SICKLE
CELL
SOCIETY

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 Financial Statements

Year Ended

31 March 2019

Company Number 2840865

Charity Number 1046631

The Sickle Cell Society

Report and financial statements
for the year ended 31 March 2019

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Professor Dame Elizabeth Anionwu CBE
Baroness Floella Benjamin OBE
Rt Hon. Lord Paul Boateng of Akyem
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	Mr John James OBE	Chief Executive
Staff	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
	Ms Grace Adejuwon	Children's Activities/Children Holiday Lead (to March 2019)
	Ms Tracy Williams	South London Gives Project Officer
	Ms Linda Chicout	Breaking Down Barriers Project Lead (to March 2019)
	Ms Valerie Oldfield	Community Support Worker
	Mrs Donna Prendergast	South London Community Manager
	Mr Adam Lloyd	Parliamentary Officer for Sickle Cell and Thalassaemia All Party Parliamentary Group - SCTAPPG)
	Ms Siann Millanaise	Patient Education & Training Lead
	Ms Gloria Ogunbadejo	Helpline & Information Officer (from May 2018)

Company information
for the year ended 31 March 2019 *(continued)*

Registered address	Sickle Cell Society, 54 Station Road, London NW10 4UA
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Registered charity number	1046631
Company registration number	2840865
Auditor	BDO LLP, 2 City Place, Beehive Ring Road, Gatwick, West Sussex, RH6 0PA
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Scientific advisors

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

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Consultant Clinical Psychologist
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Consultant in Public Health

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

Dr Moira Dick
Consultant Community Paediatrician
King's College Hospital

The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2019 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 applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

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.

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 3 members with sickle cell disorder and Trustees are also carers for family members with sickle cell. The board undertook board development training during 2018/19, jointly with the staff team of the Society.

SUMMARY REVIEW OF 2018-2019

A summary statement from the Chair and Chief Executive

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 (more can be read about this in this report and in our 2018/2019 Impact Report).

Last year we alerted you to the continuing complex and challenging environment that charities of our size have to navigate. We also signalled turbulence during 2018/2019 because of funding constraints, political uncertainty, and high expectations of the sickle cell community and other partners. That has proven to be exactly the case. It was therefore a tough but productive year. We have ended the year with a deficit of £37,377.

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

- Publishing the 2nd Edition of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK* in partnership with the UK Forum on Haemoglobin Disorders. The *Standards* were launched in the Houses of Parliament and aim to ensure that sickle cell patients across the country receive the same high level of care.
- Publishing two reports as part of our role as joint secretariat for the All-Party Parliamentary Group for Sickle Cell and Thalassaemia. The first report explored the institutional failures of Personal Independence Payment (PIP) for those living with sickle cell and thalassaemia. The second report was into the education of pre-registration nurses and midwives.
- Winning the tender to continue the delivery of a programme of work in collaboration with UK Thalassaemia Society surrounding the NHS Sickle Cell and Thalassaemia Screening Programme.
- Winning the tender for South London Community Organising in collaboration with NHS Blood and Transplant. The project, now titled South London Gives, started in January 2019.
- Our continued work with NHS England ensuring a patient perspective on a major service review of haemoglobinopathy services in England.
- Our Chief Executive being awarded an OBE for services to sickle cell disorder and health in the Queen’s Birthday Honours.

Looking forward, we know that the turbulence will continue and it will be another challenging year. Nevertheless, we remain committed to continuing the positive work we do for the sickle cell community and doing so with good governance, transparency and accountability.

We hope you enjoy reading this account of our 2018/2019 activities and achievements and that it will provide new insights in to our work.

Kye Gbangbola	**John James OBE**
Chair	**Chief Executive**

PRIORITIES IDENTIFIED IN 2017/18 ANNUAL REPORT

During 2018/19, the board were expected to make progress across the board including the following areas of specific work; all have been met.

- A strategic review of the Society's Membership and Communication strategies , including updating the current membership data base.
- To deliver, in partnership with the UK Thalassaemia Society and the NHS, the tender for managing public and service user engagement/consultation to support the NHS Sickle Cell and Thalassaemia Screening Programme.
- A continuation of our collaborative work with NHS England Specialised Commissioners and Clinical Commissioning Groups; including a potential pilot with London Ambulance Service- see page 7
- A follow up with the APPG for Sickle Cell and Thalassaemia on the progress made by local commissioners on the issues (access to Apheresis for people with Sickle Cell Disease and Sickle Cell Disease network arrangements amongst West Midlands NHS Hospitals for adults with Sickle Cell Disease) in the region.
- Successful establishment of the Big Lottery funded Sickle Cell South London Link project, covering the boroughs of Lambeth, Lewisham and Southwark.

KEY HIGHLIGHTS FROM THE YEAR 2018-19

STAKEHOLDER RELATIONSHIPS

The Society continued to form major strategic alliances with key stakeholders, such alliances as Rare Disease UK and Specialised Healthcare Alliance. Board members and staff are part of the committees of the Alliances, attending meetings and workshops.

The Society worked effectively with the NHS Sickle Cell and Thalassaemia Screening Programme. In August 2018, the Society and the UK Thalassaemia Society, won the bid for the new tender to continue with the programme for 3-5 years,

The Society worked effectively with NHS Clinical Commissioning Groups, London Ambulance Service, Industry, and the UK Thalassaemia Society.

