



*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 2020

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2020

Contents

Page:

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

The Sickle Cell Society

Company information for the year ended 31 March 2020

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	

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
Mr Matthew Neal	Communications and Social Media Officer
Mr Adam Lloyd	Parliamentary Officer for Sickle Cell and Thalassaemia All Party Parliamentary Group - SCTAPPG
Ms Tracy Williams	South London Gives Project Officer
Ms Stephanie Erivo	Engagement officer (from May 2019)
Ms Ayooluwa Adesanya	Fundraising Data Processor Administrator (from May 2019)
Ms Alinta Sara	Research & Education Co-ordinator (from August 2019)
Ms Valerie Oldfield	Community Support Worker (to September 2019)
Mrs Donna Prendergast	South London Community Manager (to September 2019)
Ms Siann Millanaise	Patient Education & Training Lead (to December 2019)

The Sickle Cell Society

Company information for the year ended 31 March 2020 (*continued*)

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

The Sickle Cell Society

Company information
for the year ended 31 March 2020 (*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 Sickle Cell Society

Trustees' report for the year ended 31 March 2020

The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2020 and confirm that they comply with the requirements of the Companies Act 2006, the Charities Act 2011, as well as the Society's Memorandum of Association (Constitution), and the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard 102 applicable in the UK and Republic of Ireland (FRS 102).

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

THE CONDITION

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

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

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

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

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

OUR CORPORATE STATUS

The Sickle Cell Society was founded in 1979 by a group of healthcare professionals, individuals and families affected by sickle cell. The Society was later established under a Memorandum of Association with the objects and powers of a charitable company and is governed under its Articles of Associations, 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 2020

OUR MISSION, AIMS AND OBJECTIVES

CHARITY OBJECTIVES

Our Charity purpose as set out in the objects contained in the Company's Memorandum of Association is:

- 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 2019/20, jointly with the staff team of the Society.

The Sickle Cell Society

Trustees' report
for the year ended 31 March 2020

SUMMARY REVIEW OF 2019-2020

This report showcases the many positive ways in which we support people living with sickle cell at a national level and increasingly with a global perspective. It also shows our stewardship of the kind donations we receive and the grants we secure. Working closely with a range of partners and service users we have worked really hard to translate our aims and objectives into visible improvements and impact for people living with sickle cell and their families.

This year we have continued to see turbulence because of funding constraints, political uncertainty, and high expectations of the sickle cell community and other partners.

Despite these circumstances, we have achieved a great number of things this year, including:

- Publishing the Hackney and City Mentoring Scheme in the British Journal of Haematology and presenting at the British Society of Haematology Conference in Glasgow in April 2019;
- Hosting several education days, focusing on key issues including employment, the Infected Blood Enquiry and clinical trials;
- Established a Sickle Cell Society archive as part of the Our Journey, Our Story heritage project;
- Published the third edition of *Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care*;
- Saw the successful completion of the South London Link and Self Over Sickle projects;
- Continued working with NHS England on the Sickle Cell Service Review, seeing the establishment of Haemoglobinopathies Coordinating Centres (HCCs) as well as the National Haemoglobinopathy Panel (NHP) across the country;
- Celebrated our 40th Anniversary with a celebratory Gala Ball hosted at the Royal National Hotel and with guests including service users, politicians, celebrities, healthcare professionals and other key Sickle Cell Society supporters;
- Continued our partnership with NHS Blood and Transplant to promote the recruitment of black heritage blood donors through the South London Gives project;
- Published *End the Blood Tax: An investigation into the impact of prescription charges for those living with sickle cell and thalassaemia* through our role as secretariat of the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG);
- Continuing to work with pharmaceutical companies on clinical trials for potentially new sickle cell modifying drugs; and
- Continuing collaborations with the Kings Fund and GSK through their leadership development programme, learning and sharing learning alongside other diverse charity leaders across the UK.

The Coronavirus (COVID-19) pandemic has had a massive impact on those living with sickle cell and their families and carers. We have worked hard to ensure sickle cell was included on shielding list and have worked with our medical advisers to keep our website up to date with the latest Coronavirus related guidance.

We know that the next year we will continue to see significant COVID-19 related turbulence and challenges. Despite this, we remain committed to supporting the sickle cell community, our staff and volunteers and continuing the positive work we have done, doing so with good governance, transparency and accountability.

We hope you enjoy reading this account of our activities and achievements in 2019/20 and that it will provide you with a deeper 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 2020

KEY HIGHLIGHTS FROM THE YEAR 2019-20

STAKEHOLDER RELATIONSHIPS

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

The Society worked effectively with NHS Clinical Commissioning Groups, London Ambulance Service, Industry, and the UK Thalassaemia Society. Our engagements extend to many organisations including National Council Voluntary Organisations (NCVO); UK Forum on Haemoglobinopathies; National Voices; NHS Blood and Transplant; NHS Trusts; NHS England; Public Health England; 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, MHRA (Medicines and Healthcare Products Regulatory Agency), NIHR (National Institute for Health Research), NHS Boards, EMA (European Medical Agency), NICE (National Institute of Health And Care Excellence), NHS BT (NHS Blood and Transplant Clinical Trials Unit), UCL (University College London). 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 3000. 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 2020

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, and Instagram. The Society has seen a significant increase in social media followings.

The Society's Instagram gained over 800 followers, the Society's Facebook gained almost 500 likes, and the Society's Twitter gained over 1000 followers.

The Sickle Cell Society website received, on average, 24,000 views per month.

HELPLINE AND INFORMATION SERVICE

Telephone calls

During 2019/20 the Sickle Cell Society received 628 calls, a total of 7,385 minutes (approximately 123 hours per annum). This was a decrease from 2018/2019 where we received 898 phone calls.

Of all the callers, 70% were new callers. The Society provided information and support for 70% of all calls, with 77% receiving information, support, or being signposted to relevant places. The most popular topics of calls were fundraising for support groups and events, managing sickle cell, benefits and awareness, and 'other'.

Emails

During 2019/20 the Sickle Cell Society Helpline received 1,070 emails. In 2018/2019 we received 1066 emails so this number has remained stable.

The Helpline provided information and support to 65% of those emails (with 76% receiving information, support or being signposted to relevant places).

