



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

*Charity Reg: 104 6631*

## **The Sickle Cell Society**

(A company limited by guarantee)

Report and Audited Financial Statements

Year Ended

31 March 2022

Company Number 2840865

Charity Number 1046631



# **The Sickle Cell Society**

## **Report and financial statements for the year ended 31 March 2022**

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# The Sickle Cell Society

## Company information for the year ended 31 March 2022

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### Patrons:

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

### Trustees - Directors

Mr Kye Gbangbola	Chair
Ms Michele Salter	Vice Chair and Treasurer
Ms Joy Adeyemo	To September 2021
Ms Carol Burt	
Dr Josephine Ruwende	
Ms Sheree Hall	
Mr Philip Udeh	To September 2021
Mr Ganesh Sathyamoorthy	
Mr Shubby Osoba	From September 2021
Mr Nathan Fordwor-Hepburn	From September 2021

### Staff

Mr John James OBE	Chief Executive
Ms Iyamide Thomas	NHS Engagement Lead
Ms Miriam Williams	Finance & administrative Manager
Ms Ainhoa Munoz	Fundraising Officer – To August 2021
Mr Matthew Neal	Communications and Social Media Officer
Mr Adam Lloyd	Parliamentary Officer for SCTAPPG – To April 2021
Ms Tracy Williams	Give Blood Spread Love Project Officer
Ms Alinta Sara	Research & Education Co-ordinator - To July 2021
Ms Valerie Oldfield	Helpline & Information Officer – To March 2022
Ms Taja Morgan	Children's Activities Leader
Ms Layla Lawson	Hackney Engagement Project Officer - To April 2021
Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation
Ms Sheri Ponle	Helpline & Information Office
Ms Micaela Valero	Fundraising Data Processor / Administrator – To October 2021
Oluwaseyi Afolabi	Parliamentary Officer for SCTAPPG – From July 2021
Sandra Reyes-Hayduk	Fundraising Manager – From October 2021

Deborah Armantrading

Charles Agbede

Fundraising & Volunteer  
Development Lead – From  
November 2021  
Animation Project Co-ordinator  
– From December 2021

# The Sickle Cell Society

## Company information for the year ended 31 March 2022 (*continued*)

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<b>Registered address</b>	Sickle Cell Society, 54 Station Road, London NW10 4UA
<b>Telephone number</b>	020 8961 7795
<b>Fax number</b>	020 8961 8346
<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>Auditor</b>	PKF Littlejohn LLP, 15 Westferry Circus, Canary Wharf, London E14 4HD
<b>Banker</b>	National Westminster Bank, Park Royal Branch, Abbey Road, London NW10 7RA
<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 Streetley Consultant in Public Health Public Health England</p> <p>Rachel Kesse-Adu Consultant Haematologist (Adults) Guys and St Thomas Hospitals</p> <p>Professor Eugene Oteng-Ntim Consultant Obstetrician Guy's and St Thomas' Hospital</p>

# The Sickle Cell Society

## Company information for the year ended 31 March 2022 (*continued*)

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### Scientific advisors

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

Professor Simon Dyson (Retired)  
De Montfort University, Leicester

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

Dr Elizabeth Dormandy (Retired)  
Consultant in Public Health

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

Giselle Padmore-Payne  
Croydon University Hospital

# **The Sickle Cell Society**

## **Trustees' report for the year ended 31 March 2022**

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The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2022 and confirm that they comply with the requirements of the Companies Act 2006, the Charities Act 2011, as well as the Society's Memorandum of Association (Constitution), and the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard 102 applicable in the UK and Republic of Ireland (FRS 102).

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

### **THE CONDITION**

Sickle Cell is an inherited blood disorder, which affects the red blood cells. One of the primary roles of the red blood cell is to carry oxygen from the lungs around the body. For an individual with a sickle cell disorder when the red blood cell gives up too much oxygen it loses its flexibility and uniform roundness adopting a sickle shape (sickling). This makes the cell difficult to pass through the blood vessels and creates blockages.