Other engagements include National Council Voluntary Organisations (NCVO); UK Forum on Haemoglobinopathies; National Voices; National Institute for Health and Clinical Excellence (NICE); NHS Blood and Transplant; NHS England; Public Health England; Sickle Cell & Thalassaemia Association of Counsellors (STAC) and other voluntary and statutory organisations involved with sickle cell.

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

MEMBERSHIP & SUPPORT GROUP BASE

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

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 have seen a significant increase in social media followings. The Society’s Instagram gained over 800 followers, the Society’s Facebook gained over 600 likes and the Society’s Twitter gained almost 900 followers.

The Sickle Cell Society website receives, on average, 19,000 views per month.

HELPLINE AND INFORMATION SERVICE

The Society received 898 requests for information by telephone from April 2018 to March 2019. In more than half the cases, we have been able to provide information immediately. The most common topics of calls were fundraising, benefits and South London Project. 56% of callers were new callers. The team spent a total of 10484 minutes (approx. 174 hours) on the phone.

As part of the helpline service we also responded to emails. The Society received a total of 1066 emails during April 2018 to March 2019. 63% of emails were responded to with information immediately.

HACKNEY AND CITY MENTORING SCHEME

The Mentoring Scheme is for people living with sickle cell aged 10-25 in Hackney and City. The programme is led by June Okochi and mentors Whitney Joseph and Michael Tsiagbe.

Between April 2018 to March 2019, the Mentoring programme covered 150 sessions with 31 new referrals. The mentoring sessions including topics such as: education, career advice / career and work experience, public speaking, treatment plans, sickle cell self-management, fitness regime, care concerns, stress and anxiety management, transitions, general wellbeing, maturity and more.

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 and a Facebook Live session with NHS England to discuss the Sickle Cell Service Review.

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 and hope that the new model will be even better at helping the public identify 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 19,000 views per month.

Staff, Trustees and Volunteers continued to provide 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.

KEY HIGHLIGHTS FROM THE YEAR 2018-19 *(continued)*

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 Cardiff with Friends of Cardiff Sickle Cell and Thalassaemia and one as part of our 39th AGM in July which focused on the Sickle Cell Service Review and the Hackney and City Mentoring Scheme.

Work on behalf of the NHS Screening Programme (2018 /19)

In June 2018, the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) successfully bid for a new NHS Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) tender which was awarded in August 2018. The tender which commissions the Societies to work collaboratively with the Programme to improve its service provision is expected to be for a period of 3-5 years.

Key Project Achievements to date:

- Formation of a Standards Working Group (SWG) of clinicians, specialist nurses and reps from SCS /UKTS/ NHSSCTSP who have produced a draft updated edition of the publication '*Sickle cell disease in childhood: standards and guidelines for clinical care' ("*Paediatric Standards"*)* last updated in 2010.
- Recruitment of a qualified Medical Writer /Editor to help the SWG edit the Paediatric Standards so it can be published and widely disseminated.
- A successful consultation on the draft standards among health professionals and other relevant stakeholders such as (NHS England, and NHR Steering Group) which gave useful feedback.
- Collaborative talks with the Writing Group of the *'Parents' Guide to Managing Sickle Cell Disease*' with regards to producing an updated version which will be guided by parents' feedback of previous editions.
- Various Society networks (e.g. talks, website, newsletter, media) used to raise awareness of the findings and recommendations from the 'Parent Stories' (personal experiences of sickle cell and thalassaemia screening) a publication produced as part of the previous NHS Screening Programme tender.
- Various Society networks (e.g. Parent support Groups, website, newsletter, media) used to raise awareness of the Screening Programme's Newborn Outcomes (data collection) System helping to improve families understanding and trust for use of their data.
- Production of user-friendly patient information leaflets and posters to raise awareness of registration onto the National Heamoglobinopathy Registry.

CHILDREN'S HOLIDAY

From the 18th to 22nd August we took 30 children with Sickle Cell on an adventure holiday to the Pioneer Centre. Alongside learning about their sickle cell, the children experienced activities such as climbing, zipline, 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, slept in shared dormitory rooms with bunk beds to give a real 'summer camp' feel to their experience. The older team had their own 'cabin' with the younger two teams sharing a 'cabin.'

The children reported that they "had a blast" on the holiday and particularly learnt lots about sickle cell, how to be caring to each other and lots of practical physical skills. Their favourite parts were the zipline, high ropes, making friends and chatting to each other.

The parents could not have been more delighted with how the holiday went and in their feedback they reported some amazing leaps in independence, knowledge and confidence once the children have returned home.

They are also still all interacting with each other via whatsapp - a support network has been built for the kids AND the parents. The holiday this year was a complete success.

CHILDREN'S HOLIDAY (continued)

Quotes:

"I am grateful to see my daughter go on a trip with others who share the same situation as she and I am grateful that I have got to know some parents as well" A parent.

“This is not just a holiday but sharing experiences, knowing that the children are not alone when dealing with sickle gives them hope and provides coping strategies which will help them build resilience on living with sickle for the rest of their lives”. A parent.

CHILDREN'S ACTIVITIES PROGRAMME

with sickle cell. This will enable them to reduce their isolation, increase their confidence and improve their wellbeing.

We have organised and delivered a number of different activities, workshops and events this year for children affected by Sickle Cell. These have included everything from a self-care mindfulness, pamper and massage therapy session, to skating in Hyde Park and a visit to Sealife on the Southbank. Children have enjoyed exciting and fun activities such as ‘Bubble mayhem football’; Go karting, Gambados soft play, bowling, and cinema and theatre trips. Workshops have included cultural diverse dance sessions, creative writing workshops, Storytelling and Martial arts.