HACKNEY AND CITY MENTORING SCHEME

This year our mentoring programme was published in the British Journal of Haematology in Spring of 2019. The coverage outlined the outcomes of the model on children and young people. Our mentors then presented their work at the British Society of Haematology Conference in Glasgow in April 2019.

The Society is in early conversations with all of the East London Clinical Commissioning Groups (CCGs) across the 7 boroughs about the potential expansion of the City and Hackney Sickle Cell Peer Mentoring Programme, which we have successfully piloted over the last 2 years.

Whilst these conversations are taking place, the programme has to pause referrals to manage demand and capacity, to ensure that the expansion across East London is successful. The break commenced from 30 June 2019: we hope the programme will resume in late 2020 with sufficient support to continue the expansion.

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 celebrated with an online awareness campaign, speaking at the GASCDO WSCD Global Conference, sharing through our membership, website and social media information and graphics.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

KEY HIGHLIGHTS FROM THE YEAR 2019-20

The Society maintained its Information Standard Certification. The scheme was developed by the Department of Health to help the public identify high quality, evidence-based health and social care information. The Information Standard is undergoing a change in how it operates. We have been involved in the process, with the aim that the new model will be even better at helping the public access high-quality information.

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 24,000 views per month.

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

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

The Society ran two education days, one in London which focused on men living with sickle cell and one as part of our 40th AGM in July which focused on the Infected Blood Enquiry, clinical trials and the Sickle Cell Work and Employment guide.

WORK ON BEHALF OF THE NHS SCREENING PROGRAMME

From 1 April 2019 – 31 March 2020 the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) worked on the second year of a collaborative tender with the NHS Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) which officially commenced on 15 August 2018. The tender which commissions the Societies to work collaboratively with the Programme to improve its service provision is expected to be funded for a period of 3-5 years.

Key Project Achievements:

- A new edition of the publication 'Sickle cell disease in childhood: standards and guidelines for clinical care' (last updated in 2010) - the new edition is available on the Society's website. This followed a successful national consultation among health professionals and other relevant stakeholders including NHS England, National Haemoglobinopathy Registry Steering Group and parents (from 32 parents and 25 health professionals).
- Successful consultation together with parents of children with sickle cell, both in person and online. The feedback will be input into the updated edition of the 'Parents' Guide to Managing Sickle Cell Disease', due to be launched in 2020.
- As part of a working group, the Sickle Cell Society were able to provide service user perspective in the review and updating of sickle cell and thalassaemia counselling competences, which will be launched in late 2020.
- Network building included public talks (6) newsletter articles (2), TV appearances (2) stalls (2) Roundtable /Conferences (3) used to raise awareness of sickle cell, screening and the findings and recommendations from the 'Parent Stories' publication which tells individuals personal experiences of sickle cell and thalassaemia screening.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2020

SCREENING PROGRAMME (*continued*)

- The SCS in collaboration with UKTS produced 4 user-friendly information posters to raise awareness of sickle cell, thalassaemia and screening. These will be distributed in 2020.

Quotes from parents from the handbook consultation

"The book is like the sickle cell bible, very useful."

"I personally have learnt so much from this book. It has been like our second doctor in my house".

"I was afraid but after I read the book, I said ok people are managing it so why don't I."

Support for the new paediatric standards:

Rt. Hon. Pat McFadden MP, Chair of the All Party Parliamentary Group on Sickle Cell and Thalassaemia stated: *"I welcome the publication of these updated standards for sickle cell care among children and thank the Sickle Cell Society and everyone involved in the preparation of this document. I very much hope these standards will be used by health professionals and NHS trusts to improve sickle cell care for children and to ensure consistency of treatment around the country. Sickle cell is a very challenging condition for families to cope with and the dissemination of good standards in care is really important"*.

CHILDREN'S HOLIDAY

From the 10th to 14th August we took 30 children with sickle cell on an adventure holiday to Conover Hall. Alongside learning about their sickle cell, the children experienced activities such as laser conquest, high ropes, caving and archery, as well as evening activities such as a talent show and disco. The children, who were split into three teams based on age group again, slept in shared dormitory rooms split by gender with bunk beds to give a real 'summer camp' feel to their experience.

The children reported that "this was the best holiday ever" and particularly learnt lots about sickle cell and how they "can do anything they believe" despite their condition. They told us they learned confidence, perseverance and lots of practical physical skills. Their favourite parts were the campfire, laser conquest, ariel trek and making lots of new friends.

The volunteers were great! A mixture of experienced and new volunteers made up the teams, providing lots of encouragement and positive energy which helped the children feel confident, supported and safe during the holiday.

The parents were absolutely thrilled with how the holiday went. In their feedback they reported that their children had grown in confidence and they were especially pleased with the knowledge that their children had gained about sickle cell. All commented that communication had been particularly good and almost all said that their child had made new friends. The WhatsApp group was enjoyed this year too!

From the wonderful feedback received from those attending, it was clear that the holiday was yet another real success.

Quotes from participants:

- *"My favourite part of camp was making friends and learning about other people's experiences"* – Camper
- *"I learnt that we are not alone with our condition and it is really easy to meet people who have sickle cell"* – Camper
- *"Huge Thank you. I got the 1st break in 9 years. I wasn't stressed either because I knew she would be taken care of"* – Parent
- *"I had an excellent time and will absolutely be volunteering next year. Fantastic experience overall"* – Volunteer

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

SICKLE CELL SOUTH LONDON LINK

April 2019 - September 2019

Children's Activities

For the last 6 months of Year 3 we have held 4 workshops, 1 family day, 1 activity day, 1 volunteer gathering and a sickle cell play to the local community in Brixton. We have had 31 children attend the activities.

Over the course of Year 3 we have provided 16 activities, 11 workshops for adults living with SCD & Parents/Carers, teenagers/young children, 1 sickle cell play, 1 volunteer gathering and a Family Fun Day. The educational aspect covered areas such as healthy eating, transitioning, managing pain, school and friendships.

Information Workshops

These have been attended by approximately 59 adults in the second half of year 3. Attendees reported that the workshops had helped them to reduce their isolation, and become more engaged in their community. Topics included first aid training, supporting someone living with sickle cell, and healthy eating. Service users mainly hear about us through three mediums: hospitals, our Sickle Cell Society Facebook page and via support groups. We have also had a project website page added to our organization website (Sickle Cell Society) where people can find out more about our project as well as register for more project information.

