality health care, treatments, and cures for the health and wellbeing of us all.'



Kye Gbangbola
Chair



John James OBE
Chief Executive

KEY HIGHLIGHTS FROM THE YEAR 2021/2022

STAKEHOLDER RELATIONSHIPS

Stakeholder relationships are a key part of the Society's work, connecting our work with national 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 Disease UK, Genetic Alliance, the Anthony Nolan Trust and 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; Public Health England; 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 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 BT (NHS Blood and Transplant Clinical Trials Unit), UCL (University College London), 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.

MEMBERSHIP & SUPPORT GROUP BASE

The Sickle Cell Society has maintained its free membership policy and the current membership stands at almost 2,519.

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 Officer 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 significant increase in social media followings.

- The Society's Instagram (@sicklecelluk) gained over 1800 followers.
- The Society's Twitter (@SickleCellUK) gained over 800 followers.
- The Society's Facebook (Sickle Cell Society UK) gained over 500 followers.
- The Society's LinkedIn (Sickle Cell Society) gained over 400 followers.

The Sickle Cell Society website received, on average, 33,000 views per month.
On average, 8500, of those views per month were specifically viewed for our Coronavirus (COVID-19) & Sickle Cell Disorder page.

HELPLINE AND INFORMATION SERVICE

By Telephone

The Society received 696 telephone calls from April 2021 to March 2022. This is a significant increase from the previous financial year of 224 telephone calls. We believe this increase was mainly due to the Covid19 pandemic and associated requests for advice and assistance.

By Email

As part of the helpline service we also responded to emails. The Society received a total of 1428 emails during April 2021 to March 2022. This is also an increase from the previous year of 1004 emails. We believe the impact of the Covid19 pandemic as well as our web based online Contact Us Automated FAQ and Form Processing facility, contributed to this increase.

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 video 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 conversation around sickle cell.

EDUCATION / INFORMATION AND AWARENESS (continued)

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 majority of these have been done virtually, to adhere to government guidelines.

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.

CORONAVIRUS (COVID-19) & SICKLE CELL DISORDER

Coronavirus (COVID-19) has had a huge impact on the sickle cell community, particularly in relation to mental health and well-being. We constantly updated our dedicated page on our website to provide the latest information and guidance, specific to sickle cell and COVID-19. The page received, on average, 8500, views per month. As well as detailing national guidelines, the website contained up-to-date data from the National Haemoglobinopathy Panel (NHP), and guidance developed by our medical advisors.

We also held two specific webinars on Covid19 vaccination. One was hosted by our Medical Adviser, Rachel – Kesse-Adu, and included patients who had had a vaccine as well as patients who were seeking more advice and information before making any decision. The second vaccine webinar took place in November 2021 and was attended by Professor Adam Finn from the national Joint Committee on Vaccinations and Immunisations (JCVI) as well as Professor David Rees; Medical Adviser to the Society. The purpose of this second webinar was to address with the latest available evidence, the continued anxiety and hesitancy about Covid vaccinations for adults and the booster vaccine for children and young people with sickle cell aged 12-16 years of age. Questions were received from patients in advance of the webinar and a wide range of questions were also taken at the live Q&A session of the webinar.

WORK ON BEHALF OF THE NHS SCREENING PROGRAMME

From 1 April 2021 to 31 March 2022 the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) continued working on the collaborative project with the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) which they officially commissioned from the Societies in August 2018. Despite the continued COVID-19 pandemic, the project team were still able to successfully deliver the project objectives for antenatal and new-born screening in England virtually and as safely as possible.

Key Project Achievements:

- SCS conducted three online focus group discussions with a total of 20 individuals (mothers, fathers and non-parents) who gave valuable user perspective on how they would like the Screening Programme to communicate new born sickle cell carrier or positive (i.e. baby has the condition) results.

- The SCS gave key input to the revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway, including recording a video describing how we work collaboratively and help the Programme address any inequalities.

- The SCS presented its work at three training sessions the NHS SCT Screening Programme conducted for nurses, midwives, and health visitors in the North of England.

- Raised awareness of sickle cell and screening by: public talks online (5) newsletter articles (3), Newspaper interview (1), TV interview (1) Workshops (5) Webinars /Conferences (3),

- Outreach using our specially designed social media screening graphics for World Sickle Cell Day, International New Born Screening Day and Rare Disease Day.

- Raised awareness of screening as part of a virtual 2021 advent calendar of Dawn Butler MP

CHILDREN'S ACTIVITIES

From 1st April 2021 to 31st March 2022 we have continued to successfully deliver virtual children's activities for young people with Sickle Cell. Although we have been running these events virtually, that hasn't stopped our young people from having fun and meeting new peers. We have also been able to reach children internationally because of the virtual nature of our activities.

The activities we have ran included:
Arts and Crafts
Meditation
Confidence building workshop
Comedy show
Quiz Night
African Dancing and Singing
Family Empowerment
Theatre show
Animal Workshop
Baking
Songwriting
Wellbeing workshop
Money management workshop

We have continued with our monthly parent talks, which parents have found very beneficial.

Feedback from families include:
- Thank you for organising these talks.
- Thoroughly enjoyed this workshop again.
- Thanks to the organisers.
- God bless you for your time and input.
- Keep the discussions coming it is so helpful. Thank you
- Thank you for putting these sessions on and all the work you do for those living with the conditions
- Thank you for such a valuable, enjoyable event. I really like the fact that these sessions are on zoom as an in person session will mean that some children cannot access it due to weather, health, transport, siblings etc. It is really useful that these sessions are run virtually.

CHILDREN'S HOLIDAY

The virtual holiday in 2021 took place from the evening of Friday 13th August to the evening of Sunday 15th August. 52 families took part, including 59 children with Sickle Cell, 58 siblings and 69 parents. We had 21 volunteers helping (8 with sickle cell, 8 doctors/nurses, 2 siblings of people with sickle cell, 1 parent of a child with sickle cell - the rest with no direct link to the condition)
We had 15 workshop practitioners and 1 BSL Interpreter.

In 2021, we ran 3 different timetables, differentiated by age group - Bears for 4-8 year olds, Tigers for 9-12 year olds and Lions for 12-17 year olds as well as a programme for parents. The activities provided for each age group were designed especially for them and included (to name a few): Cabin Chat and Games, Sickle Cell Information Sessions, Animal Magic with Exotic Explorers, Songs and Stories with Little Crowns Storyhouse, Indoor Gardening, Website Whizz Up, SCS Bake Off, Storytelling with Kwame and so much more.

Every family also received an activity and equipment box to enable them to take part in some of the workshops, including some self-led screen free activities.

We made sure we had a balance of genders within the activity providers and volunteers to ensure that there were a number of positive male role models for the kids. We also made sure to employ black and brown owned businesses, or those with a link to sickle cell, wherever possible, for both activity provision and activity equipment.

CHILDREN'S HOLIDAY (continued)

The children on the whole had a wonderful time. As they told us, the holiday made them feel 'part of something' and 'not alone' - but also, simply, 'happy'! The favourite part of the holiday, reported across the board, was meeting other children with sickle cell 'like them'.

PARLIAMENTARY & POLICY WORK

The Sickle Cell & Thalassemia APPG

The Society has continued working closely with the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG) through our work as secretariat and with our Parliamentary & Policy Officer. The SCTAPPG aims to raise awareness and prioritise sickle cell disorder and other haemoglobin disorders on the political platform. Accountability is achieved through the SCTAPPG's Chair, Pat Mc Fadden MP and the Deputy Chair, Janet Daby MP.

During the year 2021/2022, two restricted grants were awarded by Novartis and BlueBird Bio totally £20,000. A key shift in the funding for the project has been the announcement of Blue Bird Bio that they will be ending their operations in Europe. As a consequence, the previous £10,000 funding from Blue Bird Bio is no longer available.

The key functions of the SCTAPPG parliamentary work:

- Organise and execute four SCTAPPG meetings a year, plus one Annual General Meeting
- 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

No One's Listening Report

The ground breaking inquiry, led by Rt Hon Pat McFadden MP, Chair of the APPG on Sickle Cell and Thalassaemia, concluded in autumn 2021. The inquiry was held to get a nationwide picture of sickle cell care in the UK, with both writer and oral submissions received from patients. Clinicians, researchers and other key individuals. The inquiry found serious care failings in acute services for sickle cell and evidence of healthcare workers' attitudes largely underpinned by racism.

The 'No One's Listening' report, which was based on the inquiry's findings, highlighted evidence of sub-standard care for sickle cell patients admitted to general wards or attending Accident & Emergency (A&E) departments (including a widespread lack of adherence to national care standards), low awareness of sickle cell among healthcare professionals and clear examples of inadequate training and insufficient investment in sickle cell care. The inquiry also found that these concerns have led to a fear and avoidance of hospitals for many people living with sickle cell.

PARLIAMENTARY WORK (continued)

While the inquiry did find that specialist haemoglobinopathy services are generally felt to be of a good standard, the report shows that this is far from the case on general wards or A&E departments. Care failings have led to patient deaths and 'near misses' are not uncommon. The inquiry heard that awareness of sickle cell among healthcare professionals is low, with sickle cell patients regularly having to educate healthcare professionals about the basics of their condition at times of significant pain and distress and that there is routine failure to comply with national care standards around pain relief when patients attend A&E.

Among the most notable of cases reviewed by the APPG was the tragic death of sickle cell patient Evan Nathan Smith in North Middlesex University Hospital in April 2019, which received renewed focus following the publication of the coroner's inquest in April 2021. The inquest found that Evan's death would not have happened were it not for failures in the care he received. The report highlighted that high-profile cases of failings like these are sadly not isolated incidents and sickle cell patients all too often receive sub-standard care.

The 'No One's Listening Report' hopes to be a watershed moment for the care of Sickle Cell patients in the UK. Although none of the report's findings are new to Sickle Cell patients or their families, the report is an urgent call to action to various parts of our healthcare system and related entities. Whilst the SCTAPPG have celebrated positive responses to the report's release, including a Westminster Hall Debate in Parliament, The NHS Royal Health Observatory's appointment of a clinician to lead work on race and Sickle Cell and a meeting with the Secretary of State for Health and Social Care – there remains a vast amount of work still to be done to ensure the implementation of the report's recommendations.

The report received excellent national media coverage, but the group have up till recently been made aware of a number of other Sickle Cell patient failures. This reinforces the importance of ensuring that the report and its recommendations do not remain 'on the shelf' but become tangible, lived improvements for the day to day lives of those with Sickle Cell. This speaks directly to what the next year of the SCTAPPG's activities will look like.