When these blockages occur, they cause a great deal of pain, called a sickle cell crisis, for the individual. A crisis can last a few hours, days or even weeks and often requires hospital admission where the individual will be treated with high potency painkillers. Anaemia occurs due to excessive breakdown of red blood cells from frequent sickling. Management of painful crisis can range from home treatment with mild pain killers to hospital attendance for the administration of powerful drugs.

Over time, people living with sickle cell can experience damage to organs, such as the liver, kidneys, lungs, heart and spleen. As a result of these medical complications, a high proportion of this client group experience disability. There is no easy cure, and despite the progress made with bone marrow transplants for children, death is sometimes a further consequence of these complications.

Sickle cell is one of the most common genetic inherited conditions in the UK and in the World. 1 in 77 babies tested in England were found to be sickle cell carriers (i.e. sickle cell trait) - source: NHS Sickle Cell and Thalassaemia (SCT) Screening Programme Data Report 2019 to 2020. Despite improvements in NHS specialised services and clinical care, poor service support, awareness and understanding of sickle cell remain long standing issues which have been evidenced by recent Peer Reviews of NHS Sickle Cell Services and the Sickle Cell and Thalassaemia All Party Parliamentary Report; No One's Listening.

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

### **OUR CORPORATE STATUS**

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

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

# **The Sickle Cell Society**

**Trustees' report (*continued*)  
for the year ended 31 March 2021**

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## **OUR MISSION, AIMS AND OBJECTIVES**

### **CHARITY OBJECTIVES**

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

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

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

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

### **HOW OUR ACTIVITIES DELIVER PUBLIC BENEFIT**

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

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

### **HOW WE ARE ORGANISED**

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

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

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

### **Board development**

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



# **The Sickie Cell Society**

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

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### **Board development (*continued*)**

2021/2022, jointly with the staff team of the Society. All new trustee appointments are open to members and non- members of the Society. All trustee recruitment is by advertisement and application. An interview panel organised by the Chair interviews all shortlisted applicants.

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

### **SUMMARY REVIEW OF 2021/22**

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

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

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

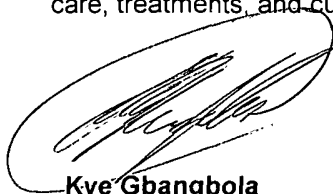
There are many good examples of positive work such as our Give Love Spread Love blood donation campaign, our collaboration with Public Health England on the national sickle cell and thalassaemia screening programme, our exciting programme of activities for young people with sickle cell and of course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

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


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

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

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



**Kye Gbangbola**  
Chair



**John James OBE**  
Chief Executive

# **The Sickle Cell Society**

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

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## **KEY HIGHLIGHTS FROM THE YEAR 2021/2022**

### **STAKEHOLDER RELATIONSHIPS**

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

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

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

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

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

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

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

### **MEMBERSHIP & SUPPORT GROUP BASE**

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

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

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

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

# **The Sickle Cell Society**

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

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### **MEDIA & COMMUNICATION**

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

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

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

### **HELPLINE AND INFORMATION SERVICE**

#### **By Telephone**

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

#### **By Email**

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

### **EDUCATION / INFORMATION AND AWARENESS**

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

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

# **The Sickle Cell Society**

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

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### **EDUCATION / INFORMATION AND AWARENESS (*continued*)**

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

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

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

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

Staff, Trustees and Volunteers continued to provide awareness talks and presentations within local and national businesses, schools, universities, churches, government and corporate organisations in order to raise awareness of sickle cell disorder and the important work of the Society. The majority of these have been done virtually, to adhere to government guidelines.

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

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

### **CORONAVIRUS (COVID-19) & SICKLE CELL DISORDER**

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

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

# **The Sickle Cell Society**

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

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### **WORK ON BEHALF OF THE NHS SCREENING PROGRAMME**

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

#### **Key Project Achievements:**

- SCS conducted three online focus group discussions with a total of 20 individuals (mothers, fathers and non-parents) who gave valuable user perspective on how they would like the Screening Programme to communicate new born sickle cell carrier or positive (i.e. baby has the condition) results.
- The SCS gave key input to the revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway, including recording a video describing how we work collaboratively and help the Programme address any inequalities.
- The SCS presented its work at three training sessions the NHS SCT Screening Programme conducted for nurses, midwives, and health visitors in the North of England.
- Raised awareness of sickle cell and screening by: public talks online (5) newsletter articles (3), Newspaper interview (1), TV interview (1) Workshops (5) Webinars /Conferences (3),
- Outreach using our specially designed social media screening graphics for World Sickle Cell Day, International New Born Screening Day and Rare Disease Day.
- Raised awareness of screening as part of a virtual 2021 advent calendar of Dawn Butler MP