In total, we delivered 30 sessions of between two and five hours each which benefited a total of 94 children.

SICKLE CELL SOUTH LONDON LINK

Children’s Activities:

For the first 6 months of Year 3 we have held 14 activities, these have been accessed by approximately 57 children. We have held 10 information workshops for adults living with SCD & Parents/Carers, teenagers/young children. These have been attended by approximately 64 adults and approximately 20 young people.

Information Workshops:

Of the 64 adults and parents/carers who have attended the information workshops there has been a high percentage of attendees reporting attending the workshops has reduced isolation and feel more engaged in their community. Service users mainly hear about us via hospital clinics, our sickle cell database, support groups and our parent’s WhatsApp group. 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. In addition, we advertise the project via our SCS Facebook page and in local press, youth organisations, local churches and community organisations.

Volunteers:

During the first half of year 3 we have recruited 3 new volunteers and 30 retained from year 1 & 2. The volunteers have been assisting with the children’s activities, information workshops and some administration work. Of these volunteers we have adults living with SCD and sickle cell trait, members affected by SCD (through family and friends) and those who just wish to support the project activities and raise awareness. We are holding an education day in June for new and existing volunteers.

Support Groups:

We have engaged both adults and children/young people living with SCD, and parents/carers in support groups. To date we have run support groups every few months alternating between these for teenagers, parents/carers and adults, and a disabled group. The feedback has been very positive and we aim to continue these meetings throughout the second part of year 3. While children aged between 12-16 have been harder to engage, we are finding that the number attending the support groups is slowly increasing and we are building on this by providing meetings that include educational learning about how to manage and live with SCD.

SICKLE CELL SOUTH LONDON LINK (continued)

On Saturday 26th January 2019 we held another building capabilities workshop for new and existing support groups. In total we had 7 support groups and approx. 20 attendees. At the workshop individuals learnt more about collaborative working. What this might look like and ways to work in partnership. Alongside this the workshop included topics covering fundraising, planning and stages of working in partnership and promotion of their support groups.

HACKNEY ENGAGEMENT PROJECT

The Hackney Engagement project started delivery in April 2017 and completed work in June 2018. Funded by London Borough of Hackney, the project was a continuation of significant previous engagement activities in the borough which has the highest levels of sickle cell disease (SCD) in London.

Between April – June 2018 we delivered 3 events: Yoga for You (2 sessions) and Eat for Health, each designed to address how people with sickle cell and their families can adopt healthy practices to alleviate some of the physical and mental impact of the condition. In the latter stages of the project we choose to deliver many of our sessions in two parts in order to build momentum around the self-care practices we introduced. This approach enabled us to further embed learning, deepen the benefits of project participation and increase attendance at sessions.

In June 2018 we submitted an extensive elevation report to our funders detailing total project delivery and impact, including case studies of project participants. The report showed:

- 13 engagement sessions delivered
- 74 attendances at health workshops
- 171 project beneficiaries.

And that taking part:

- Enhanced peoples' peer networks, leaving them feeling less isolated ("It has been good to share each other's journey")
- Provided them with valuable new learning, meaning they can address some of the symptoms and impacts of SCD more independently ("This relaxation session has shown me how I can help my child when he is having a crisis and how to calm him down using breathing techniques")
- Increased participants' levels of optimism about managing their or their child's health, building their resilience in living with sickle cell disease. (At our 'Eat for Health' session 100% of participants reported increased optimism about managing the effects of SCD.)

Throughout each project activity we disseminated information on preventative healthcare, local health and wellbeing services and the support available from the Sickle Cell Society's wider activities and services. Our participants engaged with these resources in a number of ways, including requesting referral to Homerton Hospital's psychological support, attending the Society's AGM and seeking volunteering opportunities with us.

Project funding ended in June 2018 and we plan to continue delivering this work in Hackney once financial support is received. Our learning from this year suggests that ongoing events or courses with the same theme, alongside flexible and bespoke one to one support for those with more specific needs, would enable the project to involve even more people and aid us in tracking the progress and impact of our work on individuals and families

SICKLE CELL SERVICE REVIEW

Between May and December 2018 The Sickle Cell Society carried out an extensive consultation project with sickle cell patients, carers and supporters in response to NHS England's (NHSE) planned changes to sickle cell services. The changes cover short and long stay hospital admissions for people with sickle cell disease (SCD) and include the introduction of 10 Haemoglobinopathy Coordinating Centres (HCC) which will each oversee sickle cell care in specific regions across England.

Our engagement work sought to ensure that the views of those affected by SCD were presented to NHSE, and that their concerns about the nature and impact of the changes were acknowledged and addressed. As part of the consultation we:

- Launched an online survey which gathered 86 responses, and held
- A workshop at our AGM in London with 140 participants
- A workshop in Birmingham with 22 participants; and
- A Facebook Live session which received 189 comments and questions.

The report on our findings concluded that:

- NHSE needed to express the planned changes with more clarity
- The scope of the review did not directly address many ongoing concerns that people receiving sickle cell treatment have, such as the quality of A&E care, lack of awareness of the disease among health professionals, including GPs, and the need for new treatments to be more widely available
- Where the changes were fully understood, respondents wanted the procurement of HCC's and the delivery of the changes to be implemented and monitored with the full participation of people with sickle cell and their families.