SCTAPPG & Key Policy Partners

- Vulnerable Groups to the Pandemic APPG
- Rare Diseases APPG
- Transplantation APPG
- Genetic Alliance APPG
- Thalassemia 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.

GIVE BLOOD, SPREAD LOVE, ENGLAND

Give Blood, Spread Love, England (GBSLE) engages people with Black African/Caribbean heritage on the topic of blood donation. We aim to increase the amount of ethnically matched blood available to treat people with sickle cell. There is a significant shortfall in the amount of ethnically matched being collected by the blood donation service for England, NHSBT, whose figures show that only 50% of the demand for the Ro subtype, commonly needed for sickle cell patients, is currently being met. GBSLE engages with our target communities via a range of outreach events and online engagement where we raise awareness of the need for more Black and Mixed donors, tackle the complex fears and myths that exist around blood donation, and sign people up to the blood donation register. This is the third year that the Society has delivered a programme of work on blood donation awareness.

Our achievements in 2021/2022 include:

Face-to-face events: As Covid-19 restrictions lessened in the second quarter of the year, we were able to return to in-person engagement activities. We attended 9 events and spoke with over 500 people. Part of this work included holding a successful joint event with one of our corporate partners, PwC.

Online events: We took part in online events attended by 997 people. These events were most frequently staff awareness/ training days organised by NHS Foundation Trusts, Local Authorities, and corporate organisations where we were invited or negotiated our participation.

Social media: Our social media channels continued to develop their reach, and we have 1349 followers on our Instagram account, @givebloodspreadlove. The account features emotive and engaging personal testimonies, case studies and stories featuring our volunteers, social media influencers and celebrities, all of which support us to reach younger members of our target audiences and communicate our key messages.

Recruitment: We recruited 328 new blood donors, primarily through face-to-face engagement, and shared their information with NHSBT who agree to contact our new registrants and offer them an appointment to donate.

Online engagement resources: We developed 231 new resources including 4 promotional films that we shared across our digital media and sent directly to our partner organisations to support our awareness raising and recruitment activities.

Blood donation awareness sessions: We delivered 20 sessions to our partner organisations to develop their knowledge of blood donation, the need for ethnically matched blood and the best way to tackle the barriers that can prevent people from registering to donate.

Expert-led online workshops: We held 14 workshops including, 'How Exchange Blood Transfusions Saved My Life', 'Break the Stigma: Sickle Cell and Blood Donation', and 'Positive Action: How do you Encourage Others to Advocate for Change?' These sessions were attended by a range of clinicians; people affected by sickle cell; blood donors and blood recipients and those considering giving blood. These workshops have also had global reach, attracting participants from USA, Philippines, and Nigeria.

Media: GBSLE featured in **7** online media articles, **3** radio interviews, and **2** podcasts. 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.

Group blood donation: We have facilitated 6 group blood donation sessions attended by 39 people. These sessions have been organised with input from our volunteer team and our partner organisations.

GIVE BLOOD SPREAD LOVE

Volunteer support: We held 5 volunteer support sessions to enable our team to speak confidently about blood donation and the need for more Black African/Caribbean donors.
In total, via our events and social media, Give Blood, Spread Love, England reached over **9500** people directly, and over **66,000** indirectly, during this project year.

Example of feedback from our stakeholders:
"The sessions you have delivered for us have been brilliant and engaging." ***Black-led community organisation***
"Thank you for such an amazing session. Signing up to donate right now!" ***Event attendee***
"I love seeing Black and Mixed people give blood as it's so important for our community that we have blood types that match our own." ***Social media follower***
"*Being a volunteer with GBSLE has been a wonderful experience and will continue to be for me, and I wouldn't change it for the world."* ***GBSLE Volunteer***
"I would like to invite you to come on my show at least twice a year to continue to raise awareness." ***Radio presenter***

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 education materials that can be used by parents and adult men as well as healthcare professionals during the new financial year 2022/2023.

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 £137,624 from corporate supporters, such as Pharma and Trusts & Foundations during the year 2021/2022.

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

Black History Month – October 2021.

During Black History Month October 2021, and in the run up to it, SCS staff undertook at least 18 speaking engagements bringing the SCS message to various trusts and corporates.

As part of the relationship building carried out with Sainsbury's Supermarket, they offered to organise a book shipper (sale of selected BHM related books) in 200 stores across the country which raised £4,620.

The employees of Metro Bank carried out a raffle which raised £503.

CONTRACTS

The Sickle Cell Society continued contract work with Public Health England (PHE) during the financial year. We also received funding from Vertex Pharmaceuticals (Europe) Limited to support a fundraising event in July 2021 - Rise up for Sickle Cell.

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 income for this financial year is £124,916.

The Sickle Cell Society received £10,000 from Vertex Pharmaceuticals (Europe) Limited to support a fundraising event in July 2021 - Rise up for Sickle.

PLANS FOR THE FUTURE

The trustees and staff have worked together to create our new strategy for the next year to 31 March 2023. 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

During the process of creating our strategy we experienced a global pandemic in the form of Covid-19. We will therefore be revisiting our new three-year strategy having regard to the global impact of the 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

I am pleased that we have continued delivering for people who live with Sickle Cell Disorder (SCD) and their families during the financial year 2021/2022. It was another challenging year for the Society as we are still experiencing the impact of the Covid-19 pandemic, which has affected us all. Nevertheless, with commitment and dedication from our staff, our volunteers and great support from my trustee colleagues, we have continued to provide services (information, support and activities) to the sickle cell community on a virtual basis and now slowly moving towards face-to-face activities.

At the beginning of the financial year 2021/2022, we anticipated a deficit of £155,837 having regard to the impact of Covid and the ending of some grants. However, the Society ended the year with a surplus of £194,781. This favourable outcome is solely due to the capitalisation of the refurbishment cost of £200,772. Accounting standards (including the Charities SORP) require any asset whereby the use/benefit is going to be more than one year to be capitalised. As these works will provide a benefit for more than one year, the costs are capitalised and depreciated over the useful economic life (i.e. how long the expected benefit is estimated to last). The full construction cost will be depreciated over 10 years, or less where the leasehold premises is shorter. Excluding this adjustment for capital expenditure, the Society achieved a break-even position for revenue income and expenditure.

We are pleased to inform you that phase 1 of the refurbishment project has been completed with a new look to the ground floor of 54 & 56 Station Road. This benefits the many people who visit our offices, as well as providing modern facilities for our staff. A big thank you to Brent Neighbourhood Community Infrastructure Levy (NCIL), The Clothworkers Foundation and The Bernard Sunley Foundation, who contributed £69,264, £50,000 and £10,000 respectively, (a total of £129,264) during the financial year towards the refurbishment cost and made it possible to complete the work.

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.

We look forward to 2022/2023 and for your continued support.



Michele Salter
Treasurer & Vice-Chair

07/09/22

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. The Society's premises were in need of refurbishment to ensure they remain fit for purpose: phase 1 of the refurbishment was completed in November 2021.

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 £109,728 at 31 March 2022. This policy was met during the financial year to 31 March 2022, with year-end free reserves of £345,698 (2021 - £323,575), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2021/2022 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 £871,742 which is £82,241 higher than the previous year's results. This has been achieved from restricted grant payments of £295,228 and £576,514 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools, training and consultancy, gift aid and communities and contract services.

During the year the unrestricted funds incurred a net income of £137,600 (2020/21: net income of £273,214).

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 surplus before transfers of £57,181 (2020/21: deficit of £89,087). The total restricted reserves at the end of the year were £148,253 (2020/21: £217,482).

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

and 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 like to pride ourselves on being 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 which 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 has monitored our fundraising actions closely. 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 have produced a new three year 2020/2023 Fundraising strategy.

Charity Governance Code

Sickle Cell Society recognises that good governance in a charity is fundamental to its success. 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.

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

Kye Gbangbola
Chair

Date: 07/09/22

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 2022 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 2022 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.

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:

- 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

21 September 2022

15 Westferry Circus
Canary Wharf
London E14 4HD

The Sickle Cell Society
Statement of financial activities

for the year ended 31 March 2022
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2022 £	Total Funds 2021 £
Income:					
Voluntary Income	3	576,399	295,228	871,627	789,186
Investment income	4	115	-	115	315
Total income		576,514	295,228	871,742	789,501
Expenditure					
Costs of raising funds					
Fundraising costs	5	189,328	8,260	197,588	133,353
Charitable activities	5				
Campaign		109,151	95,069	204,220	188,176
Direct services group		80,664	32,733	113,397	159,194
Provision of information and advice		46,288	72,230	118,518	100,250
Children's Activities & Holiday		13,483	29,755	43,238	24,401
Total expenditure	5	438,914	238,047	676,961	605,374
Net income for the year before transfers		137,600	57,181	194,781	184,127
Transfer between funds		126,410	(126,410)	-	-
Net movement of funds in year		264,010	(69,229)	194,781	184,127
Reconciliation of funds					
Total funds brought forward	14	336,802	217,482	554,284	370,158
Total funds carried forward	14	600,812	148,253	749,065	554,284

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 28 to 41 form part of these financial statements.

The Sickle Cell Society

Balance sheet
at 31 March 2022

Company number 2840865	Note	2022 £	2022 £	2021 £	2021 £
Tangible fixed assets					
Tangible assets	9		215,114		13,227
Current assets					
Debtors and prepayments	10	44,906		32,840	
Cash and cash equivalents	12	690,697		630,912	
		735,603		663,752	
Creditors - amounts falling due within one year					
Creditors	13	201,652		122,695	
Net current assets			533,951		541,057
Total assets less current liabilities			749,065		554,284
Represented by:					
Unrestricted funds	14		560,812		336,802
Designated Funds			40,000		-
Restricted funds	14		148,253		217,482
			749,065		554,284

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 07/09/22 and signed on its behalf by:

Trustee

Michele Salter

Trustee

Kye Gbangbola

The notes on pages 28 to 41 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows
for the year ended 31 March 2022

	Note	2022 £	2022 £	2021 £	2021 £
Cash generated in operating activities	19		276,462		180,201
Cash flows from investing activities					
Interest income		115		315	
Payments to acquire tangible fixed assets		(216,792)		(4,712)	
Net cash from investing activities			(216,677)		(4,397)
Increase in cash and cash equivalents in the year			59,785		175,804
Cash and cash equivalents at the beginning of the year	12		630,912		455,108
Cash and cash equivalents at the end of the year	12		690,697		630,912

The notes on pages 28 to 41 form part of these financial statements.

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 2022/2023. 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.

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 residential 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.

