

*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 2017

Company Number 2840865

Charity Number 1046631

# **The Sickle Cell Society**

**Report and financial statements  
for the year ended 31 March 2017**

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# The Sickle Cell Society

## Company information for the year ended 31 March 2017

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|-----------------------------|---|--|
| <b>Patrons:</b>             | Mr Michael Parker CBE, President<br>Dame Professor Elizabeth Anionwu CBE<br>Dr Floella Benjamin OBE<br>Lord Paul Boateng of Akyem<br>Mrs Millicent Simpson<br>Mr Derrick Evans<br>Sir Lenny Henry CBE<br>Dr Nola Ishmael OBE<br>Mr Clive Lloyd OBE<br>Mr Trevor Phillips OBE<br>Mrs Sherlene Rudder MBE<br>Ms Ellen Thomas  |  |
| <b>Trustees - Directors</b> | Mr Kye Gbangbola<br>Ms Michele Salter<br>Ms Florence Anichebe<br>Ms Carol Burt<br>Joseph Ezaekunne<br>Mr Kingsley Ibeke<br>Ms Sheree Hall<br>Ms Jan Baptise-Grant<br>Mr Philip Udeh<br>Ms Ima Obong-Ogbonna<br>Ms Uju Obi<br>Mr Ganesh Sathyamoorthy  | Chair<br>Vice Chair and Treasurer<br><br>(from November 2016)<br>(to July 2016)<br><br>(to September 2016)<br><br>(to November 2016)<br>(from November 2016)<br>(from November 2016)   |
| <b>Staff</b>                | Mr John James<br>Mrs Comfort Ndive<br><br>Ms Sharon Jackson<br><br>Ms Iyamide Thomas<br>Ms Miriam Williams<br>Mrs Kalpna Sokhal<br>Mr Arthur Berrain<br><br>Mr Osama El-Amin<br>Ms Zoe Williams<br><br>Mr Patrick Ojeer<br><br>Ms Jacqueline Ferguson<br><br>Ms Soorbhi Parekh<br><br>Ms Lori Hey<br><br>Ms Jessica Boatright<br><br>Ms Linda Chicout<br><br>Mr Craig Lloyd<br><br>Ms Valerie Oldfield<br><br>Mrs Donna Prendergast | Chief Executive<br>Health and Social Care Officer (to<br>September 2016)<br>Health and Social Care Support Worker<br>(to May 2017)<br>NHS Engagement Lead<br>Office Manager/Finance Lead<br>Fundraising Manager<br>Peer Support Development Officer (to<br>April 2016)<br>Fundraising Officer (to October 2016)<br>Communications and Social Media<br>Officer<br>Project Manager (NWL CLAHRC<br>Project to June 2016)<br>Children's Holiday 2016 Lead (to<br>December 2016)<br>Helpline and Information Officer ( to<br>April 2017)<br>Children's Activities/Children Holiday<br>Lead (to November 2016)<br>Children's Activities/Children's Holiday<br>Lead (from December 2016)<br>Breaking Down Barriers Project Lead<br>(from February 2017)<br>Fundraising Officer (from November<br>2016)<br>Community Support Worker (from<br>February 2017)<br>South London Community Manager<br>(from September 2016) |

# The Sickle Cell Society

## Company information for the year ended 31 March 2017 (*continued*)

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|                      |  |
|----------------------|--|
| Ms Shahnaz Qizilbash | Health and Social Care Worker (from November 2017) |
| Ms Kimberly Thompson | Community Support Worker to November 2017)         |

|                                    |   |
|------------------------------------|---|
| <b>Registered address</b>          | Sickle Cell Society, 54 Station Road, London NW10 4UA   |
| <b>Telephone number</b>            | 020 8961 7795   |
| <b>Fax number</b>                  | 020 8961 8346   |
| <b>Website and email address</b>   | www.sicklecellsociety.org, info@sicklecellsociety.org   |
| <b>Registered charity number</b>   | 1046631   |
| <b>Company registration number</b> | 2840865   |
| <b>Auditor</b>                     | BDO LLP, 2 City Place, Beehive Ring Road, Gatwick, West Sussex, RH6 0PA   |
| <b>Banker</b>                      | National Westminster Bank, Park Royal Branch, Abbey Road, London NW10 7RA   |
| <b>Medical Advisors</b>            | <p>Dr Nellie Adjaye<br/>Consultant Community Paediatrician<br/>Mid Kent Healthcare NHS Trust</p> <p>Professor Dame Sally Davies<br/>Chief Medical Officer<br/>Department of Health, London</p> <p>Dr Phil Darbyshire<br/>Consultant Haematologist, Birmingham Children's Hospital<br/>Chairman, NHS England - Clinical Reference Group for<br/>Haemoglobinopathies</p> <p>Dr Mark Layton<br/>Consultant Haematologist<br/>Hammersmith Hospital, London</p> <p>Professor Bernadette Modell<br/>Emeritus Professor, UCL, London</p> <p>Dr Norman Parker (to April 2016)<br/>Retired Consultant Haematologist<br/>Whittington Hospital NHS Trust, London</p> <p>Professor David Rees<br/>Consultant Haematologist<br/>Kings College Hospital, London</p> <p>Dr Allison Streetley<br/>Consultant in Public Health<br/>Public Health England</p> |

# The Sickle Cell Society

Company information  
for the year ended 31 March 2017 (*continued*)

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## Scientific advisors

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

Professor Simon Dyson  
De Montfort University, Leicester

Dr Kofi Anie  
Consultant Clinical Psychologist  
NW London Hospitals NHS Trust

Dr Elizabeth Dormandy  
Consultant in Public Health

# **The Sickle Cell Society**

## **Trustees' report for the year ended 31 March 2017**

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The Board of Trustees of the Sickle Cell Society present their annual report and audited accounts for the financial year ended 31 March 2017 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.

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## **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. New Trustees were appointed in 2016/17.

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 Chairman of the Board.

### **Board development**

The board of 9 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 2016/17, jointly with the staff team of the Society.

# **The Sickle Cell Society**

## **Trustees' report for the year ended 31 March 2017**

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### **SUMMARY REVIEW OF 2016-2017**

#### **A summary statement from the Chairman and Chief Executive**

The financial year April 2016 to March 2017 has been one which has clearly demonstrated the impact of the hard work and effort by everyone concerned to improve the Society's financial position and sustainability over the past 3 years.