# **The Sickle Cell Society**

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

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### **CHILDREN'S ACTIVITIES**

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

The activities we have ran included:

Arts and Crafts  
Meditation  
Confidence building workshop  
Comedy show  
Quiz Night  
African Dancing and Singing  
Family Empowerment  
Theatre show  
Animal Workshop  
Baking  
Songwriting  
Wellbeing workshop  
Money management workshop

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

Feedback from families include:

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

### **CHILDREN'S HOLIDAY**

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

We had 15 workshop practitioners and 1 BSL Interpreter.

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

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

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

# **The Sickie Cell Society**

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

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### **CHILDREN'S HOLIDAY (*continued*)**

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

### **PARLIAMENTARY & POLICY WORK**

#### **The Sickie Cell & Thalassaemia APPG**

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

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

The key functions of the SCTAPPG parliamentary work:

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

#### **No One's Listening Report**

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

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

# The Sickle Cell Society

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

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### PARLIAMENTARY WORK (*continued*)

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

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

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

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

### SCTAPPG & Key Policy Partners

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



# The Sickle Cell Society

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

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### GIVE BLOOD, SPREAD LOVE, ENGLAND

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

#### **Our achievements in 2021/2022 include:**

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

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

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

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

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

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

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

**Media:** GBSLE featured in 7 online media articles, 3 radio interviews, and 2 podcasts. Our volunteer team were most often at the centre of these appearances, sharing their experiences of living with sickle cell, receiving lifesaving blood transfusions and/or being a repeated blood donor.

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

# The Sickle Cell Society

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

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## GIVE BLOOD SPREAD LOVE

**Volunteer support:** We held 5 volunteer support sessions to enable our team to speak confidently about blood donation and the need for more Black African/Caribbean donors.

In total, via our events and social media, Give Blood, Spread Love, England reached over **9500** people directly, and over **66,000** indirectly, during this project year.

### Example of feedback from our stakeholders:

*"The sessions you have delivered for us have been brilliant and engaging."* **Black-led community organisation**

*"Thank you for such an amazing session. Signing up to donate right now!"* **Event attendee**

*"I love seeing Black and Mixed people give blood as it's so important for our community that we have blood types that match our own."* **Social media follower**

*"Being a volunteer with GBSLE has been a wonderful experience and will continue to be for me, and I wouldn't change it for the world."* **GBSLE Volunteer**

*"I would like to invite you to come on my show at least twice a year to continue to raise awareness."* **Radio presenter**

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

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

The work we have initiated aims to :

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

The project is making good progress. We hope to have education materials that can be used by parents and adult men as well as healthcare professionals during the new financial year 2022/2023.

# **The Sickle Cell Society**

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

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### **GRANTS AND DONATIONS**

During the year the Society made funding applications towards core and restricted projects and initiated or nurtured relationships to help to continue to deliver services. The Society received income of £137,624 from corporate supporters, such as Pharma and Trusts & Foundations during the year 2021/2022.

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

#### **Black History Month – October 2021.**

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

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

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

### **CONTRACTS**

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

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

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

### **PLANS FOR THE FUTURE**

The trustees and staff have worked together to create our new strategy for the next year to 31 March 2023. In doing so we reflected on our journey over the last three years and envisioned what success would look like for the future.

Our five strategic commitments for the next year are;

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

During the process of creating our strategy we experienced a global pandemic in the form of Covid-19. We will therefore be revisiting our new three-year strategy having regard to the global impact of the pandemic and the way in which it has affected the way we work with our SCD community and other stakeholders, our financial outlook and adjust accordingly with regard to the economic and pandemic context.