Volunteers

The project has also recruited 9 new volunteers, building on the 20 previously recruited in Year 1 & 2. In total we have recruited 61 volunteers over the last 3 years and retained 54. The volunteers have been assisting with the children's activities, information workshops, fundraising events and some administration work. Volunteers have also assisted with other SCS projects such as 'Self Over Sickle' & 'South London Gives'. Of these volunteers we have some adults who live with sickle cell and others who have either sickle cell trait, or a member affected by sickle cell or do not have sickle cell or trait or a family member affected but wish to support the project activities and raise awareness.

Support Groups

We also have a parent WhatsApp group which is an extension of the new parents tri-borough support group that has been developed over the life-span of the project. There are 31 parents actively using the group to share resources, advice and garner support. Parents from the group also meet one another outside of the project activities. Our colleague Iyamide Thomas also has a WhatsApp group that has around 60 service users and we have also used this to circulate events, information and resources.

We have engaged both adults and children/young people living with sickle cell, and parents/carers in support groups with days out and workshops to increase peer 2 peer support. While children aged between 12-16 have been harder to engage we found that the number attending the support groups is slowly increasing and we are building on this by providing meets that include educational learning about how to manage and live with sickle cell.

6 different support groups (14 attendees in total) participated in our Collaborative Working Support Group Building Capabilities workshop. Post workshop feedback from all 6 groups highlighted increased governance, management and promotion skills, as a result of the intervention.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

SICKLE CELL SOUTH LONDON LINK (*continued*)

The intervention included skills development in the following areas:

- Brainstorming ideas on what is collaborative working
- How support groups might work collaboratively with each other and the SCS
- Frameworks for collaborative working
- How to create an action plan
- Consultancy work and Networking

Alongside this, we continued to provide support groups with links (and include these on our website) to third party resources and organisations that support groups can use to build capacity. At these workshops attendees have raised issues such as lack of resources, lack of knowledge within their services to offer support groups. To help with this we have also signposted and helped members of staff across different hospital services link and share knowledge and resources, in addition these meetings have helped nurses and service users to link with one another. We have used various mediums such as verbal communication, email and face to face to build rapport with individuals who run the various support groups and build relationships.

We also held a training programme for volunteers and support groups (May 2019) which covered first aid training.

Alongside this we have provided support groups with links (and include these on our website) to third party resources and organisations that support groups can use to build capacity. In addition, we disseminate our Society leaflets that support groups can give out to their service users. We have used various mediums such as verbal communication, email and face to face to build rapport with individuals who run the various support groups and build relationships.

HACKNEY ENGAGEMENT PROJECT

The 2019/20 project has focused on addressing a number of key issues which had been highlighted by previous years' feedback and information. These areas were: community support for people with sickle cell, awareness and screening, improving the sickle cell experience in education, managing health and wellbeing.

Events organised to focus on these issues included a forum event, men's discussion, children's activity day and party. Due to the COVID-19 pandemic other planned events which included a health and wellbeing fair and teen logging workshop, could not take place. Instead of cancelling a women's health and wellbeing event which was also due to take place, care packages were sent out to 20 women who were either parents/carers or living with sickle cell themselves.

The project's efforts to raise awareness were demonstrated through drop-in clinics at local community spaces, outreach at a range of community events such as university open days and local community events, forum meetings and connecting with local and government organisations. The aim at any and all events was to make individuals with sickle cell aware of the support available in the borough and to make individuals and organisations without sickle cell, more aware of the disorder, not only for prevention but social action. This allowed the project to reach a wider audience and opened the doors to a number of important collaborations.

Two exciting project collaborations which have come from the projects network building efforts are: The development of a 'Sickle cell in education project' in partnership with New City College Hackney and Clapton Girls school. The project will focus on improving the education experience of students with sickle cell through creative activities that raise awareness and inform change and by offering training to teachers and other educational staff to better equip them to care for students with SCD.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

HACKNEY ENGAGEMENT PROJECT (*continued*)

The second is a monthly health and wellbeing workshop and drop-in service run in partnership with the leisure and physical activity team at Hackney council. The service is designed to meet the health and wellbeing needs of Black and Minority ethnic groups in Hackney living with long term health conditions, such as sickle cell, Lupus and MS, by focusing on holistic, mental, physical and nutritional health.

SICKLE CELL SERVICE REVIEW

Over 2018 and 2019 the Society worked on the Sickle Cell Service Review (Haemoglobinopathy Service Review) by an extensive consultation project with sickle cell patients, carers and supporters in response to NHS England's (NHSE) planned changes to sickle cell services. This year, after this extensive consultation, NHSE have introduced Haemoglobinopathies Coordinating Centres (HCCs).

HCCs are responsible for coordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services. HCCs aim to support hospitals in their area who have less expertise in these conditions, to make sure all patients have access to specialist advice when needed. This will involve offering training and advice to less experienced hospitals.

You can see the full list of HCCs including sickle cell and thalassaemia, the National Haemoglobinopathy Panel (NHP), and Specialist Haemoglobinopathies Teams (SHTs) at our website:
<https://www.sicklecellsociety.org/servicereview/>

40TH ANNIVERSARY GALA BALL

On Saturday 14th September we joined with supporters, service users, patrons and celebrity guests at a glamorous dinner and dance to celebrate the progress that has been made.

Hosted in the Royal National Hotel, the evening opened with a red carpet drinks reception before Chair of Trustees, Kye Gbangbola, opened the event with a powerful call to action for continued support and donations. The Master of Ceremonies, Chizzy Akudolu (Actress: *Holby City*, *Dead Set*, *Jinx*), then took to the stage to welcome guests and set the celebratory tone of the evening.

The guests then enjoyed a delicious three course meal; many sat at tables hosted by celebrities including: Alison Hammond (Television Personality, TV Presenter on *This Morning*), Rudolph Walker OBE (Actor: *Eastenders*, *The Thin Blue Line*, *King Ralph*), Baroness Floella Benjamin OBE (SCS Patron, Actress, Writer, Campaigner), and Kym Mazelle (1st Lady of House Music, 2X Grammy Nominated Recording Artist).

The evening saw performances from: London rapper, and sickle cell advocate, A Star; Soul/R&B singer and songwriter, Shaila Prospere; Coronation Street and *The Royals* actress, Victoria Ekanoye; and the Official NHS Blood and Transplant Choir and Britain's Got Talent finalists, B Positive.