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 2022 £	Unrestricted £	Restricted £	Total 2021 £
Donations and legacies	441,483	-	441,483	248,192	4,400	252,592
Grants	-	165,964	165,964	207,334	132,126	339,460
Capital Income NCIL – Brent	-	69,264	69,264	-	-	-
The Clothworkes Foundation	-	50,000	50,000	-	-	-
The Bernard Sunley Foundation	-	10,000	10,000	-	-	-
Contract Income	134,916		134,916	173,849	-	173,849
Other Income	-	-	-	23,285	-	23,285
	576,399	295,228	871,627	652,660	136,526	789,186

4 Investment income

	Unrestricted 2022 £	Unrestricted 2021 £
Bank and COIF deposit interest	115	315

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2022 £	Total 2021 £
Costs of raising funds					
Fundraising costs	81,502	45,439	70,647	197,588	133,353
Charitable activities					
Campaign	13,619	117,581	73,020	204,220	188,176
Direct services group	64,136	8,716	40,545	113,397	159,194
Provision of information and advice	24,804	51,338	42,376	118,518	100,250
Children's Activities & Holiday	17,190	10,589	15,459	43,238	24,401
Total expenditure	201,251	233,663	242,047	676,961	605,374

Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2022 £	Total 2021 £
Charitable activities						
Fundraising costs	6,141	21,544	34,452	8,510	70,647	48,192
Campaign	6,348	22,267	35,609	8,796	73,020	68,005
Direct services group	3,525	12,364	19,773	4,883	40,545	57,531
Provision of information and advice	3,684	12,922	20,665	5,105	42,376	36,229
Children's Activities & Holiday	1,344	4,714	7,539	1,862	15,459	8,818
Total support costs	21,042	73,811	118,038	29,156	242,047	218,775

Total expenditure in the year to 31 March 2022 was £676,961 (2021: £605,374) of which £438,914 (2021: £379,762) was unrestricted and £238,047 (2021: £225,613) was restricted.

6 Staff cost and numbers

	2022 £	2021 £
Wages and salaries	280,225	301,301
Social security	23,648	26,680
Pension	47,828	25,532
	351,701	353,513

The average number of employees during the year was 13 (2021:12).

No employee earned more than £60,000 per annum (2021: None).

No remuneration has been paid to the Trustees other than reimbursement for travel to 1 trustee (£117) and membership cost to Association of Chairs for 2 Trustees membership (£110) totalling £227, (2021: £nil).

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 £42,949 salary, £30,508 pension and £4,640 NI, total - £78,097 (2021: £62,878).

7 Net Income for the year

	2022 £	2021 £
Is stated after charging:		
Depreciation on owned assets	14,904	4,625
Auditors' remuneration (including VAT):		
- Audit fees	10,920	10,404
Equipment rental	3,800	3,634
Property Lease/Rent – 56 Station Road	9,600	9,600

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.

9 Tangible Fixed Assets

	Leasehold Improvements	Furniture & Equipment	Total
	£	£	£
Cost			
At beginning of year	-	140,552	140,552
Additions	200,772	16,020	216,792
Disposals	-	-	-
At end of the year	200,772	156,572	357,344
At beginning of year	-	127,326	127,326
Charge for the year	9,093	5,811	14,904
Disposal			
At end of the year	9,093	133,137	142,230
Net Book Value			
AS at 31 March 2022	**191,679**	**23,435**	**215,114**
AS at 31 March 2021	-	13,226	13,226

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

10 Debtors

	2022 £	2021 £
Grants and donations receivable (note 11)	20,819	20,819
Prepayments	24,087	12,021
	44,906	32,840

11 Grants receivable

	2022 £	2021 £
Public Health England (PHE)	20,819	20,819
	20,819	**20,819**

12 Cash and cash equivalents

	2022 £	2021 £
Cash in hand	196	105
NatWest Reserve Account	538,670	472,585
NatWest Current Account	100	100
COIF Charities Deposit Fund	150,533	150,469
Paypal	1,198	7,653
	690,697	630,912

13a Creditors - amounts falling due within one year

	2022 £	2021 £
Trade creditors	83,072	86,577
Accruals and deferred income	118,580	36,118
	201,652	122,695

13b Deferred Income Reconciliation

	2022 £	2021 £
Balance as at 1 April	17,044	32,400
Amount Released to Income	(17,044)	(32,400)
Amount Deferred in the year	53,952	17,044
Balance as at 31 March	53,952	17,044

14 Analysis of charitable funds

	Balance 1 April 2021	Movement in funds				Balance 31 March 2022
		Income	Expenditure	Transfers	Fixed Asset Funding Transfer	
	£	£	£	£	£	£
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	-	-
Big Lottery	-	-	-	-	-	-
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	-	51,057	49,330	-	-	1,727
Public Awareness Campaign – Priapism	-	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

£40,000 was designated from the unrestricted funds to support 2 projects in 2022/2023, Give Blood Spread Love and Mentoring Projects. Both projects will receive an equal share of £20,000 to help carry out both services during the year.

14 Analysis of charitable funds *(continued)*

Analysis of charitable funds – previous year

	Balance 1 April 2020	Movement in funds			Balance 31 March 2021
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	-	400	5,655	5,255	-
Roald Dahl's Marvellous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Research	45,227	-	-	-	45,227
Helpline Worker	-	4,000	38,069	34,069	-
CLAHRC	2,995				2,995
London borough of Hackney	7,983	20,903	25,808	5,317	8,395
Big Lottery	13,690	-	13,690	-	-
GMSN – Children's Activity	-	22,193	15,244	2,867	9,816
APPG for Sickle Cell & Thalassaemia	-	20,833	33,310	12,477	-
Refurbishment Income	121,195		46,486	17,924	92,633
Heritage Lottery fund	19,664	37,070	32,250	3,558	28,043
NHS England	2,500	-	-	-	2500
Digital Marketing – Blood Donation	-	24,066	15,100	-	8,966
Mentoring Programme	-	7,060	-	-	7060
Restricted funds	225,102	136,525	225,612	81,467	217,482
Unrestricted funds	145,056	652,975	379,762	(81,467)	336,802
General fund					
Total funds	370,158	789,501	605,374	-	554,284

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 202 - 2022 the Society held a virtual holiday because of the pandemic. A grant of £7,079 was received from Global Blood Therapeutics (GBT) towards 2021 Children's Holiday Activities and £4,030 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 had planned to use these funds as match funding for the Big Lottery Funding (BLF) however, due to other projects being underspent we did not need to use this fund in the year. We aim to contact the funders during 2021-22 to seek permission to spend the funds on similar activities in line with their funding agreement.

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 £42,867 was made from the unrestricted funds in 2021/22 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.

14 Analysis of charitable funds *(continued)*

Big Lottery – South London Sickle Link
This 3-year grant was to support the health, wellbeing and life chances of people living with sickle cell disorder and their families in the London boroughs of Lambeth, Southwark and Lewisham. It will achieve this through a range of activities incorporating; peer support, information, advice and guidance; a programme of skills development, leisure activities and social events. The project ended in September 2019 with an underspend which was confirmed and agreed by BLF to use towards further activities in South London in 2020/2021 which is in line with the Project's criteria. The underspend was used as agreed during the financial year.

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 £20,000 have been awarded by Novartis and BlueBird Bio respectively. £12,773 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 by way of a grant of £20,903 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.

Office Refurbishment
Phase 1 of the Sickle Cell Society Headquarters refurbishment has now been completed, a total of £129,264 was received during the financial year 2021/22: £69,264 was received from Brent Council – NCIL, £50,000 from The Clothworkers and £10,000 from workers Foundation and £10,000 from Bernard Sunley to carry out this work.

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). £75,000 was received from Boston Scientific International to help to support this project.

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

Sainsbury's Supermarkets Ltd	84,621
Just Giving	57,571
Payroll Giving	56,176
BB Merchant Service	36,161
Facebook International	29,148
Brent Council - Mayor of Brent	20,840
Virgin Money Giving	14,280
Franklins Clients Estates – Legacy	12,500
Online Giving	12,249
C O Sule	10,000
Vitol Foundation	9,039
Tuesday's Child - Coutts & Co CLG	8,454
HMRC Charities - Gift Aid Claim	5,898
Training & Consultancy	6,043
PWC Foundation	5,000
Paypal Giving Fund UK	4,962
Tesco Stores Ltd	3,000
Amazon Europe Core	2,966
Enugu Lodge No 5440	2,243
Capital Group	1,900
Neuberger Berman	1,246
St James' Catholic High School	1,187
Coloma Convent Girls' School	1,143
Stella Mae - Riseup for Sickle Cell	1,053
HTA Design LLP	1,010
Crown Agents Bank Limited - Heather Melville	1,000
360 Law Service - John Dudley Matthews	1,000
Elizabeth Anionwu	1,000
The Nile Valley Lodge No. 6306	1,000
Harlington Upper School Fund	980
D Kuti - CS New Covenant	874
O F Brown	840
O Griffith	840
C. E. X. Ltd - Q4	810
British Transport Police Federation Lottery Fund	800
RDF Television Ltd	800
Chris Minasians	784
M Salter - Novartis Code Red	718
Andrew Uchea	700
Timothy Jarvis - Kings Trust	686
Sudbury Primary School	615
Cathedral Church - St Pauls	608
B A Leslie	600
Hartley Taylor	600
Croudace Homes Group	550

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

Kelsey Nagles - Metrobank Raffle	503

16 Analysis of net assets between funds

	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)
Net assets	600,812	148,253	749,065

Analysis of net assets between funds – previous year

	Unrestricted £	Restricted £	2021 Total Funds £
Tangible assets	13,227	-	13,227
Current assets	446,270	217,482	663,752
Current liabilities	(122,695)	-	(122,695)
Net assets	336,802	217,482	554,284

17 Transfer between funds

During the year the Trustees agreed a transfers of £74,362 (2021: £81,467) 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, Heritage Lottery Fund and 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 and Heritage Lottery Projects, transfers were made to Projects of £4,030, £42,867, £2,370, £12,773, £2,838 and £4,333 respectively to carry out the projects during 2021/2022.

There was also a further transfer of £200,772 from restricted funds to unrestricted. This amount represents the cost for the Leasehold Improvement during 2021-22 which was capitalised and will be depreciated over the useful life.

