

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 and having no share capital)

ANNUAL REPORT

31 March 2011

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COMPANY INFORMATION

PATRONS

Mr Michael Parker CBE, President Professor Elizabeth Anionwu CBE Dr Floeila Benjamın OBE Lord Paul Boateng of Akyem Sir William Doughty Mr Derrick Evans Mr Lenny Henry CBE Dr Nola Ishmael OBE Mr Clive Lloyd OBE Mr Trevor Phillips OBE

TRUSTEES-DIRECTORS

Mrs Anne Welsh Ms Mona Adam Mr Babatunde Akıntola Mrs Carlotta Olason Mr Gary Kınnane Ms Sally - Anne Ephson Mr Joseph Ezeakunne Mr Oluwagbeminiyi Fadayini

Mrs Sherlene Rudder MBE Mrs Millicent Simpson

Mr Junior Kebbay Mr Korku Mıfetu Mr Kye Gbangbola Ms Mariama Koroma Mr Patrick Ojeer Mr Kingsley Ibeke

CO-OPTED MEMBERS

Dr Joan St John GP Ms Lucreta LaPierre MBE Mr Foluso Dawodu

STAFF 2010/11

Chief Executive Dr Philip Nortey Regional Care Advisor (London NE) Mrs Comfort Ndive Ms Ivamide Thomas Regional Care Advisor (London south) Ms Lorna Fletcher Befriending Coordinator Ms Miriam Williams Office Manager / Accounts Mr Paul Mohammad ICT Consultant (P/T) Ms Kalpna Patel Dr Asa'ah Nkohkwo Mrs Carlotta Olason

Fundraising Manager National Comprehensive Care advisor Health Info Officer (from Feb 2011)

Chairperson

Company Secretary

Treasurer

Resigned Feb 2011

COMPANY INFORMATION (continued)

REGISTERED ADDRESS

Sickle Cell Society 54, Station Road London NW10 4UA Tel 020 8961 7795 Fax 020 8961 8346

info@sicklecellsociety org www sicklecellsociety org

REGISTERED CHARITY NUMBER:

1046631

COMPANY REGISTRATION NUMBER

2840865

AUDITOR:

PKF (UK) LLP Pannell House Park Street Guildford Surrey GUI 4HN

BANKER:

National Westminster Bank

Park Royal Branch 1 Abbey Road London NW10 7RA

MEDICAL ADVISORS

Dr Nellie Adjaye

Consultant Community Paediatrician Mid Kent Healthcare NHS Trust

Professor Dame Sally Davies

Director of R&D

Department of Health, London

Dr Phil Darbyshire

Consultant Haematologist, Birmingham Children's Hospital

Chairman, UK Forum on Blood Disorders

Dr Mark Layton

Consultant Haematologist Hammersmith Hospital, London

Professor Bernadette Modell, Emeritus Professor, UCL, London

COMPANY INFORMATION (continued)

MEDICAL ADVISORS (continued)

Dr Ade Olujohungbe

Consultant Haematologist

University Hospital Aintree, Liverpool

Dr Norman Parker Consultant Haematologist Whittington Hospital, London

Dr David Rees

Consultant Haematologist Kings College Hospital, London

Dr Allison Streetly

Director

NHS Sickle & Thalassaemia Screening Programme

SCIENTIFIC ADVISORS:

Dr Mary Petrou

Director, Perinatal Centre UCL Hospital, London

Professor Simon Dyson

TASC Unit

De Montfort University, Leicester

LEGAL ADVISOR:

Mr Jamie Ritchie - Solicitor

Brent Community Law Centre

389 High Road Willesden London NW10

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

The Trustees have pleasure in presenting their report and audited financial statements for the year ended 31 March 2011. The financial statements have been prepared in accordance with the accounting policies set out in note 1 and comply with the Society's constitution, applicable law, and the requirements of the "Accounting and Reporting by Charities Statement of Recommended Practice (revised in 2005)"

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 cell. 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, 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

Over time, sickle cell individuals 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 a disability. There is no easy cure and death is sometimes a further consequence of these complications

OUR CORPORATE STATUS

The Sickle Cell Society was founded in 1979 by a group of healthcare professionals, sufferers and families affected by sickle cell in the London Borough of Brent. 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.