The evening also saw a fundraising raffle and auction hosted by founding member and patron, Professor Dame Elizabeth Anionwu and Chizzy Akudolu.

Garfield Robinson of *The Voice* newspaper then gave a few words and presented the Society with a framed article detailing the history of the Sickle Cell Society. The piece came from a 4-page spread on the Sickle Cell Society in the most recent edition of *The Voice*. Copies of the newspaper were also donated for the guest's goody-bags.

Chief Executive, John James OBE, was then welcomed to the stage to thank those involved in making the evening happen and to say a few inspiring words about the next 40 years. Chizzy Akudolu then closed the formal part of the evening and opened up the dance floor.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

ANNUAL THANKSGIVING SERVICE

To mark 40 years of serving the sickle cell community, the Sickle Cell Society held a Thanksgiving and Celebration Service at St Marks Church, Kennington. The theme for this years' service was '40 Years of Caring' and was a time to reflect on the progress made so far, remember those who have passed away and look forward to the future. Rev Canon Stephen Coulson gave the welcome and this was followed by readings, prayers and traditional hymns. Readings and prayers were given by sickle cell supporters, service users, carers and health care professionals.

The address was delivered by Rev. Rose Hudson-Wilkin, Chaplain to the Speaker of the House of Commons and was an inspirational Christian message with a bit of good humour thrown in. Rev Hudson-Wilkin also pledged her support by offering to be a blood donor for our South London Gives Project which was there to encourage attendees to sign up as blood donors.

There were also talks from Cllr Ibrahim Dogus, Mayor of Lambeth, John James OBE (Chief Executive SCS) and Michele Salter (Vice Chair SCS). To set the celebratory tone the service also included musical performances from soloist Savannah Hall and Classic Brit Award nominees, Classical Reflection.

The Thanksgiving and Celebration Service was also an opportunity to raise funds to support the work of the Sickle Cell Society. Over £575 was raised which will go to improving sickle cell care at a local and national level.

PARLIAMENTARY WORK

General

An annual work plan has been devised setting out the APPG's schedule for the year ahead. As cited in the funding proposal, there will be four APPG meetings plus one Annual General Meeting. Each meeting will have a particular focus concerning a policy issue. One of the meetings in question will be a regional meeting, whereby it will serve as an opportunity to hone in on a 'local' issue.

SCTAPPG achievements

In the last calendar year (2019), the Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) secretariat service under the auspices of the Sickle Cell Society has rerecorded the following achievements of the SCTAPPG:

All events have been consistently well attended with large appetite from service user to utilise SCTAPPG as vehicle in which to tell their story and share their experiences. The forum has had a host of stakeholders from parliamentarians to journalists, from clinicians to patients. Each meeting has had in the region of 50/60 attendees.

The SCTAPPG launched a new report in parliament in June 2019. The report, titled 'End the Blood Tax', covered the impact of prescription charges for those living with sickle cell and thalassaemia.

The report and consultation has captured the hearts and minds of service users, clinicians and parliamentarians, all united in their desire to acquire exemption for those living with sickle cell and thalassaemia and all other long term health conditions. There are countless anecdotal reports from qualified nurses, doctors, other allied health care professionals, and most significantly service users about the effect of prescription charges on the day-day lives of service users. This had provided an insight into the struggle and human cost that endless prescription charges present to those living with sickle cell disorder and thalassaemia.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2020

PARLIAMENTARY WORK (*continued*)

It offers an insight into the real life experiences of those living with sickle cell disorder and thalassaemia and how prescription charges impact their daily lives. The objective of the research is to enable our service users to have a voice in this debate and provide a condition specific analysis of how prescription charges affect their day-day lives. We hope this report can serve to add to the mounting body of evidence, which is as clear as it is vital, to exempt those with long term conditions from these charges.

- Since the meeting, the Chair has written to the Department of Health and Social Care (DHSC) and Health Select Committee to discuss the findings and recommendations of the report. Vice Chair Janet Daby MP looked to apply pressure on this matter with an oral question in the House of Commons to Secretary of State for Health and Social Care, Matt Hancock, who agreed to investigate these concerns.
- The All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG), launched a report titled *A Guide to Sickle Cell and Employment*. The report was authored by a project team called Barriers and Enablers to Employment: Black Disabled Peoples Living with Sickle Cell Disorder. The basis of research was funded by the Big Lottery and DRILL (Disability Research Independent Living and Learning), a research grant held by Professor Simon Dyson and Dr. Maria Berghs (De Montfort University); the Sickle Cell Society and OSCAR Sandwell. The report presentation featured service users, presenting personal insight into how their sickle cell affects them in the workplace, with the aim to shine a light on a major issue for the sickle cell and thalassaemia community.
- The SCTAPPG had its Annual General Meeting (AGM) on 26th February of this year where it re-established its status as an APPG for this parliament. The election of officers and a discussion of the groups business for the year ahead took place. The following officers were elected:
 - Chair & Registered Contact: Rt Hon Pat McFadden MP
 - Vice-Chair: Janet Daby MP
 - Officer: Jess Phillips MP
 - Officer: Baroness Benjamin
 - Officer: Dawn Butler MP
 - Officer: Kate Osamor MP
 - Officer: Bell Addy-Riberio MP
 - Officer: Sir David Amess MP
 - Officer: Helen Grant MP
- SCTAPPG has met with Chief Executive and Registrar, Andrea Sutcliffe and Director of Education and Standards, Dr Geraldine Walters from Nursing and Midwifery Council to discuss whether the Nursing and Midwifery Council should use their new (2018) Standards for pre-registration nursing education when revalidating all nursing curricula in 2019 and beyond, to ensure that they are committed to addressing key aspects of equality and diversity. We urged them to monitor more closely and enforce existing standards to ensure there is commitment from educational providers to maintain equity in educational subject content and evaluation. The meeting was cordial and constructive and we look forward to meeting with them in order to ensure Equality, Diversity and Inclusion are at the forefront of their thinking when thinking about sickle cell and thalassaemia.
- SCTAPPG is also to meet with Liz Fenton RN, Queen's Nurse, Deputy Chief Nurse at Health Education England (HEE) to discuss the ways in which the body can ensure how they shape the public health workforce with the demographic change ongoing. This is particularly relevant given how sickle cell and thalassaemia affect those from the BAME community. The report's findings state that most pre-registration nurses are graduating without the knowledge and understanding of the two genetic blood disorders, hence it is vital that HEE is doing their utmost once these

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2020

PARLIAMENTARY WORK (*continued*)

nurses enter the workforce. They agreed to fund and develop an e-module to provide registered nurses with a foundation introduction into sickle cell and thalassemia, this will be done in conjunction with the Royal College of Nursing.

