



*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

---

## Contents

### Page:

1	Company information
5	Trustees' report
24	Independent auditor's report
27	Statement of financial activities
28	Balance sheet
29	Statement of cashflows
30	Notes forming part of the financial statements

# 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  
Dr Matthew Sowemimo  
Ms Julia McLarty  
Ms Carol Burt  
Mr Ganesh Sathyamoorthy  
Mr Nathan Fordwor-Hepburn  
Ms Lisett Brown  
Ms Zainab Garba-Sani  
Dr Kilali Ominu- Evbota  
Ms Claudette Allerdycce  
Ms Lanre Ogundimu

Chair – To 31 March 2025  
Chair – From July 2025  
Treasurer

Vice Chair

### Staff

Mr John James OBE  
Ms Iyamide Thomas  
Ms Miriam Williams  
Ms Olivia Anastasiou

Ms Michelle McFarlane  
Ms Keyah Miller  
Ms Oluwaseyi Afolabi

Ms Sandra Reyes-Hayduk  
Ms Addassa Follet

Ms Sarah Babalola

Ms Paula Shutt  
Ms Rachel Simpson  
Ms Rashae Peart

Ms Adelaide Houlette

Chief Executive  
NHS Engagement Lead  
Finance & Administrative Manager  
Digital Marketing Officer – Blood  
Donation  
Helpline & Information Officer  
Helpline & Information Office  
Parliamentary Officer for  
SCTAPPG – To December  
2024  
Fundraising Manager  
Sickle Cell Children & Young  
People Mentoring Programme  
Manager (London)  
Give Blood Spread Love  
Manager  
Communications Manager  
Communication Officer  
Sickle Cell & Genomics England  
Partnership Manager  
Sickle Cell Children & Young  
People Mentoring Manager (NW  
England) From June 2024

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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

---

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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

## Report and financial statements for the year ended 31 March 2025

---

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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—

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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 Sickle Cell Society**

## **Report and financial statements for the year ended 31 March 2025**

---

### **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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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*

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

*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 Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### **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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

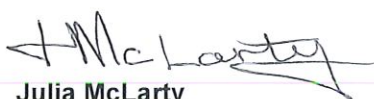
### TREASURER'S REPORT

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.



**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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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](mailto: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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 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.

# **The Sickle Cell Society**

## **Report and financial statements for the year ended 31 March 2025**

---

### **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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

- 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](http://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

*23 October 2025*

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 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 £
<b>Income:</b>					
Voluntary Income	3	950,437	453,109	1,403,546	976,153
Investment income	4	23,293	-	23,293	16,346
<b>Total income</b>		<b>973,730</b>	<b>453,109</b>	<b>1,426,839</b>	<b>992,499</b>
<b>Expenditure</b>					
<b>Costs of raising funds</b>					
Fundraising costs	5	156,015	9,648	165,663	157,047
<b>Charitable activities</b>					
Campaign	5	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
<b>Total expenditure</b>	5	<b>552,643</b>	<b>554,181</b>	<b>1,106,824</b>	<b>727,145</b>
<b>Net income for the year before transfers</b>		<b>421,087</b>	<b>(101,072)</b>	<b>320,015</b>	<b>265,354</b>
Transfer between funds		(139,851)	139,851	-	-
Net movement of funds in year		281,236	38,779	320,015	265,354
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>	14	<b>797,348</b>	<b>346,480</b>	<b>1,143,828</b>	<b>878,474</b>
<b>Total funds carried forward</b>	14	<b>1,078,584</b>	<b>385,259</b>	<b>1,463,843</b>	<b>1,143,828</b>

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

## Report and financial statements for the year ended 31 March 2025

### Balance sheet at 31 March 2025

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

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.