MISSION STATEMENT

The Society's mission is to enable and assist individuals with a sickle ceil disorder to realise their full potential. This mission will be achieved by raising awareness through education, the provision of welfare services and assisting in research.

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

CHARITY OBJECTIVES AND PUBLIC BENEFIT

The main objectives of the Society are

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

In pursuance of these objectives the Society's resources are expended primarily on

1 Welfare support provision including

The Ralma Faulkner Welfare Fund Bryan Jones Educational Fund and Children's Holiday Fund

- 2 Sickle Link Community Respite & Support Care, and Befriending Projects
- 3 Regional Advocacy & Support Advice Projects
- 4 Health Education/Information program

Leaflets, exhibitions, books and videos, tapes

Conferences, seminars, workshops and partnership networking

Internet web site and e-mail services

- 5 Assisting research into treatment
- 6 Assisting to steer statutory policy and programmes of the government, such as NHS Screening Programmes
- 7 Developing strategic collaborations and partnerships both nationally and internationally

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 objectives outlined above continue to be met and satisfy the public benefit test as outlined in the summary statement of the Chairman and Chief Executive on page 6

ORGANISATIONAL MANAGEMENT STRUCTURE

The Memorandum and Articles, as amended in 2002, allow 14 individuals from the membership to be elected on to the Board of Trustees each year at the Annual General Meeting, to serve for 2 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 supports the Trustees. The Governance list for 2010-2011 is shown under 'Company Information' (page 1)

The Board meets monthly and sub-committees and ad-hoc working groups complement meetings Management committee meetings are open to members on prior notification to the Company Secretary or Chair

The Chief Executive, heads a team of paid staff in addition to a pool of volunteers, and is responsible for the day-to-day operational activities of the organisation and also has managerial responsibility for all projects including those that are decentralised. The Chief Executive reports to the Chairman of the Board.

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

REVIEW OF ACTIVITIES AND DEVELOPMENTS DURING THE YEAR 2010-2011

A summary statement from the Chairman and Chief Executive

The Society has continued to work effectively to deliver its key objectives and a lot of activities and developments have taken place in the year. With the prevalent economic recession, there has been increasing demand on the welfare fund which is stretching our resources

In February this year the Society appointed a new Health Information officer - a vital post that has been vacant for nearly 5 years because of lack of funds The Society achieved the Information Standard Accreditation from G4S Assessment Services (Health & Social Care) The Information Standard is a new certification scheme for health and social care information producers

There was a reception at the Houses of Parliament by the All Party Parliamentary Group on 16th November 2010 hosted by Ms Dianne Abbott, Chair and Shadow Minister for Public Health At the event a petition was signed for better services for sickle cell which was delivered to the Prime Minister at 10 Downing Street on 2nd February 2011

The Annual Celebration and Thanksgiving service will be held on 5th June 2011 at The Parish Church of All Souls in Harlesden, London The Annual General Assembly will be on 16th July 2011 at the Emmanuel Centre in Westminster, London

The Society is currently undertaking five projects - Befriending (funded by Roald Dahl Foundation), Reaching out to Carers and National Comprehensive Care Advisor (both funded by DoH), Regional Care Advisors (funded by London Councils), CLAHRC (funded by NIHR - CLAHRC for NW London) The Society also continues to work with the National Screening Programme for outreach and dissemination of the DVD "Family Legacy" which is funded by Kings College

In collaboration with NHS Brent, the CLAHRC GP education project is proving to be very successful. This pilot project aims to educate and train GPs in the NW London region on sickle cell disease for improved care of patients. Data collection system has been set up in the Society's office to collect data for the project

The Society played a pivotal role in the DOH recent consultations exercises on health issues and reforms. The Society is happy to learn that funding from the London Councils for the Regional Care Advisors Project will continue to fruition next year

