

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

Charity Reg: 104 6631

The Sickle Cell Society

(A company limited by guarantee)

Report and Audited Financial Statements

Year Ended

31 March 2021

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements for the year ended 31 March 2021

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The Sickle Cell Society

Company information for the year ended 31 March 2021

Patrons:

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

Trustees - Directors

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

Staff

Mr John James OBE	Chief Executive
Ms Iyamide Thomas	NHS Engagement Lead
Ms Miriam Williams	Office Manager/Finance Lead
Ms Ainhoa Munoz	Fundraising Officer
Ms Shahnaz Qizilbash	Helpline & Information Officer (to October 2020)
Mr Matthew Neal	Communications and Social Media Officer
Mr Adam Lloyd	Parliamentary Officer for SCTAPPG
Ms Tracy Williams	South London Gives Project Officer
Ms Stephanie Erivo	Engagement officer (to May 2020)
Ms Ayooluwa Adesanya	Fundraising Data Processor Administrator (to May 2020)
Ms Alinta Sara	Research & Education Co-ordinator
Ms Valerie Oldfield	Helpline & Information Officer (from September 2020)
Ms Taja Morgan	Children's Activity Leader (from July 2020)
Ms Layla Lawson	Hackney Engagement Project Officer (from May 2020)
Ms Olivia Anastasiou	Digital Marketing Officer – Blood Donation (from July 2020)
Ms Sheri Ponle	Helpline & Information Office (from February 2021)
Ms Micaela Valero	Fundraising Data Processor/Administrator (from February 2021)

The Sickle Cell Society

Company information for the year ended 31 March 2021 (*continued*)

Registered address	Sickle Cell Society, 54 Station Road, London NW10 4UA
Telephone number	020 8961 7795
Fax number	020 8961 8346
Website and email address	www.sicklecellsociety.org , info@sicklecellsociety.org
Registered charity number	1046631
Company registration number	2840865
Auditor	PKF Littlejohn LLP, 15 Westferry Circus, Canary Wharf, London E14 4HD
Banker	National Westminster Bank, Park Royal Branch, Abbey Road, London NW10 7RA
Medical Advisors	<p>Dr Nellie Adjaye (Retired) Consultant Community Paediatrician</p> <p>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>

The Sickle Cell Society

Company information
for the year ended 31 March 2021 (*continued*)

Scientific advisors

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

Professor Simon Dyson
De Montfort University, Leicester

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

Dr Elizabeth Dormandy
Consultant in Public Health

Dr Eugene Oteng-Ntim
Consultant Obstetrician
Guy's and St Thomas' Hospital

Dr Moira Dick (Retired)
Consultant Community Paediatrician
King's College Hospital

The Sickie Cell Society

Trustees' report for the year ended 31 March 2021

The Board of Trustees of the Sickie Cell Society present their annual report and audited accounts for the financial year ended 31 March 2021 and confirm that they comply with the requirements of the Companies Act 2006, the Charities Act 2011, as well as the Society's Memorandum of Association (Constitution), and the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard 102 applicable in the UK and Republic of Ireland (FRS 102).

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

THE CONDITION

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

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

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

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

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

OUR CORPORATE STATUS

The Sickie 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**

OUR MISSION, AIMS AND OBJECTIVES

CHARITY OBJECTIVES

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

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

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

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

HOW OUR ACTIVITIES DELIVER PUBLIC BENEFIT

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

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

HOW WE ARE ORGANISED

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

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

The Chief Executive heads a small team of paid staff in addition to a pool of volunteers and is responsible with the Trustees for the strategic direction and for the day-to-day operational activities of the organisation. The Chief Executive reports to the Chair of the Board.

Board development

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

The Sickle Cell Society

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

SUMMARY REVIEW OF 2020-2021

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

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

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

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

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

The Sickle Cell Society

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

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

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



Kye Gbangbola
Chair



John James OBE
Chief Executive

The Sickle Cell Society

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

KEY HIGHLIGHTS FROM THE YEAR 2020-21

STAKEHOLDER RELATIONSHIPS

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

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

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

The Society worked effectively with the NHS Sickle Cell and Thalassaemia Screening Programme, continuing the joint tender with the UK Thalassaemia Society.