As a result we are pleased to report that we have performed strongly during the year on our corporate objectives and our financial position. We have now ended the financial year with a healthy surplus for the third consecutive year. This is no mean feat in the challenging environment in which we operate. Underpinning everything we have achieved operationally has been our focus to support people living with sickle cell and their families and to make a positive impact on the sickle cell community and beyond. More people with sickle cell and their families are contacting us for a wide range of information and advice.

Strong operational performance has not detracted from the important strategic work we do with Department of Health, Industry, NHS England, NHS Clinical Commissioning Groups, the NHS Sickle Cell and Thalassaemia Screening Programme, Local Authorities and the many more stakeholders we work with here in the UK and internationally.

We are delighted that in partnership with the United Kingdom Thalassaemia Society (UKTS), we have made excellent progress on the first year 2016/17 of the tender we secured from Public Health England. We also successfully implemented our Big Lottery funded Sickle Cell South London Link covering the London boroughs of Lambeth, Southwark and Lewisham.

We therefore enter the new financial year April 2017/ March 2018 with a strong foundation and good momentum. However we know that we continue to operate in a competitive and challenging economic environment, which will require careful financial stewardship, whilst maintaining the excellent progress that we have made over the past three years.

None of this would have been possible without the dedication and hard work of our staff, volunteers, fundraisers and other supporters across the country.

The board was sad to hear of the passing of one of the Society's Medical Advisers; Norman Parker in April 2016, our long-serving member of staff Comfort Ndiviye in October 2016 and also former trustee Cllr Sally Ann Ephson in September 2016.

We were delighted that our Patron Professor Elizabeth Anionwu received a Damehood (DBE) in the 2017 New Year's Honours.

We remain committed to fulfil the Charity aims as set out in the Company's Memorandum of Association and we have made continued progress on the sickle cell disorder agenda both in the UK and internationally. We realise that in order for the Society to be influential, we must continue to modernise our ways of working and engaging with the public and our stakeholders.

We will continue to strive to achieve the best for sickle cell patients and their families during the coming year 2017/18.

**Kye Gbangbola**  
Chairman

**John James**  
Chief Executive



# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## **PRIORITIES IDENTIFIED IN 2016/17 ANNUAL REPORT**

During 2016/17, 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- see page 7
- 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- see page 9
- 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- see page 11
- Successful establishment of the Big Lottery funded Sickle Cell South London Link project, covering the boroughs of Lambeth, Lewisham and Southwark- see page 10

## **KEY HIGHLIGHTS FROM THE YEAR 2016-17**

### **STAKEHOLDER RELATIONSHIPS**

The Society continued to form major strategic alliances with key stake holders, such alliances as Rare Disease U.K 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 & Thalassaemia Screening Programme, 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, Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO), National Institute for Health and Clinical Excellence (NICE), NHS Blood and Transplant, NHS England, Public Health England, Sickle Cell & Thalassaemia Association of Counsellors (STAC) other voluntary and statutory organisations involved with sickle cell. The Society has also been working closely with the All Party Parliamentary Group for Sickle Cell and Thalassaemia to raise awareness and prioritisation of sickle cell disorders on the political platform.

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

From early 2017, following a review of membership by the Board of Trustees, membership of the Sickle Cell Society was made free of charge.

The Sickle Cell Society's membership currently stands at 3,691 which include already-registered members aged 18 years and above, and other supporters. Sickle Cell Society members receive 3 emails a month, and two print or pdf newsletters a year.

It is important to emphasise that the membership number excludes a large population of non members, both adults and children under the age of 18 who have sickle cell disorder whom the Society supports and represents.

The Sickle Cell Society is the national umbrella for over 50 independent support groups, voluntary organisations and statutory centres across the UK.

### **MEDIA & COMMUNICATION**

The Communications & Social Media Officer has worked on increasing the Society's presence on social media platforms, such as Facebook and Twitter. Monitoring of following shows a substantial increase in engagement across these platforms, with an increase of over 1000 followers on Twitter and 500 further "likes" on Facebook. The Sickle Cell Society website receives, on average, 17,000 views per month.

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

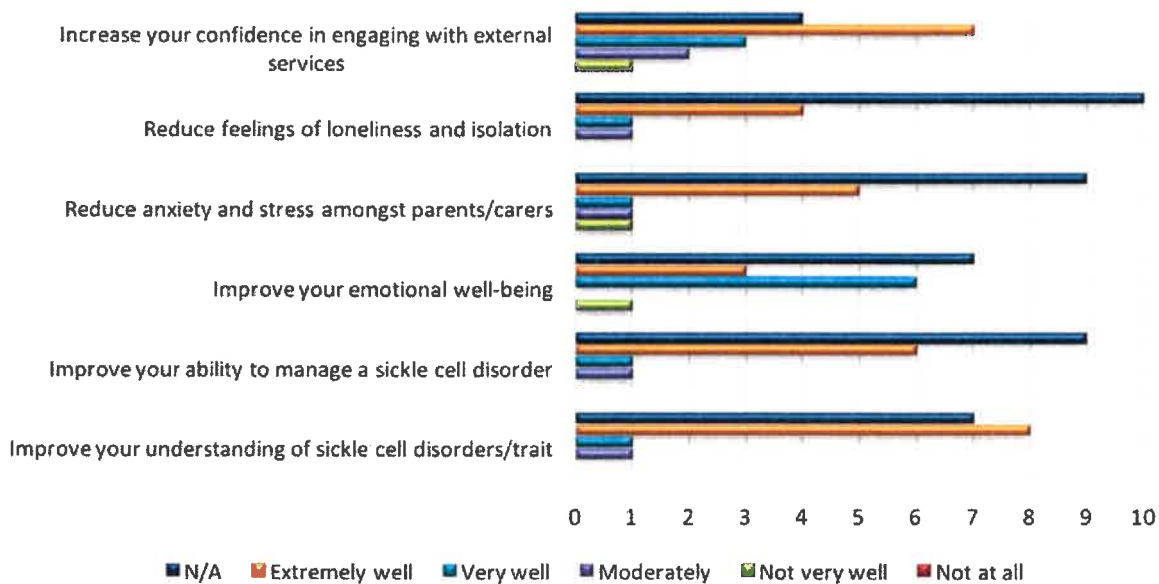
The Society has received coverage in the media including local radio stations and newspapers, BBC London news. It has contributed to features on BBC Breakfast and Channel 4.