# The Sickle Cell Society

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

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## TREASURER'S REPORT

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

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

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

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

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



**Michele Salter**  
Treasurer & Vice-Chair

07/09/22

# **The Sickle Cell Society**

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

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### **STATEMENT OF FINANCIAL POLICIES**

#### **Investment Policy**

The Trustees have the power to invest in such assets as they see fit, except for trading purposes. The Society sometimes needs to react very quickly to particular emergencies and has a policy of keeping any surplus funds in short-term deposits, which can be accessed readily. To ensure financial security, the Society needs to secure additional unrestricted funds. The Society's premises were in need of refurbishment to ensure they remain fit for purpose: phase 1 of the refurbishment was completed in November 2021.

#### **Reserves Policy**

The Trustees of the Sickle Cell Society have set a free reserves policy (which represents total unrestricted funds less tangible fixed assets) of maintaining a minimum of three months of the Society's total unrestricted expenditure which was £109,728 at 31 March 2022. This policy was met during the financial year to 31 March 2022, with year-end free reserves of £345,698 (2021 - £323,575), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2021/2022 to ensure that it is appropriate and aligned to the Society's financial performance, assessment of risk and future strategy.

#### **Risk Management**

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

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

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

#### **Financial review**

Income this year stands at £871,742 which is £82,241 higher than the previous year's results. This has been achieved from restricted grant payments of £295,228 and £576,514 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools, training and consultancy, gift aid and communities and contract services.

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

The majority of grants coming into the Society remain under restricted funds to deliver the objectives of the Society. During the year the restricted funds experienced a surplus before transfers of £57,181 (2020/21: deficit of £89,087). The total restricted reserves at the end of the year were £148,253 (2020/21: £217,482).

# **The Sickle Cell Society**

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

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### **FUNDRAISING STATEMENT**

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

The Sickle Cell Society is bound by the Code of Practice dictated by the Fundraising Regulator and should abide by the ethical standards set by the Regulator. We pride ourselves through our fundraising endeavours

and maintain the highest standards possible in order to meet the regulations set. Our approach has always been to safeguard those who are most vulnerable from inappropriate fundraising practices.

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

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

Over the course of the year, the Society has monitored our fundraising actions closely. We received no complaints in relation to any fundraising activities.

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

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

To coincide with our three year organisational strategy we also have produced a new three year 2020/2023 Fundraising strategy.

### **Charity Governance Code**

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

# The Sickle Cell Society

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

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### Trustees' responsibilities

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

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

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

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

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

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

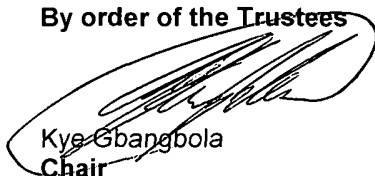
### Provision of information to auditors

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

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

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

By order of the Trustees



Kye Gbangbola  
Chair

Date: 07/09/22

# **The Sickle Cell Society**

## **Independent auditor's report for the year ended 31 March 2022**

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

#### **Opinion**

We have audited the financial statements of The Sickle Cell Society (the 'charitable company') for the year ended 31 March 2022 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### **Basis for opinion**

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

#### **Conclusions relating to going concern**

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

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

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

#### **Other information**

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

We have nothing to report in this regard.



# **The Sickle Cell Society**

## **Independent auditor's report (continued) for the year ended 31 March 2022**

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### **Opinions on other matters prescribed by the Companies Act 2006**

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

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

### **Matters on which we are required to report by exception**

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

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

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

### **Responsibilities of trustees**

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

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

### **Auditor's responsibilities for the audit of the financial statements**

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

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

# The Sickle Cell Society

## Independent auditor's report (continued) for the year ended 31 March 2022


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

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](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