We secured a response to the report from NHSE which we disseminated throughout our network. In line with the request from patients that their perspective be represented at every level of change, we contributed questions for potential HCC suppliers as part of the procurement process. We have also developed a proposal for patient engagement which has been shared with NHSE.

We remain committed to monitoring the impact of the changes upon those with sickle cell and in the coming year will continue to liaise closely with NHSE to ensure the 'patient voice' remains paramount throughout the change and implementation process.

The Society's Chief Executive, John James was awarded an OBE for his services to sickle cell disorder and health as part of the Queen's Birthday Honours.

In May, the Society published the 2nd Edition of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK.* The Standards are a collaborative effort which consulted leading sickle cell healthcare professionals and sickle cell patients. They build upon the progress made by the first edition (2008) and aims to ensure that sickle cell patients across the country receive the same high level of care.

OTHER SIGNIFICANT ACTIVITIES DURING THE YEAR

ANNUAL THANKSGIVING SERVICE

There was no Annual Thanksgiving Service held this year, as it was decided to focus efforts on our 40th Anniversary Thanksgiving Service which will be held in June 2019.

PARLIAMENTARY WORK

The Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) secretariat service under the auspices of The Sickle Cell Society and UK Thalassaemia Society has been operational since the 4 December 2017. In that time the secretariat has been a hive of activity, setting the tone well for the rest of the year ahead.

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' issues.

Governance
In the proposal for the secretariat service for the Sickle Cell and Thalassemia (SCT) All Party Parliamentary Group (APPG), it was conditional that an advisory group composed of trustees and staff of both SCS and UKTS was set up. The advisory group, chaired by the CEO of the SCS, is designed to act as a forum to provide direction and strategic leadership for the secretariat, working closely with the office of the Chair of the SCT APPG Rt Hon Diane Abbott MP. It will directly aid the development of the SCTAPPG's current work plan. Three such meetings have taken place throughout the year.

SCTAPPG achievements

Non-business

SCTAPPG held the parliamentary launch for the new Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK. It was an evening of celebration with a full house at 150 which included clinical nurse specialists, parliamentarians, academics and service users. We heard talks from consultant Dr Jo Howard, Chair of UK Forum on Haemoglobin Disorders and Chair of the Editorial/Writing Group for the development of the new adult Standards; Kye Gbangbola, Chair of Trustees and from and patients. All present were united in their determination to enhance the patient experience for the 15,000 people in the UK living with sickle cell disease.

Business
With executive oversight from both the Sickle Cell Society and UK Thalassaemia Society, a vibrant work programme has been formulated which looks to every meeting tackle a specific policy area.

- SCTAPPG published “How Did You Contract That?” report which looked into the institutional failures of Personal Independence Payment (PIP) for those living with sickle cell disease and thalassaemia ((https://www.sicklecellsociety.org/pip-report/). The report itself also received some press attention with The Canary publishing an article on the report. The report has resulted in extended dialogue with the government. The SCTAPPG, with its Chair Rt Hon Diane Abbott MP, have held a meeting with Rt Hon Esther McVey MP, the then Secretary of State for Work and Pensions; Sarah Newton MP, the then Minister of State for Disabled People and DWP officials. All parties reacted positively to the report’s recommendations and we look forward to working with them to enact change. In addition, our patron,

- Lord Boateng has looked to apply pressure on the government in the Lords with numerous interventions (written questions) outlining the need for change. The SCTAPPG met DWP officials on 30th August 2018, the aim of which was to overhaul the existing knowledge base on sickle cell disease and thalassaemia. This we hope in the long run will translate into assessors having the adequate understanding of sickle cell disease and thalassaemia. We are pleased to announce our conversations were cordial and constructive:

SCTAPPG achievements (continued)

Capita and IAS agreed to work with the Sickle Cell Society and UK Thalassaemia Society on better information and training materials for healthcare professionals that provide them with support to correctly assess the impact of both conditions on function, taking into account the fluctuating nature of the condition and the understandable reluctance of some sufferers to fully describe the conditions' impacts;

DWP agreed to consider a potential audit mechanism following this training to evaluate the impact of any revised guidance/training on the nature of awards;

DWP officials and Assessment Providers agreed to consider changes to written materials to give better Information on; the purpose of the questions asked in the PIP2 assessment, face to face interviews and the subsequent reports and decision making letter;

In terms of collecting data on race they are beginning to work on that internally and will report back to SCTAPPG in the near future.

- SCTAPPG published 'I'm In Crisis' report on the lack of representation that Sickle Cell Disease and Thalassaemia has in Pre-Registration Nurse and Midwife Education. This culminated on the 20th November whereby SCTAPPG launched the report in parliament. The genesis of this report was following anecdotal reports that qualified nurses, midwives, doctors and other health care professionals lack knowledge of sickle cell and thalassaemia and that this affects their ability to provide skilled and effective care for those with and at risk of these life-long genetic, chronic and potentially fatal conditions. The report found that a substantial number of participants had not had any formal teaching time on sickle cell or thalassemia and had not nursed anyone with sickle cell or thalassemia. The report goes on to recommend that Approved Education Institutions should incorporate sickle cell and thalassaemia into all components of training by working alongside professional bodies and charities. The report also provides other practical recommendations for how this could be achieved. At the launch, the recommendations of the report were outlined by Dr. Lola Oni OBE, Chair of the Nurses Education Advisory Group and Service Director of Sickle Cell & Thalassaemia Centre Central Middlesex Hospital London. Michelle Ellis, Senior Lecturer of Child Health at City University London, also offered the view of the educational establishment. The report is a product of an advisory group set up five months prior to the launch, to formulate strategy, this was comprised of STANMAP (Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals) Sickle Cell Society, UK Thalassaemia Society, CNO BME Group and patient voices. The report has resulted in meetings with both the Nursing and Midwifery Council and Public Health England.