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

The Society worked effectively with NHS Clinical Commissioning Groups, London Ambulance Service, Industry, and the UK Thalassaemia Society. Our engagements extend to many organisations including National Council Voluntary Organisations (NCVO); UK Forum on Haemoglobinopathies; National Voices; NHS Blood and Transplant; NHS Trusts; NHS England; Public Health England; National Institute for Health and Care Excellence (NICE); Medicines and Healthcare Products Regulatory Agency (MHRA); Sickle Cell & Thalassaemia Association of Counsellors (STAC) and other voluntary and statutory organisations involved with sickle cell.

The Society worked together with a range of research and improvement organisations, collaborating towards better understanding of Sickle Cell. These collaborations included Kings Health Partnership - part of Kings College Hospital, for work on the Sickle Cell Centre of Excellence, NIHR (National Institute for Health Research), NHS Boards, EMA (European Medical Agency), NHS BT (NHS Blood and Transplant Clinical Trials Unit), UCL (University College London), and Genomics England. This is not an exhaustive list, but it illustrates the breadth of engagement.

The Society has also continued working closely with the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG) through our work as secretariat and with our Parliamentary Officer. The SCTAPPG aims to raise awareness and prioritise sickle cell disorder and other haemoglobin disorders on the political platform.

MEMBERSHIP & SUPPORT GROUP BASE

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

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

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

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

The Sickle Cell Society

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

MEDIA & COMMUNICATION

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

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

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

HELPLINE AND INFORMATION SERVICE

By Telephone

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

By Email

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

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

HACKNEY AND CITY MENTORING SCHEME

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

EDUCATION / INFORMATION AND AWARENESS

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

We also participated and promoted 'Wear Red for Sickle Cell' an awareness initiative to get as many people as possible wearing red and starting conversation around sickle cell. We have participants from across the country, including our patron and actress Ellen Thomas, as well as around the world in places such as the USA and Sierra Leone.

The Sickle Cell Society

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

EDUCATION / INFORMATION AND AWARENESS (continued)

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

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

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

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

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

The Society ran a range of education events specifically about Coronavirus (COVID-19) & Sickle Cell Disorder which you can find in a later section.

CORONAVIRUS (COVID-19) & SICKLE CELL DISORDER

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

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

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

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

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

The Sickle Cell Society

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

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

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

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

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

WORK ON BEHALF OF THE NHS SCREENING PROGRAMME

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

Key Project Achievements:

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

Quote from attendee at Publications launch

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

The Sickle Cell Society

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

CHILDREN'S ACTIVITIES

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

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

Positive feedback that we've received:

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

CHILDREN'S HOLIDAY

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

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

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

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

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

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

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

The Sickle Cell Society

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

HACKNEY ENGAGEMENT PROJECT

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

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

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

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

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

PARLIAMENTARY WORK

COVID-19 research - National Haemoglobinopathy Panel

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

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

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

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

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

The Sickle Cell Society

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

PARLIAMENTARY WORK (*continued*)

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

Submitted work and collaborations with umbrella organisations:

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

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

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

The Sickle Cell Society

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

SOUTH LONDON GIVES

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

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

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

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

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

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

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

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

The Sickle Cell Society

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

GIVE BLOOD SPREAD LOVE

Recognising the urgent need for blood donors from black and mixed-race communities in London and Birmingham, Give Blood, Spread Love uses new media to build awareness, share facts, breakdown myths and direct people to sign up to the blood donation register online, and go a step further by asking peers to do the same.

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

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

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

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

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

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

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

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

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

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

The Sickle Cell Society

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

OUR JOURNEY, OUR STORY

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

The objectives are to:

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

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

Archiving and Research

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

Oral histories

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

Workshops

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

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

The Sickle Cell Society

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

OUR JOURNEY, OUR STORY (*continued*)

Exhibition

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

Public Lecture

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

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

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

Film Editing

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

The Sickle Cell Society

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

GRANTS AND DONATIONS

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

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

CONTRACTS

The Sickle Cell Society continued to support Public Health England (PHE) and NHS BT during the financial year.

The Sickle Cell & Thalassaemia Outreach & Engagement Project is a Public Health England (PHE) funded project in which the Sickle Cell Society works in partnership with the NHS Sickle Cell and Thalassaemia Screening Programme and United Kingdom Thalassaemia Society. Total income for this financial year is £123,703.