21 September 2022

# The Sickie Cell Society

## Statement of financial activities

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

	Note	Unrestricted funds £	Restricted funds £	Total funds 2022 £	Total Funds 2021 £
<b>Income:</b>					
Voluntary Income	3	576,399	295,228	871,627	789,186
Investment income	4	115	-	115	315
<b>Total income</b>		<b>576,514</b>	<b>295,228</b>	<b>871,742</b>	<b>789,501</b>
<b>Expenditure</b>					
<b>Costs of raising funds</b>					
Fundraising costs	5	189,328	8,260	197,588	133,353
<b>Charitable activities</b>					
Campaign	5	109,151	95,069	204,220	188,176
Direct services group		80,664	32,733	113,397	159,194
Provision of information and advice		46,288	72,230	118,518	100,250
Children's Activities & Holiday		13,483	29,755	43,238	24,401
<b>Total expenditure</b>	5	<b>438,914</b>	<b>238,047</b>	<b>676,961</b>	<b>605,374</b>
<b>Net income for the year before transfers</b>		<b>137,600</b>	<b>57,181</b>	<b>194,781</b>	<b>184,127</b>
Transfer between funds		126,410	(126,410)	-	-
Net movement of funds in year		264,010	(69,229)	194,781	184,127
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>	14	<b>336,802</b>	<b>217,482</b>	<b>554,284</b>	<b>370,158</b>
<b>Total funds carried forward</b>	14	<b>600,812</b>	<b>148,253</b>	<b>749,065</b>	<b>554,284</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 28 to 41 form part of these financial statements.

# The Sickle Cell Society

## Balance sheet at 31 March 2022

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

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

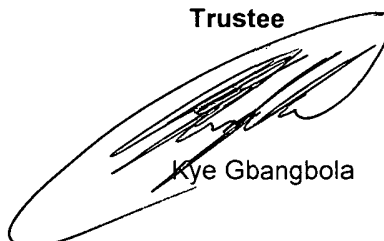
The accounts were approved and authorised for issue by the Board on 07/09/22 and signed on its behalf by:

Trustee



Michele Salter

Trustee



Kye Gbangbola

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

# The Sickle Cell Society

## Statement of cash flows for the year ended 31 March 2022

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

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

# **The Sickle Cell Society**

## **Notes forming part of the financial statements for the year ended 31 March 2022**

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### **1 Accounting policies**

#### **Basis of preparation**

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

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

#### **Going Concern**

The Board of Trustees have produced a forecast for the next 12 months from the date of the financial statement was authorised. This forecast takes into account the potential loss of income as a result of the COVID-19 pandemic and its impact on grants as well as other restricted and unrestricted income. To mitigate the impact on the Charity's income and expenditure, the board has taken action to deliver revenue savings. The Society is actively applying for new grants and exploring new fundraising opportunities for the financial year 2022/2023. In parallel, we are also developing a new 3 year fundraising strategy for the organisation. The forward look forecast for the next 12 months shows that the Charity has sufficient funds and reserves to enable us to meet our obligations as they fall due for a period of at least 12 months from the date when the financial statement is authorised for issue. As such, the board is satisfied that the organisation has adequate resources to continue to operate for at least the next twelve months. For this reason, we continue to adopt the going concern basis for preparing these financial statements.

#### **Stock**

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

#### **Income**

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

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

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

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

# The Sickle Cell Society

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

### 1 Accounting policies (*continued*)

#### Deferred income

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

#### Tangible fixed assets and depreciation

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

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

#### Expenditure

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

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

#### Allocation of Support and Governance costs

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

#### Operating leases

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

#### Pension costs

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

#### Restricted funds

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

#### Unrestricted funds

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

# The Sickle Cell Society

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

### Accounting policies (continued)

#### Designated Funds

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

#### Accounting Estimates and Key Judgements

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

### 2 Legal status of the Society

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

### 3 Voluntary Income

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

### 4 Investment income

	Unrestricted 2022 £	Unrestricted 2021 £
Bank and COIF deposit interest	<u>115</u>	<u>315</u>



# The Sickle Cell Society

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

## 5 Expenditure

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

## Analysis of support costs

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

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

# The Sickle Cell Society

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

<b>6 Staff cost and numbers</b>	<b>2022 £</b>	<b>2021 £</b>
Wages and salaries	280,225	301,301
Social security	23,648	26,680
Pension	47,828	25,532
	<hr/>	<hr/>
	351,701	353,513
	<hr/>	<hr/>

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

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

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

The key management personnel of the Society comprise of the Chief Executive Officer. The total employee benefits of the key management personnel of the Society are £42,949 salary, £30,508 pension and £4,640 NI, total - £78,097 (2021: £62,878).