The Society received £10,000 funding from the pharmaceutical company Novartis - £5000 for scholarship and £5000 towards the Annual General Meeting The Society also received Department of Health funding of £25,000 for sickle cell carers project. This aims to provide a specialist carer support service that includes information, advice, advocacy, training and counselling. Other donations were received from kind hearted individuals of which the Society is very grateful

Additionally, the Society received funds from Vodafone for continued work on the National Health Register (The Society is on the steering committee) for patient data collection to ensure a more reliable national statistics of patients population nationally

The Society has continued to work effectively with the NHS Sickle Cell and Thalassaemia Screening Programme with the key objective of pre-conception, ante-natal and new born screening across the country. The Society in collaboration with other stakeholders, has been successful for nurses competency in sickle cell to be endorsed by the Royal college of Nurses for all levels of carers and nurses who look after patients with sickle cell disease and Thalassaemia to ensure standardisation of care provision

The Society's patron, Baroness Floella Benjamin gave a speech in the House of Lords in Feb this year on standards of care and commissioning of services in the NHS with specific reference to sickle cell. There was a reception at the House of Lords funded by Novartis and hosted by Lord Smith of Clifton to increase awareness of the link between sickle cell and stroke in children

The Society is very grateful to all its funders and the public for their suppor Photo C

Anne Welsh Chairperson Chief Executive

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TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011 (continued)

KEY ISSUES FROM THE YEAR 2010-11

COMMUNITY LINK / ALLIANCE

The Society endeavoured to engage more with the sickle cell support groups by appointing members of the board to attend their meetings to discuss issues. A volunteer was also appointed as a coordinator for the support group activities. The Society continued to work with the independent youth group, Broken Silence, and Sickle Plus group.

The Society continued to form major strategic alliances with key stake holders. Board members sat on committees of the alliances attending meetings. The society worked effectively with the National Screening Programme and the UK Thalassaemia Society. Other engagements include NCVO, UK Forum of Haemoglobinopaties, National Voices, SaBTO, NICE, NW London Clinical network, OSCAR, EORA, STAC, SHCA, Genetic Interest Group.

The Hackney Council's Carer Support Grant Scheme for the Hackney Sickle Link project has ended It operated at contracted capacity, as per Service Level Agreement and provided respite care and hospital visits for children and adults in previous years

WELFARE AND ADVICE PROJECT

The work of the Regional Care Advisors Project addressing poverty alleviation to improve the financial position of sickle cell individuals, social isolation, offering advise to enable access to Direct Payments (additional payment to DLA) from statutory agencies. The work has covered all the London Boroughs and funding ends next year. The project has been successful and if new funding is received the project will be replicated in other areas.

MEMBERSHIP & SUPPORT GROUP BASE

Subscriptions to the Society membership stands at 1015 (947 in 2010) individuals as centrally registered members over 18 years of age. It should be emphasized that the membership number excludes a large number of children with sickle cell disease who are frequently served by the Society Moreover, we remain the national umbrella for over 50 independent user support groups, voluntary organisations and statutory centres

By need and affordability, we have continued to support independent support groups, some of which had originated from our community seeding outreach activities over the years. Our policy is to ensure that every one of the estimated 13,000 service users has access to solidarity, advocacy and support, regardless of their membership status, although we do encourage membership.

The Society has continued to actively recruit volunteers and has over 100 volunteers on the register at year end. The Society is happy to report that a number of the volunteers gained experiences that helped them to secure employment

THE RALMA FAULKNER WELFARE FUND

This fund provides welfare benefit to individuals with sickle cell disease in the form of household items such as carpets, curtains, beds and washing machines. The fund spent £9338 (2010 £14,929) supporting individuals with the disease. The regional spread of beneficiaries reflected the entire country.