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

PLANS FOR THE FUTURE

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

Our five strategic commitments for the next three years are;

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

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

The Sickle Cell Society

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

TREASURER'S REPORT

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

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

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

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

I would therefore like to thank all of our staff and volunteers for their personal support and commitment to the work of the Sickle Cell Society. I would also like to thank my trustee colleagues for their contributions and stewardship and, of course a big thank you to our donors, members, supporters and friends for your unwavering support and indeed, patience in what has been an unprecedented year.



Michele Salter
Treasurer & Vice-Chair

13/10/21

The Sickie Cell Society

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

STATEMENT OF FINANCIAL POLICIES

Investment Policy

The Trustees have the power to invest in such assets as they see fit, except for trading purposes. The Society sometimes needs to react very quickly to particular emergencies and has a policy of keeping any surplus funds in short-term deposits, which can be accessed readily. To ensure financial security, the Society needs to secure additional unrestricted funds. The Society's premises are in need of refurbishment to ensure they remain fit for purpose: this work was planned to be completed by late 2020 but the work was delayed due to the pandemic, estimated date for completion date is now August 2021.

Reserves Policy

The Trustees of the Sickie Cell Society have set a free reserves policy (which represents total unrestricted funds less tangible fixed assets) of maintaining a minimum of three months of the Society's total unrestricted expenditure £94,940. This policy was met during the financial year to 31 March 2021, with year-end free reserves of £323,575 (2020 - £131,917), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2020/2021 to ensure that it is appropriate and aligned to the Society's financial performance, assessment of risk and future strategy.

Risk Management

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

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

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

Financial review

Income this year stands at £789,501, which is £35,650 higher than the previous year's results. This has been achieved from restricted grant payments of £136,526 and £652,660 from unrestricted donations and contracts. The unrestricted donations consist of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools and communities and contract services.

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

The majority of grants coming into the Society remain under restricted funds to deliver the objectives of the Society. During the year the restricted funds experienced a deficit of £89,087 (2019/20: total surplus of £67,305). The total restricted reserves at the end of the year were £217,482 (2019/20: £225,102).

Fundraising Statement

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

The Sickie 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

The Sickle Cell Society

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

Fundraising Statement (*continued*)

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

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

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

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

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

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

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

Charity Governance Code

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

The Sickle Cell Society

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

Trustees' responsibilities

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

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

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

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

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

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

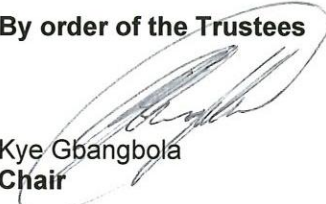
Provision of information to auditors

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

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

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

By order of the Trustees


Kye Gbangbola
Chair

Date: 13/10/21

The Sickle Cell Society

Independent auditor's report for the year ended 31 March 2021

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

Opinion

We have audited the financial statements of The Sickle Cell Society (the 'charitable company') for the year ended 31 March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

We have nothing to report in this regard.

The Sickle Cell Society

Independent auditor's report (continued) for the year ended 31 March 2021

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 2021

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

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

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

Use of our report

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


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

10 November 2021

15 Westferry Circus
Canary Wharf
London E14 4HD

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

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

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

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

The Sickle Cell Society

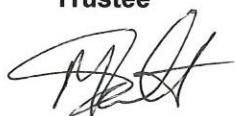
Balance sheet at 31 March 2021

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

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

The accounts were approved and authorised for issue by the Board on 13/10/21 and signed on its behalf by:

Trustee



Michele Salter

Trustee



Kye Gbangbola

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

The Sickle Cell Society

Statement of cash flows for the year ended 31 March 2021

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

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

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2021

1 Accounting policies

Basis of preparation

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

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

Going Concern

The Board of Trustees have produced a forecast for the next 12 months from the date of the financial statement was authorised. This forecast takes into account the potential loss of income as a result of the COVID-19 pandemic and its impact on grants as well as other restricted and unrestricted income. To mitigate the impact on the Charity's income and expenditure, the board has taken action to deliver revenue savings. The Society is actively applying for new grants and exploring new fundraising opportunities for the financial year 2021/2022. In parallel, we are also developing a new 3 year fundraising strategy for the organisation. The forward look forecast for the next 12 months shows that the Charity has sufficient funds and reserves to enable us to meet our obligations as they fall due for a period of at least 12 months from the date when the financial statement is authorised for issue. As such, the board is satisfied that the organisation has adequate resources to continue to operate for at least the next twelve months. For this reason, we continue to adopt the going concern basis for preparing these financial statements.