## HELPLINE AND INFORMATION SERVICE

The Society received 600 requests for information by telephone from April 2016 to March 2017, and in more than half of cases we have been able to provide information immediately. The most common topic for helpline calls was queries regarding benefits. Fundraising and general information about sickle cell were also popular.

73% of callers were new callers. The team spent a total of 5,215 minutes (approx. 87 hours) on the phone. Overall, we are seeing a general increase in the amount of time spent on the phone, meaning we are reaching out to more people, and providing comprehensive information, advice and support. In a satisfaction survey, the service was rated 4.63 stars out of 5.

### To what extent do you feel that the helpline service helped to...?



Most service users reported the Society's helpline service has helped them greatly in a number of ways where applicable.

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## **KEY HIGHLIGHTS FROM THE YEAR 2016-17 (*continued*)**

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

The Society continues to honour the United Nations declaration of World Sickle Cell Day on 19 June each year by celebrating the day and raising awareness of sickle cell disorder through various initiatives within the local community. An event was held for World Sickle Cell Day 2016, which was attended by guests including comedian Ade and Miss Ghana UK.

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. Three information resources have been produced or reviewed under the Information Standard in the year 2016-2017: Did You Know Age 5-10, Did You Know Age 11-16 and Sickle Cell Disorder and Sickle Cell Trait.

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 and Facebook posts, as well as the Society's website which receives over 17,000 visitors 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.

The Society continued to engage with various press and media whereby patients, staff and other stakeholders took part in panel interviews and discussions.

The Society has three patient education events planned for 2017, in London, Cardiff and Bristol, as well as a collaboration with the Royal Society of Medicine's Medicine and Me programme.

The Society held a Patient and Carer education event in London at the 2016 AGM featuring a talk from the Picker Institute on patient experience with sickle cell, and a workshop on what patients need from the future.

### **SCREENING PROGRAMME**

The overall aim of this tender awarded project is to work jointly with UK Thalassaemia Society (UKTS) in a partnership with the NHS Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) to consult with health professionals and users of the screening pathway in order to come up with recommendations to improve timeliness of the antenatal screening and prenatal diagnosis offers to couples at risk of having a child with sickle cell or thalassaemia. In Year two of the project (17 /18) the aim will be to improve performance of specified aspects of newborn screening, and supporting implementation of year 1 findings.

A secondary aim is to provide expert advisory input to resources produced by NHSSCTSP both from staff of the Society and sickle cell service users.

Key milestones of the NHSSCTSP project in 2016-17 were:

- Conducting User Consultation with couples at-risk of having a child with sickle cell: User stories were gathered via a set questionnaire.
- Producing final Year 1 report that contains user stories, PND Case review audit and service evaluation data provided by NHSSCTSP and recommendations Offering expert advice on resources being produced by NHSSCTSP and where needed recruiting service users to participate in focus groups.
- Focus groups were conducted in March 2017 and resources based on this work are being produced by NHSSCTSP.

### **CHILDREN'S HOLIDAY**

24 children attended the 2016 Children's Holiday, which took place from 30<sup>th</sup> July to 6<sup>th</sup> August. In total, there were 19 volunteers: 8 full time & 11 part-time (of varying days duration). Themes throughout the week were Education, Training, Development and Self-Confidence. The children benefited from the many motivational talks

# **The Sickle Cell Society**

## **Trustees' report (*continued*) for the year ended 31 March 2017**

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they were given by the Carers, Medical Team, our Chief Executive and our Chairman. The children were encouraged to be their best, pursue their goals and not be influenced by the negative thoughts/words of others. There were a range of activities for the children to participate in, both indoor and outdoor. On Tuesday the whole day was spent at Drayton Manor and on Wednesday afternoon there was a trip to Laser Zone. The team felt that it was best to cancel bowling which had been planned for Thursday afternoon. This was on the advice of the medical staff, who felt that some children may be over-exerting themselves and were at risk of a crisis. The children also participated in arts and crafts sessions and indoor and outdoor games on site.

The Society is extremely grateful to our funders; volunteers (clinicians and staff) who make their time available to support the holiday and ensure that the children and families have a safe and wonderful holiday.

Friday evening was Presentation/Disco Night. As well as being given their awards, there was also time for the children to perform by singing, dancing, telling jokes, etc. Satisfaction and learning among the children was high.

### **CHILDREN'S ACTIVITIES PROGRAMME**

This Children In Need-funded project aims to provide a programme of children's activities. A team member has been recruited to coordinate activities and the Children's Holiday. Over this financial year our priorities have been to establish a regular programme of children's activities and build the number of children with sickle cell engaging in our work, as well as delivering the annual Children's Holiday. In order to do this we liaised with support groups and hospitals to grow our network, planned and delivered an exciting programme of activities based on the participants thoughts and ideas and have developed solid registration and monitoring systems. We have also recruited a strong team of children's activities volunteers to help us run the activities and have developed our marketing and communications in order to reach as many children as possible. Since October over 30 children with sickle cell from across London and the surrounding areas have engaged with our activities, enjoying workshops in everything from pizza making to stop motion animation. All have reported a rise in confidence since taking part in the activities and most have made new friends.

### **SICKLE CELL SOUTH LONDON LINK**

The Big Lottery Fund-funded Sickle Cell South London Link (SCSLL) was launched in September 2016. Since the start of the project, SCSLL have organised eleven children's activities across London during weekends and school holidays, including drumming, museum trips, film making and go karting. Approximately 40 children have accessed these activities.

We have recruited a strong team of volunteers to help us run project activities (including children's activities) and there has been a lot of enthusiasm for this. At least half of our active volunteers have experience of Sickle Cell in their immediate family or a friend with the condition. Parents are also keen to help out during workshops and this is a good demonstration of their engagement with the program of activities that we are offering.

We have built up a database of 60 service users so far (South London Based). They heard about us through 4 mediums - Hospitals, Sickle Cell Society Facebook page, SCSLL Launch Event held in February 2017 and via Support Groups.

In addition, we are currently aiming to set up a 'teenager support group' tri-borough (Lambeth, Lewisham & Southwark). We are disseminating a questionnaire to teenagers to find out what they would like, and are also using qualitative feedback (discussed further under Support Groups) gathered at our Launch Event asking – how do we engage teenagers and what type of support group would they like. We are also making links with existing support groups – in particular Croydon, Wandsworth, Greenwich and Elephant & Castle Young Stroke Survivors to explore the best ways we can support them.

We are currently in the early stages of planning topic related Information Workshops around 'Education' & 'Nutrition' later this year. We are also in the early stages of developing a 'Health & Wellbeing' Booklet and an employment booklet, which will also include information for teenagers (as asked for by teenagers at a recent focus group at Wooden Spoon House).