- SCTAPPG also raised the issues of Sickle Cell Carriers and Military Officer deaths on 26th February 2020. Raising the profile of these issues is an important ongoing task.

SOUTH LONDON GIVES

From 1 April 2019 to 31 March 2020 South London Gives (SLG), Sickle Cell Society's blood donation project, planned and delivered a range of awareness raising, engagement and blood donor recruitment activities designed to increase the numbers of people of black heritage who regularly donate blood.

SLG has been funded by NHS Blood and Transplant from January 2019 and will run until April 2021. The project involves a team of trained volunteers (Community Advocates) who promote the need for more ethnically matched blood to treat those most severely affected by sickle cell disorder. They engage with black heritage communities in various settings, initiate conversations about blood donation and address some common barriers to giving blood that are particularly prevalent in some of our target communities.

Key achievements:

- Development of a 3-stage training programme for project volunteers
- Recruitment and training of 16 Community Advocates
- Attendance at 30 blood donation recruitment events in community, corporate and faith venues
- Signing up of 499 new people of African and Caribbean heritage to the blood donation register

In addition to the above, South London Gives has secured strong partnerships with a range of organisations who have supported the project to engage with their audiences. This includes 3 black majority churches in south London who have pledged to regularly promote blood donation in their work and a high profile appearance on Premier Christian Radio in January 2020 which enabled South London Gives to widely promote its call for more black and mixed race donors to come forward.

Key to SLG's success is the telling of our volunteer's personal stories about blood donation and sickle cell. For some, receiving regular blood transfusions save their own lives or that of their loved ones. These powerful testimonies form a central part of our presentations and conversations with potential donors and help us overcome some of the significant and embedded concerns and fears that can prevent people giving blood.

SELF OVER SICKLE

The Self Over Sickle project was designed 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 project came to an end in July 2019.

This year the Self Over Sickle project produced 4 podcasts (two live episodes and two pre-recorded episodes) covering topics ranging from relationships, careers and support services. As well as the live recordings, the project ran in-person events to raise awareness and build community.

The project also ran a 40-day social media challenge which focused on raising awareness, improving wellness and getting to know the sickle cell warriors and extended advocate family.

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

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.

Establishment of the SCS archives at the Wellcome

In addition to the SCS archival materials, we collected archives from other researchers such as Simon Dyson. We liaised with the Wellcome Collection teams who estimated that there were 25 boxes of materials. The SCS and the Wellcome collection established an agreement to acquire the archives at the end of the project. The Wellcome provided the Sickle Cell Society with boxes, before the lockdown, we started filing, and selecting some of the materials. As for the oral histories will be made on a case-by-case basis as they are submitted to the Wellcome Trust.

Heritage workshops engaging young people

We liaised with various partners to organise workshops with young people. These workshops will happen in April, May and June. We planned two workshops with OSCAR Birmingham and OSCAR Sandwell for Easter and May holidays. Due to the impacts of COVID-19 we made the decision to postpone the workshops until later in the year. Depending on the government guidance we will offer an online format. We also worked with Imperial College to take part in their summer festival.

Exhibition/Film

We held several meetings with the Black Cultural Archives (BCA) and confirmed that the exhibition will take place at the end of 2020. We shortlisted two filmmakers and we had a meeting Hat Trick production who offered some in-kind support. The filming was postponed due to COVID 19, and we are looking now at alternatives.

We are now developing an online presence. We created an Instagram page that has 60 followers at the moment. We published a campaign in the Voice Newspaper which achieves national coverage.

The Science Museum

A new display featuring a model of a red blood cell showing abnormalities was added to the display in Medicine: The Wellcome Galleries. Science Museum research fellow Shelley Angelie Saggar shows how Thalassemia and Sickle Cell have been perceived culturally throughout history.

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2020

GRANTS AND DONATIONS

The Sickle Cell Society was awarded a restricted grant of £41,000 from Global Make some Noise, the grant will be used over 2 financial years (2020-21 to 2021-22) to carry out our Children's Activities Program.

Terumo BCT provided a restricted grant of £24,066 towards the South London Gives Project which will be used in financial year 2020-21.

GBT donated £15,000 towards the Sickle Cell Society 40th Anniversary Fundraising Gala Ball.

Nova Labs donated £10,000 to support collaborative work between the Sickle Cell Society and Nova Laboratories.

Imara supported the Society by donating £7,000 towards one of our Patient Education Day held in July 2019 at the Grand Connaught Rooms.

Donation of £5,000 was received from Ms Patience Adegbite during the year, through Stewardship.

During the year The Sickle Cell Society received grants of £4,000 from PF Charitable Trust and £4,253 from Global Blood Therapeutics INC towards the Helpline and Information Service.

Employees at OdysseyRe and Newline Group in London donated £3,000 (£1,500 towards research and £1,500 towards unrestricted funds).

NatWest Markets Born to Survive team through their fundraising efforts raised £2,231, matched by NatWest (£1,750), bringing the total to £3,981.

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 £120,100.

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 £53,749.

PLANS FOR THE FUTURE

This draft strategy for 2018-20 cross-references the Fundraising, Membership and Communications Strategy. It is built on the following 6 priorities, as agreed at the Board and Staff Away Days and influenced by discussions at the AGM Education session. These priorities are:

- **Engagement** – covers membership and reach. It includes building and strengthening Support Groups, plus fundraising and media matters
- **Financially sound** – covers the actions set out in the Fundraising, Membership & Communications Strategy to develop and diversify the Society's income base. Also to continue strong financial discipline of the Society's financial resources
- **Well Led** – covers governance, including the role and wellbeing of trustees, staff and volunteers
- **Influence and Impact** – covers ongoing dialogue with policy makers and funders which advocates for the needs of people with Sickle Cell and their families

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

PLANS FOR THE FUTURE (*Continued*)

- **Making a difference for Children and Young People with Sickle Cell** - covers building on the work done with the Picker Institute and the feedback from the Society's membership on next steps
- **Supporting and engaging with Industry and the NHS on appropriate research and development on Sickle Cell**

During 2019/2020, the board and the staff are working on a Development of a new 3-year organisational strategy, which we hope to have in place in 2020/2021.