18 Leasing commitments

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

	2022 £	2021 £
Commitments expiring:		
Within 1 year	11,651	12,310
Within 2 to 5 years	23,807	33,512
	35,458	45,822

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

	2022 £	2021 £
Net Movements in Funds	194,781	184,127
Depreciation	14,904	4,625
Interest income	(115)	(315)
Decrease in Stock	-	1,919
(Increase)/Decrease in debtors	(12,066)	(7,937)
(Decrease) in creditors	78,958	(2,218)
Net cash generated from operating activities	276,462	180,201

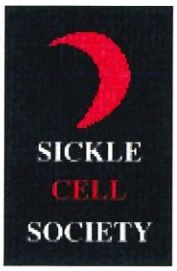
20 Related party transactions

Michele Salter, Shubby Osoba and Kye Gbangbola donated to the Society during 2021-22 as follows: £718, £100 and £10 plus £100 Amazon vouchers respectively.

THE SICKLE CELL SOCIETY

England & Wales - Charity number 1046631

Accounts



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 2021

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2021

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The Sickle Cell Society

Company information
for the year ended 31 March 2021

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	
	Sir Lenny Henry CBE	
	Sir Clive Lloyd OBE	
	Mr 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	Mr Kye Gbangbola	Chair
	Ms Michele Salter	Vice Chair and Treasurer
	Ms Joy Adeyemo	
	Ms Carol Burt	
	Dr Josephine Ruwende	
	Ms Sheree Hall	
	Mr Philip Udeh	
	Mr Ganesh Sathyamoorthy	
	Mr Shubby Osoba MBA	from September 2021
	Mr Nathan Hepburn	from September 2021
Staff	Mr John James OBE	Chief Executive
	Ms Iyamide Thomas	NHS Engagement Lead
	Ms Miriam Williams	Office Manager/Finance Lead
	Ms Ainhoa Munoz	Fundraising Officer
	Ms Shahnaz Qizilbash	Helpline & Information Officer (to October 2020)
	Mr Matthew Neal	Communications and Social Media Officer
	Mr Adam Lloyd	Parliamentary Officer for SCTAPPG
	Ms Tracy Williams	South London Gives Project Officer
	Ms Stephanie Erivo	Engagement officer (to May 2020)
	Ms Ayooluwa Adesanya	Fundraising Data Processor Administrator (to May 2020)
	Ms Alinta Sara	Research & Education Co-ordinator
	Ms Valerie Oldfield	Helpline & Information Officer (from September 2020)
	Ms Taja Morgan	Children's Activity Leader (from July 2020)
	Ms Layla Lawson	Hackney Engagement Project Officer (from May 2020)
	Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation (from July 2020)
	Ms Sheri Ponle	Helpline & Information Office (from February 2021)
	Ms Micaela Valero	Fundraising Data Processor/Administrator (from February 2021)

The Sickle Cell Society

Company information
for the year ended 31 March 2021 ***(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	Dr Nellie Adjaye (Retired) Consultant Community Paediatrician Mid Kent Healthcare NHS Trust Professor Dame Sally Davies Rector Cambridge University Cambridge Professor Mark Layton Consultant Haematologist Hammersmith Hospital, London Professor Bernadette Modell Emeritus Professor, UCL, London Professor David Rees Consultant Haematologist Kings College Hospital, London Dr Allison Streetley Consultant in Public Health Public Health England

Scientific advisors	Dr Mary Petrou Director, Perinatal Centre University London Hospital, London
	Professor Simon Dyson De Montfort University, Leicester
	Dr Kofi Anie MBE Consultant Clinical Psychologist NW London Hospitals NHS Trust
	Dr Elizabeth Dormandy Consultant in Public Health
	Dr Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital
	Dr Moira Dick (Retired) Consultant Community Paediatrician King's College Hospital

The Sickle Cell Society

Trustees' report
for the year ended 31 March 2021

The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2021 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 is an inherited blood disorder, 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. For an individual with a sickle cell disorder when the red blood cell gives up too much oxygen it loses its flexibility and uniform roundness adopting a sickle shape (sickling). This makes the cell difficult to pass through the blood vessels and creates blockages.

When these blockages occur, they cause a great deal of pain, 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. Anaemia occurs due to excessive breakdown of red blood cells from frequent sickling. Management of painful crisis can range from home treatment with mild pain killers to hospital attendance for the administration of powerful drugs.

Over time, people living with sickle cell 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 this client group suffers disability. There is no easy cure, and despite the progress made with bone marrow transplants for children, death is sometimes a further consequence of these complications.

Sickle cell is one of the most common genetic inherited conditions in the UK and in the World. There are estimated to be at least 300,000 sickle cell trait carriers (National Screening Committee for Sickle Cell and Thalassaemia 2006) and more than 15,000 people with sickle cell disorder in England. Despite improvements in NHS specialised services and clinical care, poor service support, awareness and understanding of sickle cell remain long standing issues which have been evidenced by recent Peer Reviews of NHS Sickle Cell Services.

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 new born 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. The Society was later established under a Memorandum of Association with the objects and powers of a charitable company and is governed under its 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.

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 and DVDs and CDs Conferences, seminars, workshops and partnership networking
   - Website, e-mail services, 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. 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.

Board development

The Board of 8 Trustees, excluding vacant positions, has 4 members with sickle cell disorder and Trustees are also carers for family members with sickle cell. The Board undertook board development training during 2020/21, jointly with the staff team of the Society.

SUMMARY REVIEW OF 2020-2021

This year has been a thoroughly difficult and challenging year for everyone in the UK and across the world and we know that the sickle cell community has been deeply affected. Despite seeing a big impact on our finances and having to work remotely, we have worked hard as an organisation to continue supporting the sickle cell community as best as we can, including ensuring that sickle cell was included in the shielding category and working with sickle cell experts to ensure up-to-date advice and information was available.

The annual report is an opportunity for us to showcase the ways in which we continue to support people living with sickle cell at a local and national level. Over the last year, we have continued to experience global uncertainty and turbulence leading to funding constraints and an increased workload. However, we have continued to work hard to meet the high standards of the sickle cell community and we hope that this report will show you the range of work we have been doing to continue to see visible improvements and impact for people living with sickle cell and their families. A few of these highlights include:

- Developing up-to-date and sickle cell specific advice and guidance on coronavirus and the vaccine including on our website and a series of Live Q&As and vaccine information videos to ensure that the sickle cell community and interested stakeholders had constant access to the latest information and statistics.
- Launched the Our Journey Our Story exhibition digitally on the Black Cultural Archives website
- Published Cast Aside and Forgotten an All-Party Parliamentary Group for Sickle Cell and Thalassaemia report into the impact of the COVID-19 pandemic on the sickle cell community.
- Published 'A Parent's Guide to Managing Sickle Cell Disease' (4th Edition 2021) and 'Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines' (2020).
- Joined a nation-wide charity collaboration to write an open letter to encourage those with underlying health conditions to come forward for the coronavirus vaccine
- Continuing working with the Sickle Cell World Assessment Survey (one of world's largest sickle cell surveys published in 2019) to share and educate on the survey's findings.
- Writing a letter to Boris Johnson to urge the Prime Minister to not lose smaller charity partnerships like the Sickle Cell Society in the Public Health England restructure.
- Celebrated key awareness days like World Sickle Cell Day and Rare Disease Day by hosting and participating in a range of events and awareness campaigns.
- We saw the growth of our blood donation project, building on the success of two years raising awareness of blood donation and recruiting black-heritage blood donors under our 'South London Gives' project we were able to continue this work nationally via Give Blood, Spread Love, England.
- Continuing to work with pharmaceutical companies on clinical trials for potentially new sickle cell modifying drugs
- Continued our children's activities (virtually) with funding from Global's Make Some Noise
- Ran a successful Children's Holiday virtually, engaging children and their families.
- We supported an NHS review of hospital healthcare due to community concerns at poor provision of pain relief and associated commissioning failures, this is ongoing but we are working hard for national change.

With the vaccine roll-out we are hopeful that life will be able to move to a new normal although we know that there will continue to be significant turbulence and challenges for the Society and the wider sickle cell community.

Despite these challenges, we remain committed to supporting the sickle cell community, our staff and volunteers. We will continue the positive work we have done this year, doing so with good governance, transparency, and accountability. We want to say a massive thank you to all our staff and volunteers for their unwavering commitment during this challenging period and a thank you to all of our members, donors, and other supporters, for their continued love and support.

Although the news surrounding the death of Richard Okorogheye and the inquest into the death of Evan Nathan Smith came after the dates of this Annual Report, we want to make mention of it now to reassure the community that we are working hard to see national change. You can find a full statement on our website.

We hope you enjoy reading this report of all we have been up to over 2020/21 and that it will provide you with an insight into our work.



Kye Gbangbola
Chair



John James OBE
Chief Executive

KEY HIGHLIGHTS FROM THE YEAR 2020-21

STAKEHOLDER RELATIONSHIPS

Stakeholder relationships are a key part of the Society's work, connecting our work with national 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 Disease UK and 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 tender with the UK Thalassaemia Society.

The Society continued our work as a founding member of the Global Alliance of Sickle Cell Disease Organizations (GASCDO). Inaugurated in Amsterdam, Netherlands on January 10, 2020, it is the first established entity representing individuals living with sickle cell disease globally.

The Society worked effectively with NHS Clinical Commissioning Groups, London Ambulance Service, Industry, and the UK Thalassaemia Society. Our engagements extend to many organisations including National Council Voluntary Organisations (NCVO); UK Forum on Haemoglobinopathies; National Voices; NHS Blood and Transplant; NHS Trusts; NHS England; Public Health England; 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 worked together with a range of research and improvement organisations, collaborating towards better understanding of Sickle Cell. These collaborations included Kings Health Partnership - part of Kings College Hospital, for work on the Sickle Cell Centre of Excellence, NIHR (National Institute for Health Research), NHS Boards, EMA (European Medical Agency), NHS BT (NHS Blood and Transplant Clinical Trials Unit), UCL (University College London), and Genomics England. This is not an exhaustive list, but it illustrates the breadth of engagement.

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.

MEMBERSHIP & SUPPORT GROUP BASE

The Sickle Cell Society has maintained its free membership policy and the current membership stands at almost 2000, a smaller number than last year as the number no longer includes the wide range of additional supporters, groups and stakeholders who continue to support our work.

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 Officer 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 significant increase in social media followings.

- The Society's Instagram (@sicklecelluk) gained over 1800 followers.
- The Society's Twitter (@SickleCellUK) gained over 800 followers.
- The Society's Facebook (Sickle Cell Society UK) gained over 500 followers.
- The Society's LinkedIn (Sickle Cell Society) gained over 400 followers.

The Sickle Cell Society website received, on average, 33,000 views per month.
On average, 8500, of those views per month were specifically viewed for our Coronavirus (COVID-19) & Sickle Cell Disorder page.