<b>7 Net Income for the year</b>	<b>2022 £</b>	<b>2021 £</b>
Is stated after charging:		
Depreciation on owned assets	14,904	4,625
Auditors' remuneration (including VAT):		
- Audit fees	10,920	10,404
Equipment rental	3,800	3,634
Property Lease/Rent – 56 Station Road	9,600	9,600
	<hr/>	<hr/>

## 8 Taxation

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

# The Sickle Cell Society

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

## 9 Tangible Fixed Assets

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

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

## 10 Debtors

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

## 11 Grants receivable

	2022 £	2021 £
Public Health England (PHE)	20,819	20,819
	<hr/>	<hr/>
	20,819	20,819
	<hr/>	<hr/>

# The Sickle Cell Society

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

## 12 Cash and cash equivalents

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

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

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

## 13b Deferred Income Reconciliation

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

# The Sickle Cell Society

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

## 14 Analysis of charitable funds

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

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

# The Sickle Cell Society

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

## 14 Analysis of charitable funds (continued)

### Analysis of charitable funds – previous year

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

# The Sickle Cell Society

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

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### 14 Analysis of charitable funds (*continued*)

#### **Restricted Funds**

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

#### **Annual Children's Holiday scheme**

The funding provides respite for parents, carers and families. Each year the Society takes up to 30 children with sickle cell on a residential holiday for a fun packed and educational week. During 2021 - 2022 the Society held a virtual holiday because of the pandemic. A grant of £7,079 was received from Global Blood Therapeutics (GBT) towards 2021 Children's Holiday Activities and £4,030 was transferred from the unrestricted funds to help fund the 2022 Children's Holiday.

#### **Roald Dahl's Marvellous Children's Charity**

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

#### **Jeans for Genes Campaign**

We had planned to use these funds as match funding for the Big Lottery Funding (BLF) however, due to other projects being underspent we did not need to use this fund in the year. We aim to contact the funders during 2021-22 to seek permission to spend the funds on similar activities in line with their funding agreement.

#### **Research and Development**

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

#### **Helpline Worker**

To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families. A transfer of £42,867 was made from the unrestricted funds in 2021/22 to carry out this service.

#### **Mentoring Project**

Young Person's Mentoring Scheme aims to improve the health and wellbeing of young people living with sickle disorder in East London.

# **The Sickle Cell Society**

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

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### **14 Analysis of charitable funds (*continued*)**

#### **Big Lottery – South London Sickle Link**

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

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

The SCTAPPG Project is continue to provide the secretariat of the SCTAPPG. Two restricted grants of £20,000 have been awarded by Novartis and BlueBird Bio respectively. £12,773 was transferred from the unrestricted to help carry out this service.

#### **London Borough of Hackney**

The Society has been commissioned by the London Borough of Hackney by way of a grant of £20,903 to deliver a programme of community activities and engagement sessions for people living with SCD and their families, in the borough.

#### **CLAHRC, LSHTM and Sickle Cell Society Collaborative Project**

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

#### **Office Refurbishment**

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

#### **Digital Marketing – Blood Donation**

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

#### **Public Awareness Campaign – Priapism**

Public Healthcare Awareness Campaign (specifically of priapism targeting Healthcare professionals, young boys, men and parents). £75,000 was received from Boston Scientific International to help to support this project.



# The Sickle Cell Society

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

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

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

# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2021 (*continued*)

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

Kelsey Nagles - Metrobank Raffle

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## 16 Analysis of net assets between funds

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

## Analysis of net assets between funds – previous year

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

## 17 Transfer between funds

During the year the Trustees agreed a transfers of £74,362 (2021: £81,467) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding. Transfers were made to Children's Holiday, Helpline Services, London Borough of Hackney, APPG for Sickle Cell & Thalassaemia Project, Heritage Lottery Fund and Digital Marketing Projects. Transfers were made to the following projects as a requirement of part funding: The Sickle Cell Society part funded London Borough of Hackney and Heritage Lottery Projects, transfers were made to Projects of £4,030, £42,867, £2,370, £12,773, £2,838 and £4,333 respectively to carry out the projects during 2021/2022.

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

# The Sickle Cell Society

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

### 18 Leasing commitments

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

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

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

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

### 20 Related party transactions

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