TREASURER'S REPORT

Looking back on the financial year 2019/20, I do so with pride and satisfaction with what the Sickle Cell Society has achieved. I am also apprehensive about the future because I am writing this summary whilst the world is in the midst of a global pandemic; Covid-19. Even at this early stage, this pandemic is likely to have significant implications for people living with sickle cell as well as equally significant implications for the work of the Sickle Cell Society.

As I had signalled in my summary report for the financial year 2018/19, we knew the financial outlook for 2019/20 would be extremely challenging and a controlled deficit budget was set.

We ended the year with a surplus of £78,614. However, this reflects monies for refurbishment, received but not expended in 2019/20. Without this timing imbalance of income against expenditure, the position was very close to the deficit that was budgeted. This was achieved by a combination of hard work plus careful stewardship of our income and expenditure.

In view of the present global pandemic, the financial outlook for the financial year 2020/2021 will be unprecedented because of the inevitable serious impact of government lockdown and social distancing on the work of the Society but particularly on our fundraising plans. We remain committed; trustees, staff and volunteers to do our very best to continue to support the sickle cell community and manage our finances carefully in what will be a very difficult time for everyone.

As ever, I would like to take this opportunity to thank my colleagues, trustees, staff, our donors and our volunteers for their sterling efforts in ensuring the Sickle Cell Society continues to strengthen and develop the work we do for the sickle cell community.

This support will be vital as we move in to 2020/2021.

Michele Salter
Treasurer & Vice-Chair

The Sickle Cell Society

Trustees' report (*continued*)
for the year ended 31 March 2020

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 is planned to be completed in late 2020.

Reserves Policy

The Trustees of the Sickle Cell Society have set a free reserves policy (which represents total unrestricted funds less tangible fixed assets) of maintaining a minimum of three months of the Society's total unrestricted expenditure £117,228. This policy was met during the financial year to 31 March 2020, with year end free reserves of £131,917 (2018 - £191,560), despite the difficulties encountered with securing grants. The Board updated the reserves policy during 2019/20 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 £753,851, which is £137,332 higher than the previous year's results. This has been achieved from restricted grant payments of £273,631 and £480,220 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 £11,309 (2018/19: net income of £32,748).

The majority of grants coming into the Society remain under restricted funds to deliver the objectives of the Society. During the year the restricted funds experienced a surplus of £67,305 (2018/19: total deficit of £70,124). The total restricted reserves at the end of the year were £225,102 (2019/20: £89,805).

Fundraising Statement

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

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

The Sickle Cell Society

Trustees' report (*continued*) for the year ended 31 March 2020

Fundraising Statement (*continued*)

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.

During 2019/2020, the Fundraising Working Group is working on development of a new 3 year fundraising strategy which will be cross referenced with the new 3-year original strategy. We hope this will be available in 2020/21.

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 2020

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:

The Sickle Cell Society

Independent auditor's report for the year ended 31 March 2020

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF THE SICKLE CELL SOCIETY FOR THE YEAR ENDED 31 MARCH 2020

Opinion

We have audited the financial statements of The Sickle Cell Society ("the Charitable Company") for the year ended 31 March 2020 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 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 2020 and of its incoming resources and application of resources 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 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 related to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Charitable Company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

The Sickle Cell Society

Independent auditor's report (*continued*) for the year ended 31 March 2020

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.

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.

In connection with our audit of the financial statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the Trustees' Report, which includes the 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, which are included in 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 Trustee's 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 Directors' 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 directors' report and from the requirement to prepare a strategic report.

The Sickle Cell Society

Independent auditor's report (*continued*) for the year ended 31 March 2020

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 determines 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

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder. This appointment replaces the appointment of BDO.

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.

A further description of our responsibilities for the audit of the financial statements is located at the Financial Reporting Council's ("FRC's") website at: <https://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 statutory auditor
London,
United Kingdom

Date:

The Sickle Cell Society
Statement of financial activities
for the year ended 31 March 2020
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
Income:					
Voluntary Income	3	478,829	273,631	752,460	615,481
Investment income	4	1,391	-	1,391	1,038
Total income		480,220	273,631	753,851	616,519
Expenditure					
Costs of raising funds					
Fundraising costs	5	177,835	-	177,835	129,454
Charitable activities					
Campaign	5	130,722	50,590	181,312	173,291
Direct services group		83,222	91,321	174,543	185,743
Provision of information and advice		63,303	35,548	98,851	100,740
Children's Activities & Holiday		13,829	28,867	42,696	64,668
Total expenditure	5	468,911	206,326	675,237	653,896
Net income for the year before transfers		11,309	67,305	78,614	(37,377)
Transfer between funds		(67,992)	67,992	-	-
Net movement of funds in year		(56,683)	135,297	78,614	(37,377)
Reconciliation of funds					
Total funds brought forward	14	201,739	89,805	291,544	328,921
Total funds carried forward	14	145,056	225,102	370,158	291,544

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

The notes on pages 28 to 43 form part of these financial statements.

The Sickle Cell Society

Balance sheet at 31 March 2020

Company number 2840865	Note	2020	2020	2019	2019
		£	£	£	£
Tangible fixed assets					
Tangible assets	9		13,139		10,179
Current assets					
Stocks		1,919		1,919	
Debtors and prepayments	10	24,904		30,016	
Cash and cash equivalents	12	455,108		437,872	
		<hr/>		<hr/>	
		481,931		469,806	
Creditors - amounts falling due within one year					
Creditors	13	124,912		188,442	
		<hr/>		<hr/>	
Net current assets			357,019		281,364
Total assets less current liabilities			<hr/>		<hr/>
			370,158		291,544
			<hr/>		<hr/>
Represented by:					
Unrestricted funds	14		145,056		201,739
Restricted funds	14		225,102		89,805
			<hr/>		<hr/>
			370,158		291,544
			<hr/>		<hr/>

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 _____ and signed on its behalf by:

Trustee

Michele Salter

Trustee

Kye Gbangbola

The notes on pages 28 to 43 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows for the year ended 31 March 2020