HELPLINE AND INFORMATION SERVICE

By Telephone

The Society received 224 telephone calls from April 2020 to March 2021. The Society provided information and support for 99.9% of all calls – with 83% receiving information, support or being signposted to relevant places. The most common topics of calls were Covid-19 related, managing sickle cell, benefits, fundraising and awareness. 82 % of callers were new callers. The team spent a total of 3411 minutes (approx. 57 hours) on the phone.

By Email

As part of the helpline service we also responded to emails. The Society received a total of 1004 emails during April 2020 to March 2021. This is slightly down by 66 from last year due to the new online Contact Us Automated FAQ and Form Processing facility on the Society's website.

86% of emails received information, support and advice. 11% of emails were signposted to relevant places.

HACKNEY AND CITY MENTORING SCHEME

The Hackney and City Mentoring Scheme remains on pause whilst we continue conversations with Hackney Clinical Commissioning Group as well as the other East London Clinical Commissioning Groups (CCGs) across the 7 boroughs. The conversations are about the potential expansion of the City and Hackney Sickle Cell Peer Mentoring Programme, which we have successfully piloted over 2 years. Discussions have also begun about the potential roll out of the Peer Mentoring Scheme with both Commissioners in Greater Manchester and the Sickle Cell Health Coordinating Centre for the North West of England.

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 video 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 conversation around sickle cell. We have participants from across the country, including our patron and actress Ellen Thomas, as well as around the world in places such as the USA and Sierra Leone.

EDUCATION / INFORMATION AND AWARENESS (continued)

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

- Sickle Cell Disorders and the Call for Black Blood Donors
  - An interactive workshop about the history of blood donation campaigning and its importance in sickle cell disorders treatment.
- Sickle Cell Disease and its West African Discovery
  - A free webinar about the fascinating history of sickle cell including a presentation on Dr. Africanus Horton, who first recognised and wrote about the disorder.
- Current Advocacy Work in Sickle Cell Disease: The Global Perspective
  - A joint event gathering advocates from across the globe - organised by Global Association Sickle Cell Disease Organisations (GASCDO)

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 majority of these have been done virtually, to adhere to government guidelines.

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 which you can find in a later section.

CORONAVIRUS (COVID-19) & SICKLE CELL DISORDER

Coronavirus (COVID-19) has had a huge impact on the sickle cell community. We created a dedicated page on our website to provide the latest information and guidance, specific to sickle cell and COVID-19. The page received, on average, 8500, views per month. As well as detailing national guidelines, the website contained up-to-date data from the National Haemoglobinopathy Panel (NHP), and guidance developed by our medical advisors.

The NHP data (Mar 2020 - Jan 2021, among patients with haemoglobin disorders) revealed that:

- 97% of patients with proven or suspected COVID-19 survived.
- Two thirds of all patients with COVID-19 are managed at home, and most COVID-19 cases have been clinically mild.
- Very few children have been infected, very few of those have required respiratory support, and none of them have died
- Similar to what is seen among the general public, those who were severely affected with COVID-19 were older and had other health problems such as high blood pressure or heart disease

Further to our website, we hosted three Live Q&As to answer questions from people living with sickle cell. The first Live Q&A took place on 15th May and the panel consisted of John James OBE (Chief Executive of the Sickle Cell Society) and June Okochi (Head of Program Management at NHS West Essex CCG, and Lead Mentor of SCS Mentoring Programme).

The second took place on the 5th June and the panel consisted of John, June, Professor David Rees (Consultant Paediatric Haematologist and SCS Medical Adviser), Dr Kofi Anie (Consultant Psychologist and SCS Medical Adviser) and Dr Mark Layton (Consultant Haematologist and SCS Medical Adviser).

CORONAVIRUS (COVID-19) & SICKLE CELL DISORDER (continued)

The final Live Q&A took place on 11th September and the panel included John, June and Dr Kofi Anie. This Q&A also saw a talks on 'Clinical Experience Perspective' by Keisha Osmond-Joseph, 'Experience of Shielding and coming out of lockdown' by Zainab Garba- Sani and 'UCL Covid-19 Research Study' by Professor Fenella Kirkham & Anna Hood, Ph.D.

When the vaccine began being rolled out, we were aware of concerns and hesitancy within the community. To address this, we wanted to answer your questions and get expert input. We developed a three-part series looking more deeply at sickle cell and the COVID-19 vaccine.

In the first video, we spoke with Dr Anna Goodman, to learn more about how the vaccine was developed and how it works. Following that, in our second video, Dr Rachel Kesse-Adu gave a presentation on data collected from sickle cell centres from around the country. This was followed up by a question and answer session by sickle cell patients. The final video spoke directly to people living with sickle cell to hear first-hand their experience of getting the COVID-19 vaccine.

WORK ON BEHALF OF THE NHS SCREENING PROGRAMME

From 1 April 2020 – 31 March 2021 the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) continued working on the collaborative tender with the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) which officially commenced on 15 August 2018. The unprecedented COVID-19 pandemic of 2020 affected delivery of some project objectives and caused changes in the work plan previously proposed. We found new ways of working and adapted our workplan to continue to prioritise antenatal and new-born screening in England as safely as possible. All of the year's planned outreach and face to face work was affected and all meetings were done online. in addition, a new work stream was prioritised.

Key Project Achievements:

- One positive workplan change was the major input the SCS (and UKTS) has had in the revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway.
- Review of NHS SCT Screening Programme antenatal and newborn carrier leaflets.
- Contribution to screening articles targeted at Nursing Times as part of a Manuscript Task and Finish Group
- SCS collaboration with NHS SCT Screening Programme and UKTS to hold a successful online publication launch of 'Sickle cell disease in childhood: standards and guidelines for clinical care', 'Parents' Guide to Managing Sickle Cell Disease' and 'Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines' attended by over 250 people.
- Raised awareness of sickle cell and screening – public talks given online (7) newsletter article (1), Webinars/Conferences (5), Radio Interview (1) Newspaper articles (3) PHE Blog (1)
- Outreach using specially designed social media screening graphics for World Sickle Cell Day, July SCD Awareness Month and Rare Disease Day.
- Raised awareness of screening as part of virtual advent calendar of Dawn Butler MP

Quote from attendee at Publications launch

> *"Thanks Iyamide. Overseas programmes are drawing on UK best practice, it's important to say we use the Public Health England Sickle Cell and Thalassaemia leaflets EVERY DAY".*

CHILDREN'S ACTIVITIES

The children have taken part in numerous activities virtually from July 2020-May 2021, these included a Carnival Themed Workshop, Black History Month events, a festival performance, Positive Wellbeing Workshop, Cooking Workshop, T-shirt Design Workshop, arts and crafts, meditation, confidence building and a Family Comedy Show. Although our activities have taken place online the children still enjoyed and got the most out of it from home.

We have also started running Monthly Parent Talks, giving parents who have children with sickle cell, a chance to express any concerns/worries or share any advice. The parents have found them very beneficial.

Positive feedback that we've received:

- *"Thank you for this. It's really nice of the SCS for doing all these session in coronavirus lockdown"*
- *"Bruna was great, she managed all on the call very well. The end result was superb. My son is feeling very proud of himself and has giving him the confidence in the kitchen he didn't have before"*
- *"You are doing very well and helping children with sickle cell thank you so much"*
- *"Thank you for organising these talks."*
- *"Thoroughly enjoyed this workshop again. Thanks to the organisers. God bless you for your time and input."*
- *"Keep the discussions coming it is so helpful. Thank you"*

CHILDREN'S HOLIDAY

From Friday 14th August to Sunday 16th August we hosted our first ever Virtual Children's Holiday. We have been running our Annual Children's Holiday for 8-15 year olds with sickle cell every year since the 1980s but this year, to keep everyone safe, we took our normal adventures online for the very first time! 32 families from all around the country joined us via zoom for a weekend of friendship, learning and fun.

This year the whole family took part in the holiday, not just the child with sickle cell, which was made possible by our online forum. It was fantastic to see siblings and parents getting to know one another and learning more about sickle cell too.

We got up to a whole range of activities put together by our Children's Activities Team. These included:

- Storytelling
- Tai Chi, Yoga and Meditation
- Arts and Crafts
- Cabin Chat
- Challenge Night
- Growing Cress
- A Scavenger Hunt
- Sickle Cell Information Sessions
- Parent to Parent Chats

We were delighted to have the help from our talented team of volunteers who helped us deliver the programme and made sure the young people had a fantastic time. Despite being virtual, the holiday was a fantastic way for families from around the country to come together over lockdown, support one another, and have some fun.

"I enjoyed meeting people who have sickle cell. It's nice to have friends who understand ... if I have pain they know what I'm going through" – Young Person

"I really enjoyed connecting with other people who have sickle cell, I know I'm not alone. I also liked trying something new like meditation." – Young Person

HACKNEY ENGAGEMENT PROJECT

During 2020/2021 the Hackney Engagement Project looked at how to continue its work in a virtual capacity in order to adapt to the coronavirus pandemic. The project utilised the expertise of the sickle cell community and produced a range of videos focused on physical, mental and emotional health.

The series of videos focused on physical health, detailing inspiring sickle cell workouts for #MondayMotivation. These videos were then paired with healthy eating videos in partnership with Kiddy Cook SE London.

The final set of videos was an open discussion led by people living with sickle cell or parenting children with sickle cell. These 'panel' videos were insightful discussions prompted by different topics and questions. The panels were organised groups including specific panels for men and parents.

All the videos can be enjoyed at our website or on our YouTube channel.

We are in discussions with Hackney Council about the future of the project

PARLIAMENTARY WORK

COVID-19 research - National Haemoglobinopathy Panel

The Sickle Cell and Thalassaemia All Party Parliamentary Group hosted a virtual business meeting on Wednesday 30th September 2pm-3.30pm. It served as an opportunity to hear from Dr Frederic Piel and Professor Mark Layton, from Imperial College London and Dr Paul Telfer from Barts, on a National study of Haemoglobinopathies and Covid-19 and the impact on the sickle cell community. This was the product of work developed by the National Haemoglobinopathy Panel. This was the first national study of its kind and the SCTAPPG was happy to act as a vehicle for its findings to be presented.

SCTAPPG COVID-19 Research – "Cast Aside and Forgotten About" Report

In order to determine the multi-faceted impact that the COVID-19 pandemic has had,
is having, and will continue to have on the sickle cell community, the SCTAPPG commissioned a survey into the ramification's that coronavirus would have on the sickle cell community and their primary care givers. We believed that this would serve as an opportunity for the SCTAPPG to compile a report into the experiences of those living with sickle cell in these uncertain times. Amongst a host of objectives, it was key to use this data to determine whether those living with sickle cell or caring for someone with sickle cell disorder are receiving all the information required, and whether the government guidance is suitable for their circumstances. The survey was launched on 28th of May 2020, and then distributed to sickle cell service users through the Sickle Cell Society membership. In order to increase the reliability of results the survey was widely disseminated throughout patient groups and clinical networks to garner as many responses as possible. We had considerable participation with 186 self-selected respondents, primarily through accessing the networks of patient groups and encouraging them to share the questionnaire.