THE BRYAN JONES EDUCATIONAL FUND

In the financial year to March 2011, this fund distributed £1,896 (2010 £2,400) in support of individuals with sickle cell disease who miss out on schooling, and also those requiring IT support or who are undertaking a university or college course

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

KEY ISSUES FROM THE YEAR 2010-11

EDUCATION / INFORMATION & AWARENESS:

The Society continues to honour the UN declaration of World Sickle Cell Day on 19th June by celebrating the day and raising awareness by various initiatives in the community Last year's celebration was at Central Hall in Westminster, London

The Society achieved the National Information Standard Accreditation from G4S Assessment Services (Health & Social Care) which currently is a new certification requirement for health and social care information producers

The Society continued to be the leading public source for information on sickle cell at national and international levels. We disseminated titles from our John Ellerman funded collection including

- 1 Coping with Priapism
- 2 What is Haemoglobin D Trait and who has it?
- 3 What is Haemoglobin C Trait and who has it?
- 4 What is Sickle- Beta Thalassaemia?
- 5 The Standard for the Clinical Care of Adults Living with Sickle Cell Disease.
- 6 Sickle cell disease in childhood Standards and guidelines for clinical care

The Society continued to provide information, advice and referral service in response to thousands of letters, email requests and telephone calls. Talks and presentations were given by outreach workers and Trustees. The Society's initiative aimed at training public servants (HMP, Probation, Ambulance service, and similar personnel) at our offices on the challenges faced by people living with sickle cell is being reviewed by the new Health and Information officer.

The 2nd edition of Sickle Cell disease in Childhood was published last year 2010. There have been increasing demand for the society's publication of Clinical Standards of Care for Adults with Sickle Cell Disease which is gaining worldwide popularity. The adult standards include advice and recommendations for all healthcare professionals caring for people with SCD. It sets out minimum levels of care which people with the disease should expect from healthcare professionals, whether in a GP or hospital setting, including advice for A&E staff on how to recognise and manage an acute crisis.

THE SICKLE CELL SOCIETY TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 20

KEY ISSUES FROM THE YEAR 2010-11

OTHER SIGNIFICANT ACTIVITIES DURING THE YEAR

The Society received the Department of Health funding of £25,000 for sickle cell carers project. This aims to provide a specialist service that includes information, advice, advocacy, training and counselling. This helps to improve the well being of carers and enable them to provide care effectively and safely for people with the disease.

The Society also received £10,000 funding from Novartis - £5000 each for scholarship, and towards the Annual General Meeting costs

GlaxoSmithKline gulf club nominated the Society as their charity of the year and donated £1000 to the Society Other donations were received from various good – hearted individuals and groups

The Befriending project, funded by The Roald Dahl Foundation, continued to match service users to volunteers to give them much needed support and help. Funding for the project ends this year and the Society is sourcing other avenues for new funds to continue the project which has been very effective and successful

The Society welcomed students from various London schools who completed 2 weeks work experience at the Society Other students also did community projects on sickle cell Medical students from Imperial College and Whittington Hospital in London paid an educational and familiarisation visit to our offices. Newly appointed staff from various sickle cell centres and hospitals in the UK visited the Sickle Cell Society to acquire an understanding of the role of the Society as a voluntary organisation. Also we received nurses from overseas including Guyana.

Engagement with the press and media continued, with our clients and staff taking part in panel interviews and discussions organised by various Black media channels, including OBE and Ben TV channels. The DVD entitled Family Legacy has been featured on many television programmes and continues to be popular in the sickle cell community

The Society maintained its external training activities during the year and continued to deliver seminars and workshops on sickle cell disease to diverse audience at schools, colleges, universities, hospitals, churches, both locally and nationally

The Society's website, www sicklecellsociety org, which is currently under reconstruction, continues to register a high level of visitor activity

The Society's 31st Annual General Meeting was held in July 2010 at the Emmanuel Centre, Marsham Street, Westminster, attended by members and delegates from across the country and abroad

A congregation of over 100 attended the annual Service of Remembrance & Thanksgiving at All Souls Church in Harlesden on 6 June 2010, hosted by the Reverend Michael Moorhead

The children's annual week-long holiday was at Woodrow House, Amersham, Bucks, in August 2010 with 22 children affected by sickle cell taking part