	Note	2020 £	2020 £	2019 £	2019 £
Cash generated in operating activities	19		23,841		(43,167)
Cash flows from investing activities					
Interest income		1,391		1,038	
Payments to acquire tangible fixed assets		(7,996)		(1,052)	
Net cash from investing activities			(6,605)		(14)
Increase in cash and cash equivalents in the year			17,236		(43,181)
Cash and cash equivalents at the beginning of the year	20		437,872		481,053
Cash and cash equivalents at the end of the year	20		455,108		437,872

The notes on pages 28 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 2020

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 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, which include a temporary salary reduction for some staff who are paid from the unrestricted funds. 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 2020 (*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 2020 (continued)

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 2020 £	Unrestricted £	Restricted £	Total 2019 £
Donations and legacies	304,980	5,104	310,084	255,404	7,806	263,210
Grants	-	268,527	268,527	37,000	185,138	222,138
Contract Income	173,849	-	173,849	130,133	-	130,133
	<u>478,829</u>	<u>273,631</u>	<u>752,460</u>	<u>422,537</u>	<u>192,944</u>	<u>615,481</u>

4 Investment income

	Unrestricted 2020 £	Unrestricted 2019 £
Bank and COIF deposit interest	<u>1,391</u>	<u>1,038</u>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2020 (*continued*)

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2020 £	Total 2019 £
Costs of raising funds					
Fundraising costs	79,300	39,405	59,130	177,835	129,454
Charitable activities					
Campaign	4,882	116,143	60,287	181,312	173,291
Direct services group	65,626	50,881	58,036	174,543	185,743
Provision of information and advice	14,546	51,437	32,868	98,851	100,740
Children's Activities & Holiday	28,500	-	14,196	42,696	64,668
Total expenditure	192,854	257,866	224,517	675,237	653,896

Analysis of support costs

	Other support costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2020 £	Total 2019 £
Charitable activities						
Fundraising costs	5,190	14,137	27,125	12,679	59,130	41,678
Campaign	5,291	14,413	27,655	12,928	60,287	55,792
Direct services group	5,094	13,875	26,623	12,444	58,036	59,800
Provision of information and advice	2,885	7,858	15,078	7,047	32,868	32,433
Children's Activities & Holiday	1,246	3,394	6,512	3,044	14,196	20,820
Total support costs	19,706	53,677	102,993	48,142	224,517	210,523

Total expenditure in the year to 31 March 2020 was £675,237 of which £468,911 was unrestricted and £206,326 was restricted.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2020 (*continued*)

6 Staff cost and numbers	2020	2019
	£	£
Wages and salaries	306,290	306,274
Social security	27,432	27,486
Pension	27,137	27,245
	<hr/>	<hr/>
	360,859	361,006
	<hr/>	<hr/>

The average number of employees during the year was 14 (2019:14).

No employee earned more than £60,000 per annum (2019: Nil).

No remuneration has been paid to the Trustees other than the reimbursement to them for their travel, training and recruitment cost for new trustees, expenses totalling £2,319 for trustees (2019: £1,565) for 8 trustees including trustees who resigned during the year), incurred when attending meetings or other Society business.

The key management personnel of the Society comprise the Chief Executive Officer. The total employee benefits of the key management personnel of the Society is £62,899 (2019: £57,382).

7 Net Income for the year	2020	2019
	£	£
Is stated after charging:		
Depreciation on owned assets	5,036	4,509
Auditors' remuneration (including VAT):		
- Audit fees	10,200	11,160
Equipment rental	3,508	4,143
	<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 2020 (*continued*)

9 Tangible fixed assets

	Furniture and equipment £
<i>Cost</i>	
At beginning of year	127,844
Additions at cost	7,996
	<hr/>
At end of year	135,840
	<hr/>
<i>Depreciation</i>	
At beginning of year	117,665
Charge for year	5,036
	<hr/>
At end of year	122,701
	<hr/>
<i>Net book value</i>	
At 31 March 2020	13,139
	<hr/>
At 31 March 2019	10,179
	<hr/>

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

10 Debtors

	2020 £	2019 £
Grants and donations receivable (note 11)	13,749	15,000
Prepayments	11,155	15,016
	<hr/>	<hr/>
	24,904	30,016
	<hr/>	<hr/>

11 Grants receivable

	2020 £	2019 £
NHS BT	13,749	15,000
	<hr/>	<hr/>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2020 (*continued*)

12 Cash and cash equivalents

	2020	2019
	£	£
Cash in hand	383	249
NatWest Reserve Account	301,588	285,863
NatWest Current Account	1,600	1,060
COIF Charities Deposit Fund	150,291	149,375
Paypal	1,246	1,324
	<u>455,108</u>	<u>437,872</u>

13a Creditors - amounts falling due within one year

	2020	2019
	£	£
Trade creditors	76,862	103,139
Accruals and deferred income	48,050	85,303
	<u>124,912</u>	<u>188,442</u>

13b Deferred Income Reconciliation

	2020	2019
	£	£
Balance as at 1 April	61,769	109,437
Amount Released to Income	(61,769)	(104,401)
Amount Deferred in the year	32,400	56,733
	<u>32,400</u>	<u>61,769</u>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2020 (*continued*)

14 Analysis of charitable funds

	Balance 1 April		Movement in funds			Balance 31 March 2020	
	2019	£	Income	Expenditure	Transfers	£	£
Restricted funds							
Children Holiday scheme	-		5,104	21,687	16,583		-
Roald Dahl's Marvelous 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 2020 (*continued*)

14 Analysis of charitable funds (*continued*)

Analysis of charitable funds – previous year

	Balance	Movement in funds			Balance
	1 April 2018 £	Income £	Expenditure £	Transfers £	31 March 2019 £
Restricted funds					
Children Holiday scheme	-	7,806	24,416	16,611	-
Roald Dahl's Marvellous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Public Health England Research	8,317 43,727	- -	8,317 -	- -	- 43,727
Brent Council In Memory of Dr Ade	8,270	-	-	-	8,270
Olujohnungbe	6,961	-	6,961	-	-
Helpline Worker	5,000	-	24,468	19,468	-
CLAHRC	-	7,292	4,548	-	2,744
Hackney CCG	10,873	7,667	14,253	-	4,287
London borough of Hackney	-	7,284	7,284	-	-
Big Lottery	4,228	89,670	82,533	-	11,365
Children in Need	-	19,059	19,523	7,644	-
Breaking Down Barriers Patient Education & Training	3,333 884	- 29,424	7,699 29,923	4,366 -	- 385
APPG for Sickle Cell & Thalassaemia	-	24,743	33,142	8,399	-
Restricted funds	103,442	192,944	263,069	56,488	89,805
Unrestricted funds					
General fund	225,479	423,575	390,827	(56,488)	201,739
Total funds	328,921	616,519	653,896	-	291,544

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2020 (*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. £16,583 was transfer from the unrestricted funds to help fund the 2019 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

During 2018/19 we had planned to use these funds as matched funding against our Big Lottery Funding (BLF) grant for South London - Sickle Link. The contract with the funder Genetic Disorders UK for these resources are in line with the aims of the BLF grant. In achieving an underspend on the BLF project, during 2019/2020 we did not contact Genetic Disorders UK to progress matched funding request.