The report aspires to provide you with the prevailing issues that are affecting our service users during this pandemic as well as, in respondents' own words, offering you an insight into the reality of living day-to-day during the government lockdown. It also seeks to examine this COVID-19 pandemic through the lens of the structural injustices that exist which have only served to exacerbate the plight of our service users.

The key findings have aided the SCTAPPG to be in a position to make a host of substantive policy recommendations in order to ensure the safety of this clinically vulnerable cohort going forward.

PARLIAMENTARY WORK (continued)

The report launched on 17th December 2020 at a virtual business meeting, the research is also in the process of being potentially published in a peer reviewed journal.

Submitted work and collaborations with umbrella organisations:

The SCTAPPG collaborates and submits work to a variety of bodies and inquiries such as:

- **SCTAPPG acting as a consultee** on Betibeglogene autotemcel for treating transfusion-dependent beta-thalassaemia
- **All-Party Parliamentary Group (APPG) on Stem Cell Transplantation** - The inquiry aims to understand how a patient's background can lead to barriers in accessing treatment and care and will explore options for addressing the identified barriers.
- **Vulnerable Groups to Pandemics APPG** – which provides a forum for parliamentarians and stakeholders to consider the needs of vulnerable groups to pandemics and to provide an effective voice in parliament; to raise awareness of specific vulnerable patients; to encourage actions to promote a greater priority for prevention, treatment and support for those groups; to inform better policy decisions and public debate related to the needs of vulnerable groups.
  The Specialised Healthcare Alliance is 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. Established in 2003, the Alliance has a broad and growing membership of over 120 patient-related organisations, with eight corporate supporters. Members represent the broad range of specialised services from mental and paediatric health to genetic and neurological conditions.
- **Nursing and Midwifery Education Steering Group** - In collaboration with Health Education England, a steering group has been established to shape the first e-module on sickle cell for NHS health professionals. It will guarantee a foundational level of understanding and knowledge for these with an appetite to learn more about the conditions. It is chaired by Dr Lola Oni OBE, other members are Professor Laura Serrant, Dr Joan Walters and Professor Stacy Johnson.
- **Infected Blood Inquiry** - The Inquiry will examine why men, women and children in the UK were given infected blood and/or infected blood products; the impact on their families; how the authorities (including government) responded; the nature of any support provided following infection; questions of consent; and whether there was a cover-up.
- **The House of Lords COVID-19 Committee** launched an inquiry into the long-term impacts of COVID-19 entitled 'Life Beyond COVID'. The SCTAPPG submitted a document to their call for evidence.
- Coordinated Parliamentary activity on improving access to treatments for rare diseases with MACPharma has been established to raise awareness of the need for reform to NICE appraisal processes for treatments for rare diseases and to give a sense of urgency to the requirement for political intervention
- The SCTAPPG has submitted evidence to the joint inquiry led by Rt Hon Jeremy Hunt MP on 'lessons to be learned' from the pandemic response. It was announced and launched by the House of Commons Health and Social Care and Science and Technology Committees.

During 2020/2021, South London Gives (SLG) delivered the second year of a pilot project focused on blood donation awareness among people of black heritage in England. The project aimed to test the effectiveness of a formulised Community Organising approach in encouraging more black heritage people to engage with the subject of blood donation and become blood donors. Ethnically matched blood is essential for treating many people affected by sickle cell disorder and project funders, NHS Blood and Transplant, require significant numbers of new black heritage donors each year to meet demands.

SOUTH LONDON GIVES

SLG made a number of adaptations to its work during its run, including remodelling the use of community organising to a more flexible approach that better met the needs of project volunteers, and incorporating outreach and engagement activities with black-led organisations. The Covid 19 pandemic had a significant impact upon South London Gives with project delivery suspended between April and June 2020. When SLG recommenced its work, all group awareness and recruitment activities moved online, and collaboration with our digital blood donation project, Give Blood, Spread Love, became important in refining the project's approach to online engagement.

Engagement Activities - SLG delivered 48 awareness raising and recruitment activities to organisations including workplaces, churches and community groups. These online presentations explained sickle cell disorder, its relation to blood donation and answered common questions about the blood donation process. SLG's volunteers, the Community Advocates, were key to delivering this work and shared their experiences of being blood transfusion recipients or repeated blood donors through inspiring testimonies.

"The personal stories were really powerful. They helped highlight the need (for blood) within the BAME community. The information was also really helpful. Participants were able to understand why blood donation was important, why there is an increased need for certain donors and the practicalities of it all." Organisation

Community Advocates - The project recruited 21 Community Advocate volunteers, most of whom had a close connection to sickle cell. Once trained, Community Advocates promoted the need for black heritage blood donors among their family, work and leisure contacts, providing information about blood donation and challenging common myths and fears that exist within some groups about the process. Utilising volunteers from our target communities was key to our approach to this work and supported us to discuss our themes and requests from a position of trust and racial awareness.

"There is an inherent distrust of the NHS for some people in black communities due to inequality and discrimination over the years. I understand (this) and can relate to black heritage communities, with our beliefs, cultures and nuances." Community Advocate

Community Advocates also took part in press interviews with the BBC, community radio station, Supreme Radio, and online news journals. One volunteer appeared in an internationally promoted film produced for Terumo BCT on how developments in blood transfusion processes have improved the lives of people with sickle cell.

"Such an inspiring story. This has definitely encouraged me to continue to give blood." Viewer

Blood Donor Recruitment – During the life of the project, South London Gives recruited over 650 new people to the blood donation register and directly reached over 5000 people through its face-to-face and online engagement activities. Our work on this topic has highlighted the pivotal role Sickle Cell Society can play in educating communities on sickle cell and blood donation, addressing the barriers that exist in engaging and retaining black heritage blood donors and working with partner organisations to improve blood donation practices.

GIVE BLOOD SPREAD LOVE

Recognising the urgent need for blood donors from black and mixed-race communities in London and Birmingham, 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.

Through building a community of social media users, the "Give Blood Squad", to represent and share our message, the campaign aims to address young and socially engaged audiences, as well as build partnerships with likeminded community groups, universities, Haemoglobinopathy Coordinating Centre's (HCCs), hospitals and businesses of interest.

Our digital strategy has been to increase engagement from younger, socially engaged audiences through the use of influencers. Young people listen to other young people, especially those they admire. The strategy aims to spread awareness and register new blood donors from BAME communities through positive social influencing.

We used the ERSO Research (2015) on "Blood Donation in BAME Communities", produced for NHSBT, to inform our strategy.

We have made a significant digital impact over our year-long project, and we are excited to continue to grow our engaged following, recruit new members to the squad and reach the wider community.

- 1137 / Follower Growth
  - The number of people we have following the campaign on Instagram.
- 46 / GIVE BLOOD SQUAD
  - Our support network of individuals, which includes influential people, spreading awareness of our campaign.
- 114 / Digital Resources
  - The amount of content we have developed and shared online.
- 23,504 / Reach rate
  - The direct number of users who have seen our content online.
- 5,111 / Content interactions
  - The direct number of users who have interacted with our content online.
- 76,423 / Impressions
  - The direct number of users who have seen GBSL content.
- 8 / Organisations
  - We have worked with 8 organisations to promote awareness and recruit new black-heritage donors.
- 5 / Events
  - We have held 5 virtual events to educate and promote blood donation.

We have received some great feedback. 100% of users involved in the GBSL project that have been questioned stated that they have had a positive experience:

"You are all doing an amazing job! Such a great movement which is so needed! You've helped provide amazing opportunities for me to speak out about something so important in our community." - Individual with sickle cell

"Thanks, guys, for such a great conversation with a lot of insight into sickle cell, and with two different perspectives. Sickle cell and blood donation awareness is a must." - Attendee of GBSL event

"GBSL have been solely instrumental in me finally giving blood." - New blood donor

"A really strong cause and I will continue to promote and donate giving blood" - New blood donor

OUR JOURNEY, OUR STORY

Our Journey, Our Story is collecting oral history as part of the Sickle Cell Society's Heritage Project funded by the Heritage Lottery Fund. The project will chart a history of sickle cell disorders (SCD) in the UK since the Windrush generation's arrival. This project will look at the issues faced by people with SCD (and carriers of the trait) and their families, the role of the NHS, patient support groups and the Sickle Cell Society, how campaigning and lobbying has dramatically increased awareness and understanding of SCD.

The objectives are to:

- Create a film
- Establish a Sickle Cell Society archive
- Develop Heritage workshops engaging young people and the over 50s affected by SCD
- Bring together oral histories obtained from campaigners, pioneers, patients, and other prominent individuals
- Produce an exhibition accompanied by public events

The project started in September 2019. The heritage project has recruited five volunteers in London and three outside of London to assist with the interviewing. The volunteers received an induction training from the SCS as well as the Oral History Society. The project consultant, the project coordinators and the volunteers have started to conduct the interviews.

Archiving and Research

We undertook research on SCD at the Sickle Cell Society office. Moreover, we gathered literature from NHS professionals and researchers. Professor Simon Dyson and Professor Sergeant Graham donated their personal archives. Some of the literature and archives were used for the online exhibition. Due to Covid-19, most of our research was conducted online. However, we had access to the BCA archives and we used some of their resources for the exhibition. We have been liaising with the Wellcome Collection regarding the creation of Sickle Cell Society archives. In January 2020, they agreed that it would be best to transfer the material when the project concludes in Dec 2020 so that we would have easy access to the records for any engagement activities we have planned then. In May 2021, we listed 22 boxes of archival materials that will be collected by the Wellcome Collection at a later date.

Oral histories

We collected 32 interviews from patients, family and health professionals. From March 2020, the interviews were conducted remotely via Zoom and we followed the guidance given by the Oral History Society. The collected interview will be part of the SCD archives. Some of the interviews were selected to feature on the exhibition and the film. Other interviews will be used for the website.

Workshops

We delivered 4 workshops that targeted children with SCD in London and Birmingham. The workshops were an opportunity to engage young people with the history of SCD and explore the importance of archives and oral history. We collaborated with OSCAR Birmingham for to deliver the workshop to young people in the Midlands.

In January and February 2021, we collaborate with Chocolate film production to offer a 4 filmmaking masterclass to young people with SCD. They were able to create their own film about their experience of living with SCD.