BREAKING DOWN BARRIERS

In September 2016, the Sickle Cell Society partnered with the Breaking Down Barriers project which is funded by the Sylvia Adams Trust. After a successful first year, the Sylvia Adams Trust agreed to renew funding for a second consecutive year. This enabled the Society to continue supporting Francophone and Lusophone service users with French and Portuguese resources.

In addition to this, the Breaking Down Barriers project has expanded by working closely with the following local organisations: The Help Your Health Programme, Universal Credit in Practice, Action West London, Genetic Alliance, NHS England and others. In order to enable service users with fast track access to employability services and wellbeing services locally.

The Breaking Down Barriers project also worked with the South London Link designing a 'Sickle Cell Journal' for young people which was trialled in March.

The project ended in March 2018 but the resources designed will remain available for free online at the Sickle Cell Society website.

SOUTH LONDON GIVES

In January 2019, we won a tender from NHS Blood and Transplant to deliver South London Gives. The project aims to increase the numbers of people of black African and black Caribbean origin donating blood and will initially run for one year. There is a need to recruit a significant number of new blood donors from black and mixed heritage communities due to an increase in demand for specific types of blood to treat sickle cell patients. People needing blood transfusions due to sickle cell benefit most from ethnically matched blood.

South London Gives covers four London boroughs: Greenwich, Lambeth, Lewisham and Southwark and will involve a team of 18 volunteer Community Organisers. Community Organising is an approach that involves bringing people with joint interests together to take action and overcome areas of social injustice or inequality. Volunteers will connect with individuals and communities in their designated area to build a sustainable and resilient network of black blood donors who are committed to giving blood and positively impacting upon the lives of others.

The project is currently in its developmental stage - planning delivery, recruiting and training volunteers and securing involvement from partner organisations. Future annual reports will detail achievement to project targets, including how we have countered the barriers to blood donation that exist in some black communities, and our contribution to raising the number of people from this demographic who present to give blood.

SELF OVER SICKLE

Following the birth of the Self Over Sickle project back in January 2018, a number of developments have taken place to ensure the reach of this project is relevant and enjoyable to the young adults that need it. Targeting 18-25 year olds, the project has moved away from committing itself to 30 face-to-face workshops in the localities of South London, The Midlands, Manchester and Yorkshire and has instead focused on offering young people the ability to participate in the project from the comfort of their own home, tuning in to podcast episodes on topics covering relationships, mental health and wellbeing, entrepreneurship, employment and support and services available. The buzz generated has helped form a community of young and older people with sickle cell, as well as supporters, carers and advocates enabling greater attendance at events and enhanced interaction on Social Media.

3 episodes in, the podcast has received over 300 plays since its launch in February 2019. The face-to-face launch event held in March in Croydon had over 70 young people and their families sign up to attend and concluded with a total of 40 attending on the night. The project so far has seen interest from over 900 people on social media via comments, likes, website/profile clicks and has directly engaged over 177 people with 133 people engaging weekly with us on Instagram, via our project page (@selfoversickle).

It is hoped that the podcast continues to unite young people with sickle cell cross-regionally and show them that support is not just in their local area or hospital but nationwide with the Sickle Cell Society as a central hub.

GRANTS, DONATIONS AND CONTRACTS

Terumo BCT provided an unrestricted grant of £37,000 to support Patient Education Days, Health Promotion activities and Website development.

Edward Harvist Trust Fund provided a restricted grant of £5,000 towards to the Children's Holidays 2018.
Global's Make Some Noise is supporting the Sickle Cell Society with a restricted grant of £24,149 that will be split in two consecutive years commencing in 2020/2021.

GSK provided to the Sickle Cell Society its Impact Award of £30,000 unrestricted fund.

Imara provided, in the second quarter of the financial year, an unrestricted grant of £2,050.

The Sickle Cell Society was awarded 2 contracts during the financial year through tendering process

1) Public Health England (PHE) £115,132 for this financial year. The Sickle Cell & Thalassaemia Outreach & Engagement Project is in partnership with United Kingdom Thalassaemia Society and the NHS Sickle Cell and Thalassaemia Screening Programme

2) The Society has secured a competitive tender from NHS BT 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 £15,000.

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 & 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
- **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**

TREASURER'S REPORT

The financial year 2018/2019 was a year of continued progress in delivering services for people who live with Sickle Cell Disorder (SCD) and their families. This is despite the Society ending the year with a deficit of £37,377. This was not a surprise because at the outset of the 2018/2019 financial year, we set ourselves a deficit control total of budget £37,145.

This performance reflects the fact that we are operating in much more challenging financial times. Something I referred to in my 2017/2018 Treasurer's Report and also a point highlighted by the Chair and Chief Executive in their Annual Report summary statement.

The outlook for the financial year 2019/2020 will continue to be very challenging for the organisation with a combination of cessation of grant funding, public sector austerity and economic uncertainty. Nevertheless, based on our consistent stewardship and good governance, we plan to navigate these serious challenges as best we can to ensure continued services for people who live with SCD and their families.

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

Michele Salter
Treasurer & Vice-Chair

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.