Public Health England- NHS Sickle Cell and Thalassaemia Screening Programme

To support the community engagement effort of the Society, which enables the successful implementation of the NHS Sickle Cell and Thalassaemia screening programme objectives, agreed with the Society.

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. A transfer of £24,070 was made from the unrestricted funds in 2019/2020 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.

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2020 (*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 which is in line with the Project's criteria.

The Sylvia Adams Charitable Trust

The Society was awarded a grant by the Sylvia Adams Charitable Trust in collaboration with Alstrom UK for a project entitled Breaking Down Barriers.

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 2019-20, 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 £12,500 have been awarded by Novartis and BlueBird Bio respectively. UK Thalassaemia also contributed £1,250 to the Project, £19,520 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 £27,872 to deliver a programme of community activities and engagement sessions for people living with SCD and their families, in the borough. We have since secured further funding for the next 2 years from April 2020.

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

£125,516 was received this financial year towards the refurbishment cost of the Sickle Cell Society Headquarters. This income consists of amounts awarded by Brent Council NCIL of £133,958 towards the refurbishment Project to the Sickle Cell Society, of which £64,694 was received this financial year, £30,822 towards a part time project manager post and £30,000 from Garfield Weston Foundation.

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2020 (*continued*)

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

Payroll Giving	57,860
SCS 40th Anniversary Gala Ball	36,499
Just Giving	35,891
Facebook	28,872
Blackbuad Merchant Service	19,637
Online Giving	13,122
Nova Labs	10,000
Imara	7,000
Virgin Money Giving	6,994
Stewardship - Patience Adegbite	5,000
L Morgan & Co	3,885
In Memoriam Donations	3,442
OdysseyRe and Newlin Group - London	3,000
The Thinking Schools Academy Fund	2,554
International CH RCCG-ICC - Chuka NWA	2,250
Borntosurvive (NatWest Markets)	2,231
Westcliff High School for Girls	1,828
Human Race Foundation	1,719
Mitchell Plampin Partnership Solicitors - Late Iris Louise Market	1,680
NUGA Golf	1,500
Greencore Food to Go Limited - Northampton	1,369
HM Send - Sian Watling	1,273
Royal Russell School Trust - Mrs N Hart	1,261
British Nigeria Black Forum	1,160
Leicester Central PAEB Youth Club	1,055
First Give - nominated by The Sacred Heart Language College Students	1,000
Natural Motion	1,000
Barclays Match Funding	1,000
Belmont School YY3	949
Valintnes High School	900
SVGA Reading - Pol Exeter	850
O F Brown	840
The Parish Church of St Mary Willesden	800
Charities Trust - RBS	750
Bancroft's School	717
Oasis Academies	712
V Ruddock	655
Applegarth Academy Trust in memory of Javarne Smith	651
Parish of Sandal Magna	651
BA Leslie	620
Relief Chest Scheme - L1601 Ravensbourne Lodge	600
Powerhouse International Ministries – LBB Sickle Cell Centre	580

The Sickle Cell Society

**Notes forming part of the financial statements
for the year ended 31 March 2020 (continued)**

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

Heart & Soul Uplifting Concert	550
Sere Simon-Ellison	540
Parish of Herne Hill	540
Linklaters LLP – On behalf of Heather Melvin OBE	501
Royal Mail Carers Society Ilford & Romford	500
Bestway Foundation - Mayor of Brent	500
Action Hill Methodist & United Reform Church	500
Drugstars APS	500
Natural Motion Game	500
Anonymous	500

16 Analysis of net assets between funds

	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)
	<hr/>	<hr/>	<hr/>
Net assets	145,056	225,102	370,158
	<hr/>	<hr/>	<hr/>

Analysis of net assets between funds – previous year

	Unrestricted £	Restricted £	2019 Total Funds £
Tangible assets	10,179	-	10,179
Current assets	380,001	89,805	469,807
Current liabilities	(188,442)	-	(188,442)
	<hr/>	<hr/>	<hr/>
Net assets	201,738	89,805	291,544
	<hr/>	<hr/>	<hr/>

The Sickle Cell Society

Notes forming part of the financial statements for the year ended 31 March 2020 (continued)

17 Transfer between funds

During the year the Trustees agreed a transfer of £67,992 (2019: £56,488) from unrestricted funds to make good the deficits on the restricted funds and as a requirement of part funding for Big Lottery & Heritage Lottery Fund. The Sickle Cell Society part funded the Big Lottery and Heritage Lottery Projects, transfers were made to the Projects of £1,215 and £2,187 respectively to carry out the projects during 2019-20.

18 Leasing commitments

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

	2020	2019
	£	£
Commitments expiring:		
Within 1 year	10,006	3,500
Within 2 to 5 years	12,223	8,564
	<hr/>	<hr/>
	22,229	12,064
	<hr/>	<hr/>

The Sickle Cell Society

Notes forming part of the financial statements
for the year ended 31 March 2020 (*continued*)

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

	2020 £	2019 £
Net Movements in Funds	78,614	(37,377)
Depreciation	5,036	4,509
Interest income	(1,391)	(1,038)
(Increase)/ Decrease in debtors	5,112	(19,682)
(Decrease)/Increase in creditors	(63,530)	10,420
	<hr/>	<hr/>
Net cash generated from operating activities	23,841	(43,167)
	<hr/> <hr/>	<hr/> <hr/>

20 Analysis of cash and cash equivalents

	2020 £	2019 £
Cash in Hand	455,108	437,872
	<hr/>	<hr/>
	455,108	437,872
	<hr/> <hr/>	<hr/> <hr/>

21 Related party transactions

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