OUR JOURNEY, OUR STORY (continued)

Exhibition

Due to the pandemic, the exhibition had to be postponed and was launched online in January 2021. Since 2019, we have been liaising with the Black Cultural Archives to build the display. The exhibition was initially planned for October 2020 but has been postponed to January 2021. Through our social media pages, we engaged with the broader public around the exhibition's themes. After the 17th May 2021 the exhibition will be in person at the BCA.

Public Lecture

The first webinar "Sickle Cell Disorders and the call for Black blood donors" on 20th June 2020.This webinar gathered health professionals as well as SCD patients. We had 55 attendees.

The second webinar was organised in collaboration with Imperial College and the Sickle Cell Society on sickle cell disorders (SCD) in the UK (History, Culture and Sciences). This multidisciplinary gathered a range of speakers from academia, the charity sector as well as the sickle cell community. 54 people signed up for the webinar.

In March 2021 as part of the exhibition we hold a streamed live event with Professor Dame Elizabeth Anionwu and BCA director Arike Oke.

Film Editing

We are in the process of finalising the film editing. Due to the pandemic, we could not film and therefore the film project will be constituted of online interviews, archives and images that we gathered. In January 2020, we met with Hattrick production about the film project. They offered us consultancy. Between January and August 2020, we gathered some interviews. We also drafted the film project script. From October to December, we gathered additional archives, images and audio for the film. We seek permission for the copyright holders. We are now finalising the script and the film will be editing by Chocolate Films in May 2021.

GRANTS AND DONATIONS

During the year the Society made numerous applications for emergency funding towards core funding and help to continue the work of the Sickle Cell Society. The Society received income of £203,334 from emergency grant applications during the year 2020/2021 as follows:

- City Bridge Trust £46,351
- Hoare Trustees, The Julia Hans, Rausing Trust £45,261
- The National Lottery Community Fund £36,752
- Novartis Pharmaceuticals £17,000
- The London Community £10,000
- Charitable Giving £10,000
- GSK £10,000
- Vertex £10,000
- Terumo BCT £7,970
- Euromonitor International £5,000
- PWC Foundation – Colour Brave Charity - £5,000

CONTRACTS

The Sickle Cell Society continued to support Public Health England (PHE) and NHS BT 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 income for this financial year is £123,703.

The Sickle Cell Society and NHS BT works to increase the number of black and minority ethnic people donating blood in the area of South London. The name given to this project is South London Gives which started in January 2019. Total income for this financial year is £41,127.

PLANS FOR THE FUTURE

The trustees and staff have worked together to create our new strategy for the next three years, to 31 March 2023. 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 three years 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

During the process of creating our strategy we experienced a global pandemic in the form of Covid-19. We will therefore be revisiting our new three-year strategy having regard to the global impact of the 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

The financial year 2020/2021 has been the most challenging year for the Society because of the impact of the dreadful Covid-19 pandemic, which has affected us all. Nevertheless, with commitment and dedication from all staff, we have continued to provide services (information, support and activities) to the sickle cell community on a virtual basis. Despite the very real challenges and uncertainty caused by the pandemic, it was a year of continued progress in delivering virtual services for people who live with Sickle Cell Disorder (SCD) and their families.

In February 2020, we set an emergency budget for the financial year April 2020 to March 2021, with an expected deficit of £155,837. We anticipated that unrestricted funding such as fundraising activities would be severely affected by the pandemic.

We have all worked really hard and I am pleased to report that the hard work has resulted in the Society ending the 2020/2021 financial year with a surplus of £184,127. This remarkable achievement was due to two factors. Firstly, we were able to secure one-off emergency grants from donors. Secondly, we had a significant underspend on our office refurbishment project which was delayed during the pandemic lockdown. I would like to take this opportunity to thank the trusts and donors who provided much needed emergency funding support, which was critical in enabling us to navigate this unprecedented financial year.

As we emerge from 2020/2021 into the new financial year 2021/2022, we must remember that Covid-19 is still with us and in particular new variants of Covid-19, even though good progress is being made on the national vaccination programme. The outlook for the financial year 2021/2022 will therefore continue to be very challenging for the organisation with a combination of Covid-19 uncertainties, cessation of grant funding, limited face to face fundraising and so on. Nevertheless, there is still so much for us to do, but ending the 2020/2021 financial year with a surplus of £184,127 whilst working remotely and differently, is simply a great achievement.

I would therefore like to thank all of 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 in what has been an unprecedented year.



Michele Salter
Treasurer & Vice-Chair
13/10/21

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. The Society's premises are in need of refurbishment to ensure they remain fit for purpose: this work was planned to be completed by late 2020 but the work was delayed due to the pandemic, estimated date for completion date is now August 2021.

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 £94,940. This policy was met during the financial year to 31 March 2021, with year-end free reserves of £323,575 (2020 - £131,917), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2020/2021 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 £789,501, which is £35,650 higher than the previous year's results. This has been achieved from restricted grant payments of £136,526 and £652,660 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools and communities and contract services.

During the year the unrestricted funds incurred a net income of £273,214 (2019/20: net income of £11,309).

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 of £89,087 (2019/20: total surplus of £67,305). The total restricted reserves at the end of the year were £217,482 (2019/20: £225,102).

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

Fundraising Statement *(continued)*

and 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 like to pride ourselves on being 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 which 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 has monitored our fundraising actions closely. 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 new three year organisational strategy we also have produced a new three year 2020/2023 Fundraising strategy.

Charity Governance Code

Sickle Cell Society recognises that good governance in a charity is fundamental to its success. 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.

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

Kye Gbangbola
Chair

Date: 13/10/21

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 2021 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 2021 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.

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:

- 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

10 November 2021

15 Westferry Circus
Canary Wharf
London E14 4HD

The Sickle Cell Society

Statement of financial activities
for the year ended 31 March 2021
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2021 £	Total Funds 2020 £
Income:					
Voluntary Income	3	652,660	136,526	789,186	752,460
Investment income	4	315	-	315	1,391
Total income		652,675	136,526	789,501	753,851
Expenditure					
Costs of raising funds					
Fundraising costs	5	123,113	10,240	133,353	177,835
Charitable activities	5				
Campaign		125,315	62,861	188,176	181,312
Direct services group		75,222	83,972	159,194	174,543
Provision of information and advice		54,483	45,767	100,250	98,851
Children's Activities & Holiday		1,627	22,773	24,401	42,696
Total expenditure	5	379,762	225,613	605,374	675,237
Net income for the year before transfers		273,214	(89,087)	184,127	78,614
Transfer between funds		(81,467)	81,467	-	-
Net movement of funds in year		191,746	(7,619)	184,127	78,614
Reconciliation of funds					
Total funds brought forward	14	154,056	225,101	370,158	291,544
Total funds carried forward	14	336,802	217,482	554,284	370,158

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 43 form part of these financial statements.

The Sickle Cell Society

Balance sheet
at 31 March 2021

Company number 2840865	Note	2021 £	2021 £	2020 £	2020 £
Tangible fixed assets					
Tangible assets	9		13,227		13,139
Current assets					
Stocks		-		1,919	
Debtors and prepayments	10	32,840		24,904	
Cash and cash equivalents	12	630,912		455,108	
		663,752		481,931	
Creditors - amounts falling due within one year					
Creditors	13	122,695		124,912	
Net current assets			541,057		357,019
Total assets less current liabilities			554,284		370,158
Represented by:					
Unrestricted funds	14		336,802		145,056
Restricted funds	14		217,482		225,102
			554,284		370,158

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 13/10/21 and signed on its behalf by:

Trustee

Michele Salter

Trustee

Kye Gbangbola

The notes on pages 30 to 43 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows
for the year ended 31 March 2021

	Note	2021 £	2021 £	2020 £	2020 £
Cash generated in operating activities	19		180,202		23,841
Cash flows from investing activities					
Interest income		315		1,391	
Payments to acquire tangible fixed assets		(4,712)		(7,996)	
Net cash from investing activities			(4,397)		(6,605)
Increase in cash and cash equivalents in the year			175,805		17,236
Cash and cash equivalents at the beginning of the year	20		455,108		437,872
Cash and cash equivalents at the end of the year	20		630,913		455,108

The notes on pages 30 to 43 form part of these financial statements.

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 2021/2022. 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.

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 residential value of each asset over its expected useful life, as follows:

Fixtures, fittings and equipment	-	25% straight line

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.

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 2021 £	Unrestricted £	Restricted £	Total 2020 £
Donations and legacies	257,091	4,400	261,491	304,980	5,104	310,084
Grants	207,334	132,126	339,460	-	268,527	268,527
Contract Income	173,849	-	173,843	-	-	173,849
Other Income	23,285	-	23,285	-	-	-
	652,660	136,526	789,186	478,829	273,631	752,460

4 Investment income

	Unrestricted 2021 £	Unrestricted 2020 £
Bank and COIF deposit interest	315	1,391

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2021 £	Total 2020 £
Costs of raising funds					
Fundraising costs	53,652	31,509	48,192	133,353	177,835
Charitable activities					
Campaign	1,098	119,074	68,005	188,176	181,312
Direct services group	55,412	46,252	57,531	159,194	174,543
Provision of information and advice	17,328	46,693	36,229	100,250	98,851
Children's Activities & Holiday	8,282	7,301	8,818	24,401	42,696
Total expenditure	135,771	250,829	218,775	605,374	675,237

Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2021 £	Total 2020 £
Charitable activities						
Fundraising costs	12,297	9,098	22,619	4,177	48,182	59,130
Campaign	17,353	12,838	31,918	5,895	68,005	60,287
Direct services group	14,680	10,861	27,002	4,987	57,531	58,036
Provision of information and advice	9,245	6,840.	17,004	3,140	36,229	32,868
Children's Activities & Holiday	2,250	1,665	4,139	764	8,818	14,196
Total support costs	55,825	41,302	102,683	18,964	218,775	224,517

Total expenditure in the year to 31 March 2021 was £605,374 of which £379,762 was unrestricted and £225,613 was restricted.

6 Staff cost and numbers

	2021 £	2020 £
Wages and salaries	301,301	306,290
Social security	26,680	27,432
Pension	25,532	27,137
	353,512	360,859

The average number of employees during the year was 12 (2020:14).

No employee earned more than £60,000 per annum (2020: Nil).

No remuneration has been paid to the Trustees. No expense was incurred by Trustees during the year (2020: £2,319).

The key management personnel of the Society comprise the Chief Executive Officer. The total employee benefits of the key management personnel of the Society are £50,000 salary, £7,190 pension and £5,688 NI, total - £62,878 (2020: £62,899).