Stock

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

Income

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

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

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

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

The Sickle Cell Society

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

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 2021 (continued)

Accounting Estimates and Key Judgements

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

2 Legal status of the Society

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

3 Voluntary Income

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

4 Investment income

	Unrestricted 2021 £	Unrestricted 2020 £
Bank and COIF deposit interest	<u>315</u>	<u>1,391</u>

The Sickie Cell Society

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

5 Expenditure

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

Analysis of support costs

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

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

The Sickle Cell Society

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

6 Staff cost and numbers	2021 £	2020 £
Wages and salaries	301,301	306,290
Social security	26,680	27,432
Pension	25,532	27,137
	<hr/>	<hr/>
	353,512	360,859
	<hr/>	<hr/>

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

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

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

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

7 Net Income for the year	2021 £	2020 £
Is stated after charging:		
Depreciation on owned assets	4,625	5,036
Auditors' remuneration (including VAT):		
- Audit fees	10,404	10,200
Equipment rental	3,634	3,508
	<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 2021 (*continued*)

9 Tangible fixed assets

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

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

10 Debtors

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

11 Grants receivable

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

The Sickle Cell Society

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

12 Cash and cash equivalents

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

13a Creditors - amounts falling due within one year

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

13b Deferred Income Reconciliation

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

The Sickle Cell Society

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

14 Analysis of charitable funds

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

14 Analysis of charitable funds (continued)

Analysis of charitable funds – previous year

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

The Sickle Cell Society

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

14 Analysis of charitable funds (continued)

Restricted Funds

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

Annual Children's Holiday scheme

The funding provides respite for parents, carers and families. Each year the Society takes up to 30 children with sickle cell on a residential holiday for a fun packed and educational week. During 2020-2021 the Society held a virtual holiday because of the pandemic. £5,255 was transferred from the unrestricted funds to help fund the 2020 Children's Holiday.

Roald Dahl's Marvellous Children's Charity

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

Jeans for Genes Campaign

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

Research and Development

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

Brent Council (London Borough of Brent)

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

Helpline Worker

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

Hackney CCG

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

Mentoring Project

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

The Sickle Cell Society

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

14 Analysis of charitable funds (*continued*)

BBC Children in Need (BBC CiN)

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

Big Lottery – South London Sickle Link

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

Patient Education & Training

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

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

During the year 2020-21, the Society in collaboration with the UK Thalassaemia Society have taken on the responsibility for providing the secretariat of the SCTAPPG. Two restricted grants of £20,833 have been awarded by Novartis and BlueBird Bio respectively. £12,477 was transferred from the unrestricted to help carry out this service.

London Borough of Hackney

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

CLAHRC, LSHTM and Sickle Cell Society Collaborative Project

Following the work of the BUPA-funded 'Self Over Sickle' project which provides advice, support and testimonials for young adults around transition, this work will drive visibility of the person behind the sickle cell via an ad campaign in London and aim to build confidence of young adults with the condition via an online resource pack signposting services and techniques to enhance one's quality of life living with sickle cell. This project ended in December 2019 with a small underspend.

Office Refurbishment

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

Digital Marketing – Blood Donation

A grant of £24,066 was received from Terumo BCT to complement the South London Gives programme which aims to increase the number of black people donating blood in areas beyond South London. Give Blood, Spread Love uses new media to build awareness, share facts, breakdown myths and direct people to sign up to the blood donation register online, and go a step further by asking peers to do the same.

The Sickle Cell Society

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

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

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

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)

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

16 Analysis of net assets between funds

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

Analysis of net assets between funds – previous year

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

17 Transfer between funds

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

The Sickle Cell Society

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

18 Leasing commitments

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

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

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

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

20 Analysis of cash and cash equivalents

	2021 £	2020 £
Cash in Hand	630,912	455,108
	<hr/>	<hr/>
	630,912	455,108
	<hr/>	<hr/>

21 Related party transactions

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