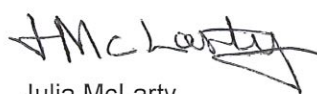
The accounts were approved and authorised for issue by the Board on 20/10/2025 and signed on its behalf by:

Trustee



Dr Matthew Sowemimo

Trustee



Julia McLarty

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### STATEMENT OF CASH FLOWS for the year ended 31 March 2025

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

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### Deferred income

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

### Tangible fixed assets and depreciation

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

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

### Expenditure

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

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

### Allocation of Support and Governance costs

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

### Operating leases

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

### Pension costs

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

### Restricted funds

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

### Unrestricted funds

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 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

	Unrestrict ed £	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
	<u>950,437</u>	<u>453,109</u>	<u>1,403,546</u>	<u>674,626</u>	<u>301,527</u>	<u>976,153</u>

### 4 Investment income

	Unrestricted 2025 £	Unrestricted 2024 £
Bank and COIF deposit interest	<u>23,293</u>	<u>16,346</u>

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2025 £	Total 2024 £
<b>Costs of raising funds</b>					
Fundraising costs	57,384	64,304	43,975	165,663	157,047
<b>Charitable activities</b>					
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
<b>Total expenditure</b>	<b>447,301</b>	<b>365,714</b>	<b>293,809</b>	<b>1,106,824</b>	<b>727,145</b>

### Analysis of support costs

	Other Support Costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2025 £	Total 2024 £
<b>Charitable activities</b>						
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
<b>Total support costs</b>	<b>75,930</b>	<b>88,046</b>	<b>102,105</b>	<b>27,728</b>	<b>293,809</b>	<b>265,914</b>

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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

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
		<hr/>	<hr/>
		467,820	356,606
		<hr/>	<hr/>

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
		<hr/>	<hr/>

## 8 Taxation

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 9 Tangible Fixed Assets

	Leasehold Improvements	Furniture & Equipment	Total
	£	£	£
<b>Cost</b>			
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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 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
	<u>1,746,829</u>	<u>1,028,962</u>

### 13a Creditors - amounts falling due within one year

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

### 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
	<u>388,840</u>	<u>92,249</u>
Balance as at 31 March		

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 14 Analysis of charitable funds

	Balance 1 April	Movement in funds			Balance 31 March
	2024	Income	Expenditure	Transfers	2025
	£	£	£	£	£
<b>Restricted funds</b>					
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
<b>Restricted funds</b>	<b>346,480</b>	<b>453,109</b>	<b>554,181</b>	<b>139,851</b>	<b>385,259</b>
<b>Unrestricted funds</b>					
General fund	788,315	973,730	552,643	(309,851)	899,551
<b>Designated Funds</b>	<b>9,033</b>	<b>-</b>	<b>-</b>	<b>170,000</b>	<b>179,033</b>
<b>Total funds</b>	<b>1,143,828</b>	<b>1,426,839</b>	<b>1,106,824</b>	<b>-</b>	<b>1,463,843</b>

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### Analysis of charitable funds – previous year

	Balance 1 April	Movement in funds			Balance 31 March 2024
	2023	Income	Expenditure	Transfers	2024
	£	£	£	£	£
<b>Restricted funds</b>					
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
<b>Restricted funds</b>	216,791	301,527	272,257	100,419	346,480
<b>Unrestricted funds</b>					
General fund	652,650	690,972	454,888	(100,419)	788,315
<b>Designated Funds</b>	9,033	-	-	-	9,033
<b>Total funds</b>	878,474	992,499	727,145	-	1,143,828

# The Sickie Cell Society

## Report and financial statements for the year ended 31 March 2025

---

### 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 Sickie 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 Sickie 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 Sickie 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.

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

---

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
Boguslawas 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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

Daniel Poser	500
Adetola Oyegbite (Varo Partners)	500

### 16 Analysis of net assets between funds

	2025		
	Unrestricted £	Restricted £	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

	2024		
	Unrestricted £	Restricted £	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:

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

# The Sickle Cell Society

## Report and financial statements for the year ended 31 March 2025

### 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
	<hr/>	<hr/>
Net cash generated from operating activities	704,644	315,508
	<hr/>	<hr/>

### 20 Related party transactions

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