7 Net Income for the year

	2021 £	2020 £
Is stated after charging:		
Depreciation on owned assets	4,625	5,036
Auditors' remuneration (including VAT):		
- Audit fees	10,404	10,200
Equipment rental	3,634	3,508

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.

9 Tangible fixed assets

	Furniture And Equipment £
Cost	
At beginning of year	135,840
Additions at cost	4,712
At end of year	140,552
Depreciation	
At beginning of year	122,701
Charge for year	4,625
At end of year	127,326
Net book value	
At 31 March 2021	13,227
At 31 March 2020	13,139

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

10 Debtors

	2021 £	2020 £
Grants and donations receivable (note 11)	20,819	13,749
Prepayments	12,020	11,155
	32,840	24,904

11 Grants receivable

	2021 £	2020 £
NHS BT	-	13,749
Public Health England (PHE)	20,819	-
	20,819	**13,749**

12 Cash and cash equivalents

	2021 £	2020 £
Cash in hand	105	383
NatWest Reserve Account	472,585	301,588
NatWest Current Account	100	1,600
COIF Charities Deposit Fund	150,469	150,291
Paypal	7,653	1,246
	630,912	455,108

13a Creditors - amounts falling due within one year

	2021 £	2020 £
Trade creditors	86,576	76,862
Accruals and deferred income	36,118	48,050
	122,695	124,912

13b Deferred Income Reconciliation

	2021 £	2020 £
Balance as at 1 April	32,400	61,769
Amount Released to Income	(32,400)	(61,769)
Amount Deferred in the year	17,044	32,400
Balance as at 31 March	17,044	32,400

14 Analysis of charitable funds

	Balance 1 April 2020	Movement in funds			Balance 31 March 2021
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	-	400	5,655	5,255	-
Roald Dahl's Marvelous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Research	45,227	-	-	-	45,227
Helpline Worker	-	4,000	38,069	34,069	-
CLAHRC	2,995				2,995
London borough of Hackney	7,983	20,903	25,808	5,317	8,395
Big Lottery	13,690	-	13,690	-	-
GMSN – Children's Activity	-	22,193	15,244	2,867	9,816
APPG for Sickle Cell & Thalassaemia	-	20,833	33,310	12,477	-
Refurbishment Income	121,195		46,486	17,924	92,633
Heritage Lottery fund	19,664	37,070	32,250	3,558	28,043
NHS England	2,500	-	-	-	2500
Digital Marketing – Blood Donation	-	24,066	15,100	-	8,966
Mentoring Programme	-	7,060	-	-	7060
Restricted funds	225,102	136,626	225,613	81,467	217,482
Unrestricted funds General fund	145,056	652,975	379,762	(81,467)	336,802
Total funds	370,158	789,501	605,374	-	554,284

14 Analysis of charitable funds *(continued)*

Analysis of charitable funds – previous year

	Balance 1 April 2019	Movement in funds			Balance 31 March 2020
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	-	5,104	21,687	16,583	-
Roald Dahl's Marvellous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Research	43,727	1,500	-	-	45,227
Brent Council	8,270	-	8,270	-	-
Helpline Worker	-	8,254	32,324	24,070	-
CLAHRC	2,744	10,208	9,957	-	2,995
Hackney CCG	4,287	-	4,287	-	-
London borough of Hackney	-	27,872	19,889	-	7,983
Big Lottery	11,365	38,192	37,082	1,215	13,690
Children in Need	7,180	-	7,180	-	-
Patient Education & Training	384	5,035	9,836	4,417	-
APPG for Sickle Cell & Thalassaemia	-	13,750	33,270	19,520	-
Refurbishment Income	-	125,516	4,321	-	121,195
Heritage Lottery fund	-	35,700	18,223	2,187	19,664
NHS England	-	2,500	-	-	2,500
Restricted funds	89,805	273,631	206,326	67,992	225,102
Unrestricted funds					
General fund	201,739	480,220	468,911	(67,992)	145,056
Total funds	291,544	753,851	675,237	-	370,158

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 2020-2021 the Society held a virtual holiday because of the pandemic. £5,255 was transferred from the unrestricted funds to help fund the 2020 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 had planned to use these funds as match funding for the Big Lottery Funding (BLF) however, due to other projects being underspent we did not need to use this fund in the year. We aim to contact the funders during 2021-22 to seek permission to spend the funds on similar activities in line with their funding agreement.

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.

Brent Council (London Borough of Brent)
To provide support and care services for individuals and families living with sickle cell in the London Borough of Brent. The underspend of £8,270 was returned to London Borough of Brent in August 2019 as we were not permitted to use the funds towards another project.

Helpline Worker
To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families. £4,000 was received from The Edward Gosling Foundation towards this service and a transfer of £34,069 was made from the unrestricted funds in 2019/20 to help carry out this service.

Hackney CCG
The Society has been commissioned by City and Hackney Clinical Commissioning Group (CCG) Innovation Fund to deliver an innovative mentoring service for young people with SCD in City and Hackney, working in close partnership with the NHS- City and Hackney Sickle Cell and Thalassaemia Centre and The Royal London NHS Foundation Trust. The objective is to empower people with SCD and their families to better manage their condition, improving their short and long term health outcomes, independence, wellbeing and reducing reliance on emergency care services where appropriate. This Project ended in June 2020.

Mentoring Project
Grant of £7,060 was received from IMARA Inc, to support the Sickle Cell Society Mentoring Project.

14 Analysis of charitable funds *(continued)*

BBC Children in Need (BBC CiN)
The BBC CiN project delivered a programme of regular activities to children and young people with sickle cell disorder. This enabled them to reduce their isolation, increase their confidence and knowledge of the condition and also improve their health and wellbeing.

Big Lottery – South London Sickle Link
This 3-year grant was to support the health, wellbeing and life chances of people living with sickle cell disorder and their families in the London boroughs of Lambeth, Southwark and Lewisham. It will achieve this through a range of activities incorporating; peer support, information, advice and guidance; a programme of skills development, leisure activities and social events. The project ended in September 2019 with an underspend which was confirmed and agreed by BLF to use towards further activities in South London in 2020/2021 which is in line with the Project's criteria. The underspend was used as agreed during the financial year.

Patient Education & Training
Bupa UK Foundation awarded the Society a grant of £31,893 to support young adults in the transition to independence with advice, information, practical training, signposting and opportunities to meet others with sickle cell disorder (SCD). The work will target 5 regions in England where SCD is primarily prevalent; South London (in collaboration with Merton Clinical Commissioning Group funding), Manchester, South Yorkshire, West Midlands and South Midlands. This project was for a period of 18 months which came to an end in July 2019.

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)
During the year 2020-21, the Society in collaboration with the UK Thalassaemia Society have taken on the responsibility for providing the secretariat of the SCTAPPG. Two restricted grants of £20,833 have been awarded by Novartis and BlueBird Bio respectively. £12,477 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 by way of a grant of £20,903 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. This project ended in December 2019 with a small underspend.

Office Refurbishment
Phase 1 of the Sickle Cell Society Headquarters refurbishment was due to be completed in 2020-21, however because of the pandemic the work was delayed. Work is now due to be completed in 2021-2022.

Digital Marketing – Blood Donation
A grant of £24,066 was received from Terumo BCT to complement the South London Gives 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.

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

Payroll Giving	57,264
City Bridge Trust	46,351
Hoare Trustees, The Julia Hans Rausing Trust	45,261
The National Lottery Community Fund	37,582
Blackbaud Merchant Service	35,221
John Lewis & Partners Waitrose	20,269
Novartis Pharmaceuticals	17,000
Just Giving	14,287
BDO LLP	13,348
GlaxoSmithKline (GSK)	10,000
The London Community	10,000
Charitable Giving	10,000
Vertex	10,000
Terumo BCT	7,970
Benjart ltd	6,000
Online Giving	5,171
Tesco Stores Ltd	5,000
Selita Miller	5,000
PWC Foundation - Colour Brave Charity	5,000
Euro Monitor International	5,000
Barclays	3,498
Motability Operations	2,558
Virgin Money Giving	1,882
Bloomberg LP	1,837
Netflix	1,500
The Pension Trust - Late CE Honeyghan	1,360
GCO Global	1,193
Sytner Coventry	1,000
SnapNoir Europe (part of Snapchat)	1,000
Chubb Services UK	1,000
Polypipe Limited	1,000
Oswald Griffith	840
Brain FUD LTD	800
Wing Yip	800
Nigerian Healthcare Professionals UK (NHCPUK)	783
Positive Paces Inc Limited	700
Olivet Brown	700
Crowdfunder LTD	684
GW Pharmaceuticals	680

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

BA Leslie	500
Ope Agbaje	500
Olayinka Omisore	500
SylverSoft Ltd	500
City University, London	500
Di Bu Ugo Club Social UK	500

16 Analysis of net assets between funds

	Unrestricted £	Restricted £	2021 Total Funds £
Tangible assets	13,227		13,227
Current assets	446,270	217,482	663,752
Current liabilities	(122,695)		(122,695)
Net assets	336,802	217,482	554,284

Analysis of net assets between funds – previous year

	Unrestricted £	Restricted £	2020 Total Funds £
Tangible assets	13,139	-	13,139
Current assets	256,829	225,102	481,931
Current liabilities	(124,912)	-	(124,912)
Net assets	145,056	225,102	370,158

17 Transfer between funds

During the year the Trustees agreed a transfer of £81,467 (2020: £67,992) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding for Heritage Lottery Fund, Hackney Council, Global Make Some Noise (MSN) and Refurbishment Project. The Sickle Cell part funded the London Borough of Hackney Engagement – Project, Refurbishment Project, Heritage Lottery Project and GMSN – Children's Activity Project. transfers were made to the following projects as a requirement of part funding: Projects, transfers were made to the Projects of £5,317, £17,924, £3,558 and £2,867 respectively to carry out the projects during 2020/2021.

18 Leasing commitments

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

	2021 £	2020 £
Commitments expiring:		
Within 1 year	12,310	10,006
Within 2 to 5 years	33,512	12,223
	45,822	22,229

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

	2021 £	2020 £
Net Movements in Funds	184,127	78,614
Depreciation	4,625	5,036
Interest income	(315)	(1,391)
Decrease in Stock	1,919	-
(Increase)/Decrease in debtors	(7,937)	5,112
(Decrease) in creditors	(2,217)	(63,530)
Net cash generated from operating activities	180,202	23,841

20 Analysis of cash and cash equivalents

	2021 £	2020 £
Cash in Hand	630,912	455,108
	630,912	455,108

21 Related party transactions

There are no related party transactions requiring disclosure in either year.