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

KEY ISSUES FROM THE YEAR 2010-11

PARTNERSHIPS & NETWORKING

The Society's major national network of over 20 strategic linkages include membership to the UK Forum for Haemoglobinopathies, the National Council for Voluntary Organisation. The Society is represented on the steering group and sub groups of the NHS Screening Programme for Sickle & Thalassaemia, National Confidential Enquiry into Patients' Outcomes & Deaths (NCEPOD), National Institute for Clinical Excellence (NICE), TAPS Trial steering group, Dept of Health Clinical Services Development Group, National Voices, Sickle Cell and Thalassaemia Association of Counsellors (STAC), Safety of Blood Tissues and Organs (SaBTO) and many more nationally and internally

Work on the Sickle Cell Anaemia Detector tripartite collaborative research project has successfully completed phase one of the project from the Big Lottery Fund. New funding is still actively being sought for phase-II of the project, when further clinical investigation shall be undertaken to refine the technology.

The CEO of the society attended a conference in Ghana on Sickle Cell Centenary organised by Professor Kwaku Frempong, a world expert on sickle cell in July 2010 The National Comprehensive Care Advisor attended the International Forum on Quality in Healthcare in Amsterdam in April this year

The Society's Advisors

The Society maintained a top-level team of consultants as a pool of Medical Advisors and Scientific Advisors

Dr Nellie Adjaye (Kent Community NHS Trust), Dr Mark Layton (Hammersmith Hospital), Dr David Rees (King's College Hospital), Professor Bernadette Modell (UCLH, London) and Professor Dame Sally Davies (DoH), Dr Phil Darbyshire (Birmingham Children's Hospital & the UK Forum on Haemoglobin Disorders), Dr Ade Olujohungbe (Aintree University Hospital, Liverpool) and Dr Allison Streetly (Director, NHS Sickle Cell & Thalassaemia Screening Programme), Dr Norman Parker of Whittington Hospital London as Medical Advisor, and Professor Simon Dyson of De Montfort University and Dr Mary Petrou (UCLH, London), as Scientific Advisors

ORGANISATIONAL PERSPECTIVES FOR NEXT YEAR

The Society shall continue in its efforts towards its Constitutional goals and objectives. The following objectives were our Metrology targets for the year 2010-2011, and will continue to drive our efforts for the next year as well

- aim for a 10 percent increase across the range of our current services figures;
- continue to nurture the young people towards a Youths Forum,
- secure all staff posts, through an on-going revenue generation drive,
- maintain active engagement and commitment with our stakeholders,
- to maintain the all-day AGM format with great regional representation and take forward issues from the floor
- SCS to call for improvement for care in the community,
- SCS to raise awareness in schools and colleges and among the UK population at large,
- to continue embedding Standards of Care for Adults (and children) with SCD into the NHS system,
- to continue to lobby government agents including the APPG and the DoH for implementation and evaluation of the standards and for better service,
- To continue to conduct stakeholder satisfaction surveys for an improved service delivery

The Society continued to lobby stakeholders to improve community care through our outreach projects. The Society's user-provider engagement efforts continued to influence the providers of NHS clinical haematology.

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

KEY ISSUES FROM THE YEAR

TREASURER'S REPORT

There is no doubt that the past year has been a challenging one for the society. Like the majority of UK charities, we've seen a reduction in revenues, without there being a corresponding decrease in the number of those who require our services.

Revenue for the year ending 31 March 2011 was £384,756 whilst expenditure was £465,808 resulting in a deficit of £81,052. The difference is made up by funds from the reserves

The decision to draw on the society's reserves to maintain and hopefully improve service levels to our users and create a functional website enabling the society to generate an additional revenue stream was not taken lightly. Our fundraising efforts were hampered by the fact that our reserve levels were judged to be excessive by a number of potential donors, and out of step with recommended practice. The board does not anticipate drawing on the reserves in such a manner on an ongoing basis. Instead, now that reserve levels have been reduced in line with major donor requirements, the goal will be to maintain them at the new lower level, in line with best practice currently prevailing within the voluntary sector.