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## OTHER SIGNIFICANT ACTIVITIES DURING THE YEAR

The Brent Sickle Cell Advice and Support Service, funded by Brent Clinical Commissioning Group was independently evaluated for its first year. The independent evaluation found that the service was meeting and exceeding many key performance indicators. Service users provided overwhelming positive feedback augmented this. Nonetheless, the CCG decided to decommission the service and instead seek to incorporate health and social care for sickle cell into an existing programme designed for a wide range of long-term health conditions, but not specifically for sickle cell. The Society is not convinced that this is the most effective course of action and is monitoring the situation.

## ANNUAL THANKSGIVING SERVICE

The annual Thanksgiving Service was held in June 2016. It fell on Fathers' Day, so the theme was "Men and Sickle Cell". It was attended by the Mayors of Lambeth and Southwark as well as *EastEnders* actress Ellen Thomas.

## PARLIAMENTARY WORK

In May 2016, following the London Assembly elections, the Society met with a newly-elected Assembly member to discuss issues facing children with SCD. The Society has maintained close relationships with the All Party Parliamentary Group on Sickle Cell & Thalassaemia and attended their AGM in early 2017. Following an event chaired by Diane Abbott in 2015 to raise awareness of access issues to apheresis in the West Midlands, in the 2016/17 year, a new regional centre was set up at City Hospital, Birmingham B18 7QH..

## GRANTS AND DONATIONS

Terumo BCT provided an unrestricted grant of £40,000 to support Patient Education Days, Health Promotion activities and Website development.

Novartis Oncology Ltd provided an unrestricted grant of £7,480 to support The Sickle Cell Society Annual General Meeting 2016.

Hackney CCG Innovation Fund secured a restricted grant of £23,000 to provide a mentoring scheme for young people aged 10-24 with sickle cell disease living in the City and Hackney area over a 12 month period.

Hackney VCS Grants: A Place for Everyone secured a restricted grant of £29,134 to provide 12 engagement events in community venues across Hackney, supporting individuals/families to engage with others in similar circumstances, access screening and engage with other services and activities.

Alstron Syndrome UK/Sylvia Adams CT: Breaking Down Barriers provided a restricted grant of £10,000 over 2 years to work with support groups.

PF Charitable Trust provided a restricted grant of £5,000 towards the Helpline and Information Service.

London School of Economics & Political Science African Caribbean Society provided a restricted donation of £840 towards the Annual Children's Holiday 2017.

The Sir Jules Thorn Charitable Trust provided a restricted grant of £750 towards the Helpline and Information Service.

Selco Trading Centres Ltd provided a restricted donation of £1,000 towards the Annual Children's Holiday 2017.

John James CEO provided a restricted donation of £1,200 towards the Annual Children's Holiday 2017.

St John's & St Clements CE Primary School provided a restricted donation of £2,247 towards the Annual Children's Holiday 2017.

# The Sickle Cell Society

## Trustees' report (*continued*) for the year ended 31 March 2017

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Edward Harvist Trust provided a restricted donation of £5,000.00 towards the Annual Children's Holiday 2017.

Nexen Petroleum UK Ltd provided a restricted donation of £5,000 towards the Annual Children's Holiday 2017.

Mike Osafo gave a restricted donation of £2,000 towards Children Activities.

### PLANS FOR THE FUTURE

This draft strategy for 2017-20 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 well being 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

Despite the continued climate of austerity in recent years, particularly for the charity and public sectors, the Society with good financial management and transparency, has countered this financially challenging backdrop to enable a healthy surplus in the financial year 2016/2017. This is the fourth consecutive year that the Society has continued to improve its financial performance.

Moreover, the surplus has been generated whilst at the same time expanding our range of services for people with sickle cell and their families.

The 2016/17 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.

I would like to take this opportunity to thank our many supporters, our generous donors, as well as our dedicated staff and volunteers, for their excellent support throughout the year. I would especially like to recognise the invaluable contribution and generosity shown to us in the year from 3 legacy donations that further boosted our surplus thus ensuring that the Society has funds reserved for future direct work.

With everyone's support the Society has built on the improved financial management and performance of the financial year 2015/2016, which has resulted in achieving an increased surplus for the third consecutive year. This is a very significant achievement in the context of additional activities delivered with greater competition for limited funds.

The outlook for the financial year 2017/2018 remains very challenging, but I believe with continued financial discipline and governance, we are now even better equipped to see the Society grow both financially and in service delivery.

**Michele Salter**

Treasurer & Vice-Chair

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## STATEMENT OF FINANCIAL POLICIES

### Investment Policy

The Trustees have the power to invest in such assets as they see fit, except for trading purposes. The Society sometimes needs to react very quickly to particular emergencies and has a policy of keeping any surplus funds in short-term deposits, which can be accessed readily.

### 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. This policy was met during the financial year to 31 March 2017, which currently stands at £206,422 (2016: £150,403), despite the difficulties encountered with securing grants. The board updated the reserves policy during 2016/17 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 2016/17, good progress has been made on these strategic priorities. Key to this in 2016/17 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 £607,169, which is £133,233 higher than previous year's results. This has been achieved from restricted grant payments of £305,522 and £301,647 from unrestricted donations. The unrestricted donations consists of legacies, general fundraising, payroll giving, corporate, individuals, churches, schools and communities.

During the year the unrestricted funds incurred a net income of £60,876 (2015/16: net income of £45,289).

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 net income of £35,660 (2015/16: £13,989). The total restricted reserves at the end of the year were £101,348 (2015/16: £65,688).

# The Sickle Cell Society

Trustees' report (*continued*)  
for the year ended 31 March 2017

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## Fundraising Statement

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

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

We realise that fundraising is one of the key ways in which we interact with our supporters, donors and the general public. Therefore, the approach we have as a charity is one which ensures that the reputation of the Society is maintained at a high level. At the Society, we are professional 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.

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 only one complaint concerning fundraising practices, specifically linked to a lack of communication with a donor/fundraiser. The case was reported to the board and addressed directly by the CEO with a formal written letter of apology. Moreover, the complaint was included in our annual complaints return to the Fundraising Regulator.

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.