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 expenditure £163,474. This policy was met during the financial year to 31 March 2019, which currently stands at £191,560 (2018 - £211,842), despite the difficulties encountered with securing grants. The board updated the reserves policy during 2018/19 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. In the current political and economic climate this uncertainty is likely to continue. Our focussed approach on strong financial management, good governance and review of our reserves policy will help us to mitigate this risk.

The Board put a new Corporate Plan for 2013-2016 in place during the year with a focus on a number of strategic priorities. During 2017/18, good progress has been made on these strategic priorities. Key to this in 2017/18

Risk Management (continued)

remains a new fundraising strategy designed towards increased 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 £616,519, which is £28,614 higher than previous year's results. This has been achieved from restricted grant payments of £192,944 and £423,575 from restricted, 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 £32,748 (2017/18: net income of £7,578).

All grants coming into the Society remain under restricted funds to deliver the objectives of the Society. During the year the restricted funds experienced a total deficit of £70,124 (2017/18: surplus of £2,094). The total restricted reserves at the end of the year were £89,805 (2017/18: £103,442).

Fundraising Statement

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

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

We realise that fundraising is one of the key ways in which we interact with our supporters, donors and the general public. Therefore, the approach we have as a charity is one which ensures that the reputation of the Society is maintained at a high level. At the Society, we are professional on 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. This is all the more important in view of the new General Data Protection Regulations which came into effect in May 2018.

We have a Fundraising Working Group which included 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.

Charity Governance Code

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

Trustees' responsibilities

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

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

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

- Select suitable accounting policies and then apply them consistently;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- 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

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF THE SICKLE CELL SOCIETY FOR THE YEAR ENDED 31 MARCH 2019

Opinion

We have audited the financial statements of The Sickle Cell Society (“the Charitable Company”) for the year ended 31 March 2019 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 2019 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.

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.

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.

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.

Julia Poulter (Senior Statutory Auditor)
For and on behalf of BDO LLP, Statutory Auditor
London,
United Kingdom

Date:

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127).

The Sickle Cell Society
Statement of financial activities
for the year ended 31 March 2019
(Incorporating the Income and Expenditure Account)

	Note	Unrestricted funds £	Restricted funds £	Total funds 2019 £	Total funds 2018 £
Income:					
Voluntary Income	3	422,537	192,944	615,481	587,474
Investment income	4	1,038	-	1,038	432
Total income		423,575	192,944	616,519	587,905
Expenditure					
Costs of raising funds					
Fundraising costs	5	129,454	-	129,454	121,421
Charitable activities	5				
Campaign		101,943	71,348	173,291	102,980
Direct services group		72,206	113,537	185,743	206,529
Provision of information and advice		65,151	35,589	100,740	78,274
Children's Activities & Holiday		22,073	42,595	64,668	69,029
Total expenditure	5	390,827	263,069	653,896	578,233
Net income for the year before transfers		32,748	(70,125)	(37,377)	9,672
Transfer between funds		(56,488)	56,488	-	-
Net movement of funds in year		(23,740)	(13,637)	(37,377)	9,672
Reconciliation of funds					
Total funds brought forward	14	225,479	103,442	328,921	319,249
Total funds carried forward	14	201,739	89,805	291,544	328,921

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 26 to 39 form part of these financial statements.

The Sickle Cell Society

Balance sheet
at 31 March 2019

Company number 2840865	Note	2019 £	2019 £	2018 £	2018 £
Tangible fixed assets					
Tangible assets	9		10,179		13,637
Current assets					
Stocks		1,919		1,919	
Debtors and prepayments	10	30,016		10,334	
Cash and cash equivalents	12	437,872		481,053	
		469,806		493,306	
Creditors - amounts falling due within one year					
Creditors	13	188,442		178,022	
Net current assets			281,364		315,284
Total assets less current liabilities			291,544		328,921
Represented by:					
Unrestricted funds	14		201,739		225,479
Restricted funds	14		89,805		103,442
			291,544		328,921

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	**Trustee**
Michele Salter	Kye Gbangbola

The notes on pages 26 to 39 form part of these financial statements.

The Sickle Cell Society

Statement of cash flows
for the year ended 31 March 2019

	Note	2019 £	2019 £	2018 £	2018 £
Cash generated in operating activities	19		(43,167)		27,132
Cash flows from investing activities					
Interest income		1,038		432	
Payments to acquire tangible fixed assets		(1,052)		(5,271)	
Net cash from investing activities			(14)		(4,839)
Increase in cash and cash equivalents in the year			(43,181)		22,293
Cash and cash equivalents at the beginning of the year	20		481,053		458,761
Cash and cash equivalents at the end of the year	20		437,872		481,053

The notes on pages 26 to 39 form part of these financial statements.

1 Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (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.

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 a treated as a contingent asset and disclosed if material.

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

Deferred income

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

1 Accounting policies *(continued)*

Tangible fixed assets and depreciation

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

Fixtures, fittings and equipment - 25% straight line

Expenditure

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

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

Allocation of Support and Governance costs

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

Operating leases

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

Pension costs

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

Restricted funds

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

Unrestricted funds

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

Designated funds

Designated funds are unrestricted funds earmarked by the Trustees for a particular purpose.