# The Sickle Cell Society

## Trustees' report (*continued*) for the year ended 31 March 2017

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### Trustees' responsibilities

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

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

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

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

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

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

### Provision of information to auditors

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

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

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

### By order of the Trustees

Kye Gbangbola  
Chairman

Date

# The Sickle Cell Society

## Independent auditor's report

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### INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF THE SICKLE CELL SOCIETY FOR THE YEAR ENDED 31 MARCH 2017

We have audited the financial statements of The Sickle Cell Society for the year ended 31 March 2017 which comprise specify the Statement of Financial Activities (incorporating the Income and Expenditure Account), the Balance Sheet, the Statement of Cash Flows and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charity'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 charity'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 charity and the charity's members as a body, for our audit work, for this report, or for the opinions we have formed.

#### Respective responsibilities of trustees and auditors

As explained more fully in the statement of trustees' responsibilities, 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. We have been appointed auditor under the Companies Act 2006 and report in accordance with [that Act. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Financial Reporting Council's (FRC's) Ethical Standards for Auditors.

#### Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the FRC's website at [www.frc.org.uk/auditscopeukprivate](http://www.frc.org.uk/auditscopeukprivate).

#### Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2017 and of the charity's net income and application of resources, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

# The Sickle Cell Society

## Independent auditor's report (*continued*)

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### Opinion on other matters prescribed by the Companies Act 2006

In our opinion the information given in the trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements and the trustees' report has been prepared in accordance with applicable legal requirements.

Based on our knowledge and understanding of the charity and its environment obtained during the course of the audit we have identified no material misstatements in the trustees' report.

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

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

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

*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).

|   | Note | Unrestricted funds<br>£ | Restricted funds<br>£ | Total funds<br>2017<br>£ | Total funds<br>2016<br>£ |
|---|------|-------------------------|-----------------------|--------------------------|--------------------------|
| <b>Income:</b>  |      |                         |                       |                          |                          |
| Donations, grants and legacies                                | 3    | 170,891                 | 305,522               | 476,413                  | 370,934                  |
| <i>Income from other activities:</i>                          |      |                         |                       |                          |                          |
| Advertising, promotions and fundraising                       |      | 130,064                 | -                     | 130,064                  | 102,309                  |
| Investment income   | 4    | 692                     | -                     | 692                      | 693                      |
| <b>Total income</b>   |      | <b>301,647</b>          | <b>305,522</b>        | <b>607,169</b>           | <b>473,936</b>           |
| <b>Expenditure</b>  |      |                         |                       |                          |                          |
| <b>Costs of raising funds</b>                                 |      |                         |                       |                          |                          |
| Fundraising costs   | 5    | 75,647                  | -                     | 75,647                   | 48,668                   |
| <b>Charitable activities</b>                                  |      |                         |                       |                          |                          |
| Campaign  | 5    | 31,890                  | 59,560                | 91,450                   | 66,082                   |
| Direct services group   |      | 50,280                  | 168,672               | 218,952                  | 205,323                  |
| Provision of information and advice                           |      | 45,479                  | 18,692                | 64,171                   | 66,932                   |
| Children's holiday  |      | 24,380                  | 36,033                | 60,413                   | 27,653                   |
| <b>Total expenditure</b>                                      | 5    | <b>227,676</b>          | <b>282,957</b>        | <b>510,633</b>           | <b>414,658</b>           |
| <b>Net income/(expenditure) for the year before transfers</b> |      | <b>73,971</b>           | <b>22,565</b>         | <b>96,536</b>            | <b>59,278</b>            |
| Transfer between funds  |      | (13,095)                | 13,095                | -                        | -                        |
| Net movement of funds in year                                 |      | 60,876                  | 35,660                | 96,536                   | 59,278                   |
| <b>Reconciliation of funds</b>                                |      |                         |                       |                          |                          |
| <b>Total funds brought forward</b>                            | 14   | <b>157,025</b>          | <b>65,688</b>         | <b>222,713</b>           | <b>163,435</b>           |
| <b>Total funds carried forward</b>                            | 14   | <b>217,901</b>          | <b>101,348</b>        | <b>319,249</b>           | <b>222,713</b>           |

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

The notes on pages 21 to 34 form part of these financial statements.

# The Sickle Cell Society

## Balance sheet at 31 March 2017

| <b>Company number 2840865</b>                          | <b>Note</b> | <b>2017</b>    | <b>2017</b>    | <b>2016</b>    | <b>2016</b>    |
|--|-------------|----------------|----------------|----------------|----------------|
|  |             | <b>£</b>       | <b>£</b>       | <b>£</b>       | <b>£</b>       |
| <b>Tangible fixed assets</b>                           |             |                |                |                |                |
| Tangible assets  | 9           |                | 11,479         |                | 6,622          |
| <b>Current assets</b>                                  |             |                |                |                |                |
| Stocks   |             | 90             |                | 549            |                |
| Debtors and prepayments                                | 10          | 10,035         |                | 34,968         |                |
| Cash and cash equivalents                              | 12          | 458,761        |                | 277,801        |                |
|  |             | <u>468,886</u> |                | <u>313,318</u> |                |
| <b>Creditors - amounts falling due within one year</b> |             |                |                |                |                |
| Creditors  | 13          | 161,116        |                | 97,227         |                |
| <b>Net current assets</b>                              |             |                | <u>307,770</u> |                | <u>216,091</u> |
| <b>Total assets less current liabilities</b>           |             |                | <u>319,249</u> |                | <u>222,713</u> |
| Represented by:  |             |                |                |                |                |
| <b>Unrestricted funds</b>                              | 16          |                | 217,901        |                | 157,025        |
| <b>Restricted funds</b>                                | 16          |                | 101,348        |                | 65,688         |
|  |             |                | <u>319,249</u> |                | <u>222,713</u> |

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

The accounts were approved and authorised for issue by the Board on  
by:

and signed on its behalf

**Trustee**

**Trustee**

The notes on pages 21 to 34 form part of these financial statements.

# The Sickle Cell Society

## Statement of cash flows for the year ended 31 March 2017

|   | Note | 2017<br>£ | 2017<br>£ | 2016<br>£ | 2016<br>£ |
|---|------|-----------|-----------|-----------|-----------|
| <b>Cash generated in operating activities</b>                 | 19   |           | 187,625   |           | 92,841    |
| <b>Cash flows from investing activities</b>                   |      |           |           |           |           |
| Interest income   |      | 692       |           | 693       |           |
| Payments to acquire tangible fixed assets                     |      | (7,357)   |           | (1,861)   |           |
| <b>Net cash from investing activities</b>                     |      |           | (6,665)   |           | (1,168)   |
| <b>Increase in cash and cash equivalents in the year</b>      |      |           | 180,960   |           | 91,673    |
| <b>Cash and cash equivalents at the beginning of the year</b> | 20   |           | 277,801   |           | 186,128   |
| <b>Cash and cash equivalents at the end of the year</b>       | 20   |           | 458,761   |           | 277,801   |

The notes on pages 21 to 34 form part of these financial statements.

# The Sickle Cell Society

## Notes forming part of the financial statements for the year ended 31 March 2017

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### 1 Accounting policies

#### Basis of preparation

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

# The Sickle Cell Society

## Notes forming part of the financial statements for the year ended 31 March 2017 (continued)

### 1 Accounting policies (continued)

#### Income (continued)

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.

#### 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.



# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 (continued)

## 1 Accounting policies (continued)

### 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 Donations

|                          | Unrestricted<br>£ | Restricted<br>£ | Total<br>2017<br>£ | Unrestricted<br>£ | Restricted<br>£ | Total<br>2016<br>£ |
|--------------------------|-------------------|-----------------|--------------------|-------------------|-----------------|--------------------|
| Donations and legacies   | 170,390           | -               | 170,390            | 161,766           | -               | 161,766            |
| Grants                   | -                 | 305,522         | 305,522            | -                 | 208,443         | 208,443            |
| Membership subscriptions | 501               | -               | 501                | 725               | -               | 725                |
|                          | <u>170,891</u>    | <u>305,522</u>  | <u>476,413</u>     | <u>162,491</u>    | <u>208,443</u>  | <u>370,934</u>     |

## 4 Interest receivable

|                                | Unrestricted<br>2017<br>£ | Unrestricted<br>2016<br>£ |
|--------------------------------|---------------------------|---------------------------|
| Bank and COIF deposit interest | <u>692</u>                | <u>693</u>                |

# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 (continued)

## 5 Expenditure

|                                     | Direct costs<br>£ | Staff costs<br>£ | Support costs<br>£ | Total 2017<br>£ | Total 2016<br>£ |
|-------------------------------------|-------------------|------------------|--------------------|-----------------|-----------------|
| <b>Raising funds</b>                |                   |                  |                    |                 |                 |
| Cost of fundraising                 | 53,504            | 22,143           | -                  | 75,647          | 48,668          |
| <b>Charitable activities</b>        |                   |                  |                    |                 |                 |
| Campaign                            | 5,930             | 46,468           | 39,052             | 91,450          | 66,081          |
| Direct services group               | 53,987            | 71,467           | 93,498             | 218,952         | 205,323         |
| Provision of information and advice | 15,181            | 21,588           | 27,402             | 64,171          | 66,932          |
| Children's holiday                  | 18,889            | 15,726           | 25,798             | 60,413          | 27,654          |
| <b>Total expenditure</b>            | <b>147,491</b>    | <b>177,392</b>   | <b>185,750</b>     | <b>510,633</b>  | <b>414,658</b>  |

### Analysis of support costs

|                                     | Other support costs<br>£ | Office and IT costs<br>£ | Staff related costs<br>£ | Governance costs<br>£ | Total 2017<br>£ | Total 2016<br>£ |
|-------------------------------------|--------------------------|--------------------------|--------------------------|-----------------------|-----------------|-----------------|
| <b>Charitable activities</b>        |                          |                          |                          |                       |                 |                 |
| Campaign                            | 4,807                    | 10,244                   | 17,259                   | 6,742                 | 39,052          | 26,188          |
| Direct services group               | 11,508                   | 24,526                   | 41,322                   | 16,142                | 93,498          | 81,369          |
| Provision of information and advice | 3,372                    | 7,189                    | 12,110                   | 4,731                 | 27,402          | 26,525          |
| Children's holiday                  | 3,175                    | 6,767                    | 11,402                   | 4,454                 | 25,798          | 10,959          |
| <b>Total support costs</b>          | <b>22,862</b>            | <b>48,726</b>            | <b>82,093</b>            | <b>32,069</b>         | <b>185,750</b>  | <b>145,041</b>  |

Total expenditure in the year to 31 March 2016 was £414,658 of which £214,623 was unrestricted and £200,035 was restricted.

# The Sickle Cell Society

## Notes forming part of the financial statements for the year ended 31 March 2017 (continued)

| 6 Staff cost and numbers | 2017<br>£ | 2016<br>£ |
|--------------------------|-----------|-----------|
| Wages and salaries       | 222,479   | 206,095   |
| Social security          | 19,336    | 15,157    |
| Pension                  | 17,670    | 15,123    |
|                          | 259,485   | 236,375   |

The average number of employees during the year was 12 (2016: 10).

No employee earned more than £60,000 per annum (2016: £60,000).

No remuneration has been paid to the Trustees other than the reimbursement to them for their travel and training expenses totalling £283 for (2016: £280), 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 £ 53,206 (2016: £43,971).

| 7 Incoming resources for the year       | 2017<br>£ | 2016<br>£ |
|---|-----------|-----------|
| Is stated after charging:               |           |           |
| Depreciation on owned assets            | 2,500     | 1,620     |
| Auditors' remuneration (including VAT): |           |           |
| - Audit fees                            | 9,984     | 10,320    |
| - Accountancy and other services        | -         | 1,800     |
| Equipment rental                        | 8,544     | 6,572     |
|   | 13,028    | 20,312    |

## 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 2017 (*continued*)

## 9 Tangible fixed assets

|                             | <b>Furniture<br/>and<br/>equipment<br/>£</b> |
|-----------------------------|--|
| <i>Cost</i>                 |  |
| At beginning of year        | 114,164                                      |
| Additions at cost           | 7,357  |
|                             | 121,521                                      |
| <i>Depreciation</i>         |  |
| At beginning of year        | 107,542                                      |
| Charge for year             | 2,500  |
|                             | 110,042                                      |
| Depreciation at end of year | 110,042                                      |
| <i>Net book value</i>       |  |
| At 31 March 2017            | 11,479                                       |
| At 31 March 2016            | 6,622  |

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

## 10 Debtors

|   | 2017<br>£ | 2016<br>£ |
|---|-----------|-----------|
| Grants and donations receivable (note 11) | -         | 31,896    |
| Prepayments                               | 10,035    | 3,072     |
|   | 10,035    | 34,968    |