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 2019 £	Unrestricted £	Restricted £	Total 2018 £
Donations and legacies	255,404	7,806	263,210	120,905	43,272	164,177
Grants	37,000	185,138	222,138	40,000	273,255	313,255
Contracts	130,132	-	130,132	-	-	-
	422,536	192,944	615,480	160,905	316,528	477,433

4 Interest receivable

	Unrestricted 2019 £	Unrestricted 2018 £
Bank and COIF deposit interest	1,038	432

5 Expenditure

	Direct costs £	Staff costs £	Support costs £	Total 2019 £	Total 2018 £
Raising funds					
Cost of fundraising	65,166	22,611	41,678	129,454	121,421
Charitable activities					
Campaign	8,404	109,095	55,792	173,291	102,980
Direct services group	62,404	63,539	59,800	185,743	206,529
Provision of information and advice	9,679	58,627	32,433	100,740	78,274
Children's holiday	25,149	18,699	20,820	64,668	69,029
Total expenditure	170,802	272,571	210,523	653,896	578,233

Analysis of support costs

	Other support costs £	Office and IT costs £	Staff related costs £	Governance costs £	Total 2019 £	Total 2018 £
Charitable activities						
Raising Funds	3,063	8,517	17,508	12,590	41,678	39,632
Campaign	4,101	11,402	23,436	16,853	55,792	33,613
Direct services group	4,395	12,221	25,120	18,064	59,800	67,412
Provision of information and advice	2,384	6,628	13,624	9,797	32,433	25,549
Children's holiday	1,530	4,255	8,746	6,289	20,820	22,531
Total support costs	15,473	43,023	88,434	63,593	210,523	188,737

Total expenditure in the year to 31 March 2019 was £653,896 of which £263,069 was unrestricted and £390,827 was restricted.

6 Staff cost and numbers

	2019 £	2018 £
Wages and salaries	306,274	257,130
Social security	27,486	22,247
Pension	27,245	23,007
	361,006	302,385

The average number of employees during the year was 14 (2018: 12).

No employee earned more than £60,000 per annum (2018: £60,000).

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 £1,565 for trustees (2018: £3,543 for 9 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 were £57,382 (2018: £57,455).

7 Net Income for the year

	2019 £	2018 £
Is stated after charging:		
Depreciation on owned assets	4,509	3,114
Auditors' remuneration (including VAT):		
- Audit fees	11,160	10,560
Equipment rental	4,143	4,918

8 Taxation

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

9 Tangible fixed assets

	Furniture and equipment £
Cost	
At beginning of year	126,792
Additions at cost	1,052
At end of year	127,844
Depreciation	
At beginning of year	113,156
Charge for year	4,509
Depreciation at end of year	117,665
Net book value	
At 31 March 2019	10,179
At 31 March 2018	13,637

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

10 Debtors

	2019 £	2018 £
Grants and donations receivable (note 11)	15,000	1,250
Prepayments	15,016	9,084
	30,016	10,334

11 Grants receivable

	2019 £	2018 £
NHS BT	15,000	-
United Kingdom Thalassaemia Society	-	1,250

12 Cash and cash equivalents

	2019 £	2018 £
Cash in hand	249	284
NatWest Reserve Account	285,863	332,006
NatWest Current Account	1,060	100
COIF Charities Deposit Fund	149,375	148,663
Paypal	1,324	-
	437,872	481,053

13 Creditors - amounts falling due within one year

	2019 £	2018 £
Trade creditors	103,139	51,278
Accruals and deferred income	85,303	126,744
	188,442	178,022

13 Deferred Income Reconciliation

	2019 £	2018 £
Balance as at 1 April	109,437	65,743
Amount Released to Income	(104,401)	(65,743)
Amount Deferred in the year	56,733	109,437
Balance as at 31 March	61,769	109,437

14 Analysis of charitable funds

	Balance 1 April 2018	Movement in funds			Balance 31 March 2019
		Income	**Expenditure**	**Transfers**	
	£	**£**	**£**	**£**	**£**
Restricted funds					
Children Holiday scheme	-	7,806	24,416	16,611	-
Roald Dahl's Marvelous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Public Health England	8,317		8,317		-
Research	43,727	-	-	-	43,727
Brent Council	8,270	-	-	-	8,270
In Memory of Dr Ade 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	7,180
Breaking Down Barriers	3,333		7,699	4,366	-
Patient Education & Training	884	29,424	29,923	-	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	225,479	423,575	390,827	(56,488)	201,739
General fund					
Total funds	328,921	616,519	653,896	-	291,544

14 Analysis of charitable funds *(continued)*

Analysis of charitable funds – previous year

	Balance 1 April 2017	Movement in funds			Balance 31 March 2018
		Income	Expenditure	Transfers	
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	9,300	4,545	24,213	10,368	-
Roald Dahl's Marvelous Children's Charity	268	-	-	-	268
Jeans for Genes	11,580	-	-	-	11,580
Public Health England	5,134	109,907	106,724	-	8,317
Research	5,000	38,727			43,727
Brent Council	8,270	-	-	-	8,270
In Memory of Dr Ade Olujohnungbe	6,961	-	-	-	6,961
Helpline Worker	7,212	15,000	26,991	9,779	5,000
Brent CCG	8,628	-	8,628	-	-
Hackney CCG	9,766	15,333	14,226		10,873
London borough of Hackney		21,850	22,405	555	-
Big Lottery	12,825	86,843	95,440		4,228
Children in Need	13,086	2,583	19,281	3,613	-
Breaking Down Barriers	3,318	5,000	8,156	3,172	3,333
Patient Education & Training	-	7,316	6,432	-	884
APPG for Sickle Cell & Thalassaemia	-	9,424	10,776	1,352	-
Restricted funds	101,348	316,528	343,273	28,838	103,442
Unrestricted funds					
General fund	217,901	271,377	234,960	(28,838)	225,479
Total funds	319,249	587,905	578,233	-	328,921

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. £16,611 was transfer from the unrestricted funds to help fund the 2018 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. The balance of £268 will be transfer to the Children’s Holiday fun to use towards 2019 residential holiday.