## 11 Grants receivable

|                                       | 2017<br>£ | 2016<br>£ |
|---------------------------------------|-----------|-----------|
| Public Health England (Kings College) | -         | 365       |
| Brent Council                         | -         | -         |
| Terumo BCT                            | -         | 13,000    |
| NHS Brent CCG                         | -         | 18,531    |
|                                       | -         | 31,896    |

# The Sickle Cell Society

## Notes forming part of the financial statements for the year ended 31 March 2017 (*continued*)

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| <b>12 Cash and cash equivalents</b>                       | <b>2017</b> | <b>2016</b> |
|---|-------------|-------------|
|   | <b>£</b>    | <b>£</b>    |
| Cash in hand  | 159         | 321         |
| NatWest Bank Accounts                                     | 309,053     | 128,542     |
| SCS Bank Accounts   | 1,238       | 1,200       |
| COIF Charities Deposit Fund                               | 148,311     | 147,738     |
|   | <hr/>       | <hr/>       |
|   | 458,761     | 277,801     |
|   | <hr/>       | <hr/>       |
| <br>  |             |             |
| <b>13 Creditors - amounts falling due within one year</b> | <b>2017</b> | <b>2016</b> |
|   | <b>£</b>    | <b>£</b>    |
| Other creditors   | 78,474      | 56,295      |
| Accruals and deferred income                              | 82,642      | 40,932      |
|   | <hr/>       | <hr/>       |
|   | 161,116     | 97,227      |
|   | <hr/>       | <hr/>       |

# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 (*continued*)

## 14 Analysis of charitable funds

|  | Balance              | Movement in funds |                  |                | Balance               |
|--|----------------------|-------------------|------------------|----------------|-----------------------|
|  | 1 April<br>2016<br>£ | Income<br>£       | Expenditure<br>£ | Transfers<br>£ | 31 March<br>2017<br>£ |
| <b>Restricted funds</b>                      |                      |                   |                  |                |                       |
| Children Holiday scheme                      | 9,422                | 19,300            | 19,422           | -              | 9,300                 |
| Roald Dahl's Marvelous<br>Children's Charity | 268                  | -                 | -                | -              | 268                   |
| Jeans for Genes                              | 11,580               | -                 | -                | -              | 11,580                |
| Public Health England<br>Research            | -                    | 109,907           | 104,773          | -              | 5,134                 |
| Brent Council<br>In Memory of Dr Ade         | 5,000                | -                 | -                | -              | 5,000                 |
| Olujohnungbe                                 | 8,270                | -                 | -                | -              | 8,270                 |
| Helpline Worker                              | 6,961                | -                 | -                | -              | 6,961                 |
| Brent CCG                                    | 6,471                | 17,750            | 17,009           | -              | 7,212                 |
| Hackney CCG                                  | 1,657                | 70,802            | 63,831           | -              | 8,628                 |
| CLAHRC                                       | 11,309               | -                 | 1,543            | -              | 9,766                 |
| Big Lottery                                  | 4,750                | -                 | 4,750            | -              | -                     |
| Children in Need                             | -                    | 66,161            | 53,336           | -              | 12,825                |
| Breaking Down Barriers                       | -                    | 16,602            | 16,611           | 13,095         | 13,086                |
|  | -                    | 5,000             | 1,682            | -              | 3,318                 |
| <b>Restricted funds</b>                      | <b>65,688</b>        | <b>305,522</b>    | <b>282,957</b>   | <b>13,095</b>  | <b>101,348</b>        |
| <b>Unrestricted funds</b>                    |                      |                   |                  |                |                       |
| General fund                                 | 157,025              | 301,647           | 227,676          | (13,095)       | 217,901               |
| <b>Total funds</b>                           | <b>222,713</b>       | <b>607,169</b>    | <b>510,633</b>   | <b>-</b>       | <b>319,249</b>        |

## The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 (*continued*)

### Analysis of charitable funds – previous year

|  | Balance<br>1 April<br>2015<br>£ | Movement in funds |                  |                | Balance<br>31 March<br>2016<br>£ |
|--|---------------------------------|-------------------|------------------|----------------|----------------------------------|
|  |                                 | Income<br>£       | Expenditure<br>£ | Transfers<br>£ |                                  |
| <b>Restricted funds</b>                      |                                 |                   |                  |                |                                  |
| Children Holiday scheme                      | 2,317                           | 18,310            | 16,786           | 5,581          | 9,422                            |
| Roald Dahl's Marvelous<br>Children's Charity | 268                             | -                 | -                | -              | 268                              |
| Jeans for Genes                              | 11,580                          | -                 | -                | -              | 11,580                           |
| Public Health England<br>Research            | -                               | 48,745            | 48,745           | -              | -                                |
| Brent Council                                | 5,000                           | -                 | -                | -              | 5,000                            |
| In Memory of Dr Ade<br>Olujohnungbe          | 10,073                          | -                 | 1,803            | -              | 8,270                            |
| Helpline Worker                              | 6,961                           | -                 | -                | -              | 6,961                            |
| Brent CCG                                    | 15,500                          | 2,000             | 11,029           | -              | 6,471                            |
| Hackney CCG                                  | -                               | 61,772            | 60,115           | -              | 1,657                            |
| CLAHRC                                       | -                               | 46,816            | 35,507           | -              | 11,309                           |
| Southwark Council                            | -                               | 30,000            | 25,250           | -              | -                                |
|  | -                               | 800               | 800              | -              | 4,750                            |
|  | <hr/>                           | <hr/>             | <hr/>            | <hr/>          | <hr/>                            |
| <b>Restricted funds</b>                      | 51,699                          | 208,443           | 200,035          | 5,581          | 65,688                           |
| <b>Unrestricted funds</b>                    |                                 |                   |                  |                |                                  |
| General fund                                 | 111,736                         | 265,493           | 214,623          | (5,581)        | 157,025                          |
|  | <hr/>                           | <hr/>             | <hr/>            | <hr/>          | <hr/>                            |
| <b>Total funds</b>                           | 163,435                         | 607,169           | 414,658          | -              | 222,713                          |
|  | <hr/> <hr/>                     | <hr/> <hr/>       | <hr/> <hr/>      | <hr/> <hr/>    | <hr/> <hr/>                      |

# The Sickle Cell Society

## Notes forming part of the financial statements for the year ended 31 March 2017 (continued)

### 14 Analysis of charitable funds (continued)

#### Restricted Funds

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

#### Annual Children Holiday scheme

The funding provides respite for parents, carers and families. Each year the Society takes up to 35 children with sickle cell on a residential holiday for a fun packed and educational week.