Jeans for Genes Campaign
During 2018/19 we plan 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.

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 2018/19.

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. We will be considering the use of this funding during 2018/19 now that the outcome of the Brent Clinical Commissioning Group (CCG) decision on the future of the Brent Sickle Cell Advice and Support Service has been resolved.

In Memory of Dr Ade Olujohnungbe
Following the sad loss of one of the Society's Medical Advisers; Dr Ade Olujohnungbe in May 2013, many of his friends, family and peers donated funds to recognise the excellent work he did on developing sickle cell standards of care for adults. His children's school friends from Cheadle Hulme School also contributed funds in his memory.

During 2017/18 plans for two awards with supporting criteria were made available for applications from NHS clinicians and multi-disciplinary teams for excellence in the care of adults with sickle cell. Unfortunately, no applications were received by the closing date of 31 March 2019. We have re-launched the award in late autumn of 2017 with a focus on patients making nomination of clinicians for the award. The funds were allocated to winners at our AGM in July 2018.

Helpline Worker
To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families. A transfer of £19,468 was made from the unrestricted funds in 2018/2019 to help carry out this service.

Brent Clinical Commissioning Group (CCG)
The Brent Sickle Cell Advice and Support Service is supported by Brent CCG in partnership with the Society and London North West University Hospitals NHS Trust to provide help and support to sickle cell patients resident and registered with a GP in Brent, being discharged from hospital and to continue to support patients' pre and post discharge to better manage their own care and treatment at home thus helping to prevent future hospital admissions.

14 Analysis of charitable funds *(continued)*

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

It has been agreed with the funders that the grant is to be used to contribute towards the salary of our Helpline and Information service, with a specific focus on advice, information, signposting and engagement with individuals and families with sickle cell disorder from French and Portuguese communities in England.

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.

To empower people with SCD and their families to better manage their condition thereby improving their short and long term health outcomes, independence, wellbeing and reducing reliance on emergency care services where appropriate.

BBC Children in Need (BBC CiN)
The BBC CiN project will deliver a programme of regular activities to children and young people with sickle cell disorder. This will enable 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 is 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.

Patient Education & Training
Bupa UK Foundation have 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.

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)
From November 2018, 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 Blue Bird Bio respectively. UK Thalasseamia also contributed £5,000 to the Project, £8,399 was transfer 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 £29,134 to deliver a programme of community activities and engagement sessions for people living with SCD and their families, in the borough.

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

15 Unrestricted donations, legacies and fundraising

	£
Payroll Giving	58,819
Facebook	51,870
GSK	30,000
Just Giving	25,059
UCLU - RAG Society	5,800
In Memoriam	2,775
Virgin Money Giving	2,337
CAF	2,096
Much Loved Charitable Trust	2,083
Imara	2,050
NUGA - Golf	1,500
Towers Watson Limited	1,472
Patrick Okolo - Willis Ltd	1,472
Lola Kehinde	1,324
TV Game Shows	1,250
Yvonne Coghill	1,245
Steeles Law Solicitors Limited	1,000
Yvonne Knight	890
UCLU	852
AWEDIS Investment Club NO 3 Account	850
O F Brown	840
The Herfordshire & Essex High School	814
Wintersun Development	750
Mansfield Road Baptist Church	750
HMP Send	708
The Parish of Herne Hill	700
HMP Frankland - Governor L Robson	694
Birmingham Black Law	635
Abio Oluremi	600
Azzees Dee Minott - Family Fun Day	600
N Nicholas - TUC Black Workers	600
Queens Park Community School	600
The Coopers School - Victor Sossany	590
Lucreta La Pierre	543
Wanstead High School	551
Anonymous	500
Here & Now 365 Ltd - Tollyboy	500
Medical Association	500
Team Catford	500
The Rochester Grammar School	500

16 Analysis of net assets between funds

	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)
Net assets	201,738	89,805	291,544

Analysis of net assets between funds – previous year

	Unrestricted £	Restricted £	2018 Total Funds £
Tangible assets	13,637	-	13,637
Current assets	389,864	103,440	493,306
Current liabilities	(178,022)	-	(178,022)
Net assets	225,479	103,440	328,921

17 Transfer between funds

During the year the Trustees agreed a transfer of £56,488 (2018: £28,838) from unrestricted funds to make good the deficits on the restricted funds.

18 Leasing commitments

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

	2019 £	2018 £
Commitments expiring:		
Within 1 year	3,500	2,892
Within 2 to 5 years	8,564	10,803
	12,064	13,695

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

	2019 £	2018 £
Net Movements in Funds	(37,377)	9,672
Depreciation	4,509	3,114
Interest income	(1,038)	(432)
Decrease in stocks	-	(1,829)
(Increase) in debtors	(19,682)	(299)
Increase in creditors	10,420	16,906
Net cash generated from operating activities	(43,167)	27,132

20 Analysis of cash and cash equivalents

	2019 £	2018 £
Cash in Hand	437,872	481,053
Overdraft facility	-	-
	437,872	481,053

21 Related party transactions

Sheree Hall donated £3,000 to the Society in the year 2018/2019 restricted for August 2019 children’s Holiday
There is no other related party transactions requiring disclosure.