#### 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 2017/18 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 2017/18.

#### Collaboration for Leadership in Applied Health Research and Care (CLAHRC)

To support the collaborative work undertaken between the Society, North West London CLAHRC and the Picker Institute Europe to develop a patient reported experience measure survey ( PREM).

#### 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 2017/18 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 2016/17 two awards of £3,500 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 2017. During 2017/18 we will aim to re-launch the awards with a different focus.

#### Helpline Worker

To provide dedicated telephone advice, information and support for people living with Sickle Cell Disorder, Carers and families.

#### 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.



## **The Sickle Cell Society**

### **Notes forming part of the financial statements for the year ended 31 March 2017 (continued)**

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#### **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 SCS has been commissioned by City and Hackney Clinical Commissioning Group (CCG) Innovation Fund to deliver an innovative advice, training and support service for people with SCD in City and Hackney, working in close partnership with the NHS- City and Hackney Sickle Cell and Thalassaemia Centre and Homerton 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.

# The Sickle Cell Society

**Notes forming part of the financial statements  
for the year ended 31 March 2017 (continued)**

## 15 Unrestricted donations, legacies and fundraising

|  | £      |
|--|--------|
| Payroll Giving   | 61,448 |
| Just Giving - OnLine   | 38,293 |
| CAF online   | 37,216 |
| Linda Okagbue - Legacy ( Late Mabel Rosalind Cole)                   | 30,252 |
| McAndrew & CO - Late Marietta Adelta King                            | 8,300  |
| Blackbaud Europe Merchant - OnLine                                   | 7,903  |
| Novartis Pharmaceuticals   | 7,480  |
| PF Charitable Trust  | 5,000  |
| Virgin Money Giving - OnLine   | 4,379  |
| Lewisham and Greenwich NHS Choir                                     | 4,348  |
| The Inheritance Planning Company - Late Cornelia Iton                | 3,522  |
| The Office of Health Economics                                       | 3,000  |
| Powerhouse International Ministries                                  | 3,000  |
| St John's & St Clements CE Primary School                            | 2,247  |
| Mr Mike Osafo  | 2,000  |
| Extra Mile Challenges  | 1,997  |
| Shodokan UK Karate   | 1,800  |
| Caterine Akobeng   | 1,500  |
| Davina Allen - Ex Fundraising  | 1,322  |
| Bancroft's School  | 1,200  |
| Selco Trading Centres Ltd  | 1,000  |
| Carl Nurse   | 1,000  |
| Hounslow Methodist Church - Margaret Logan                           | 850    |
| Mrs O F Brown  | 840    |
| Anonymous Donor  | 830    |
| Plumstead Manor School - Julie Appleton                              | 838    |
| HM Prison Service - HMPYOI Thorn Cross                               | 798    |
| Heathrow Community Fund - Naomi White London Marathon Matched Giving | 751    |
| Jenny Hammond Primary School - Diana Williams                        | 750    |
| Alexandra Park School  | 714    |
| The Freemason Grand Charity - Biggin Hill Chapter Rose Croix No. 936 | 700    |
| The Palmer Catholic Academy - J Bovvington                           | 680    |
| Relief Chest Scheme - LS7 Egyptian Lodge                             | 600    |
| Thamesview Health Centre - Catherine Lawson                          | 505    |
| Red Triangle Lodge   | 500    |
| Global Harvest Ministries - Samantha Oquaye-Oteng                    | 500    |
| NBM London   | 500    |

# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 *(continued)*

## 16 Analysis of net assets between funds

|                     | Unrestricted   | Restricted     | Total<br>Funds<br>2017 |
|---------------------|----------------|----------------|------------------------|
|                     | £              | £              | £                      |
| Tangible assets     | 11,479         | -              | 11,479                 |
| Current assets      | 367,538        | 101,348        | 468,886                |
| Current liabilities | (161,116)      | -              | (161,116)              |
|                     | <hr/>          | <hr/>          | <hr/>                  |
| Net assets          | <b>217,901</b> | <b>101,348</b> | <b>319,249</b>         |
|                     | <hr/>          | <hr/>          | <hr/>                  |

## Analysis of net assets between funds – previous year

|                     | Unrestricted   | Restricted    | Total<br>Funds |
|---------------------|----------------|---------------|----------------|
| Tangible assets     | 6,622          |               | 6,622          |
| Current assets      | 247,630        | 65,688        | 313,318        |
| Current liabilities | (97,227)       | -             | (97,227)       |
|                     | <hr/>          | <hr/>         | <hr/>          |
|                     | <b>157,025</b> | <b>65,688</b> | <b>222,713</b> |
|                     | <hr/>          | <hr/>         | <hr/>          |

## 17 Transfer between funds

During the year the Trustees agreed a transfer of £13,095 (2016: £5,581) 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:

|                       | 2017<br>£     | 2016<br>£     |
|-----------------------|---------------|---------------|
| Commitments expiring: |               |               |
| Within 1 year         | 1,043         | 6,984         |
| Within 2 to 5 years   | 13,572        | 3,870         |
|                       | <hr/>         | <hr/>         |
|                       | <b>14,615</b> | <b>10,854</b> |
|                       | <hr/>         | <hr/>         |

# The Sickle Cell Society

Notes forming part of the financial statements  
for the year ended 31 March 2017 (continued)

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

|  | 2017<br>£      | 2016<br>£     |
|--|----------------|---------------|
| Net Movements in Funds                       | 96,536         | 59,278        |
| Depreciation                                 | 2,500          | 1,620         |
| Interest income                              | (692)          | (693)         |
| Decrease in stocks                           | 459            | 774           |
| Decrease in debtors                          | 24,933         | 1,925         |
| Increase in creditors                        | 63,889         | 29,937        |
|  | <hr/>          | <hr/>         |
| Net cash generated from operating activities | <b>187,625</b> | <b>92,841</b> |
|  | <hr/>          | <hr/>         |

## 20 Analysis of cash and cash equivalents

|                    | 2017<br>£      | 2016<br>£      |
|--------------------|----------------|----------------|
| Cash in Hand       | 458,761        | 277,801        |
| Overdraft facility | -              | -              |
|                    | <hr/>          | <hr/>          |
|                    | <b>458,761</b> | <b>277,801</b> |
|                    | <hr/>          | <hr/>          |

## 21 Related party transactions

There were no donations that was pledged or given from the Trustees of The Sickle Cell Society in the current year and in the prior year. There are no other related party transactions requiring disclosure.