In the coming year, we will be seeking to improve our financial position in a number of ways. The board will implement plans to ensure that expenditure is brought in line with revenue so as to prevent a continuing deficit. In addition we need to diversify the society's income as it has become apparent that the charities that have done best during the recession are those which do not rely on donations alone. Furthermore, we are reforming our fundraising process in order to make it more effective and ensure that we learn from all our applications, successful and otherwise.

Our thanks go to everyone who has donated time, money, resources and knowledge to the society and its operations. We literally would not exist without you. As a sickle cell sufferer myself, I appreciate your efforts more than I could ever express in words.

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Lituade Akintola

Tunde Akıntola Treasurer

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TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

KEY ISSUES FROM THE YEAR

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 reserves policy of maintaining a minimum of three months of the Society's total expenditure. This policy was met during the financial year to 31 March 2011, despite the difficulties encountered with securing grants.

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 above. 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, which we face and confirm that they have established systems to mitigate the significant risks.

The Corporate Plan of 2004 is currently under review by the Board Key to this 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

Unrestricted Funds

During the year the unrestricted funds experienced a deficit of £22,890 (£35,795 in 2009)

Restricted Funds

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 £58,163 (£46,782 surplus in 2010) The total restricted reserves at the end of the year were £56,962 (£101,419 in 2010)

Designated Funds

These monies, on which there was no restriction, will be used as the Society's Reserves on which we will endeavour to build year-on-year. The Trustees have allocated a portion of this fund for ongoing developmental and service provision work, including

- Review and development of information materials
- The continued development of our ICT and website
- Welfare Fund & Educational Grants disbursements

Organisational Development

Projects are developed via boundary-worker feedback from our client group and the deliberations of our sub-committees and board

With difficulties in achieving a full complement of staff, amid financial difficulties and an increasing workload due to public demand for our services, internal overhaul continued towards increased multi-skilling at our national head office less stress on Metrology (a rate-determinant task monitoring), and more recourse to Structured Volunteering. Due to the absence of a full-time volunteers coordinator function, there was also less interaction with nationwide Support Groups, through programmed visits, but wherever possible through electronic communication.

TRUSTEES' REPORT FOR THE YEAR ENDED 31 MARCH 2011

KEY ISSUES FROM THE YEAR 2010-11

BOARD DEVELOPMENT

The board has been developed to closely match our client group The board of 14Trustees have 8 members with the sickle cell disease. There are 3 co-opted members

TRUSTEES' RESPONSIBILITIES

The Trustees are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom accounting standards ('United Kingdom Generally Accepted Accounting Practice')

Company law requires the Trustees to prepare financial statements for each financial year that give a true and fair view of the state of affairs of the Society and of the incoming resources and application of resources of the Society, including its income and expenditure, for the year. In preparing these financial statements the Trustees are required to

- select suitable accounting policies and then apply them consistently,
- observe the methods and principles in the Charities SORP,
- · make judgments and estimates that are reasonable and prudent,
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Society will continue in business

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Society 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 Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

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Anne Welsh Chairperson

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INDEPENDENT AUDITORS' REPORT FOR THE YEAR ENDED 31 MARCH 2011

We have audited the financial statements of The Sickle Cell Society for the year ended 31 March 2011 which comprise the statement of financial activities, the balance sheet 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 auditors' 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 auditor

As explained more fully in the statement of trustees' responsibilities, the Trustees (who are also directors of the 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 as auditor under the Companies Act 2006 and report in accordance with that Act. Our responsibility is to audit the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of whether the accounting policies are appropriate to the charity's circumstances and have been consistently applied and adequately disclosed, the reasonableness of significant accounting estimates made by the trustees, and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Annual report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent misstatements or inconsistencies we consider the implications for our report

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 2011 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended,
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and
- have been properly prepared in accordance with the Companies Act 2006

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' annual report for the financial year for which the financial statements are prepared is consistent with the financial statements

INDEPENDENT AUDITORS' REPORT FOR THE YEAR ENDED 31 MARCH 2011

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 in respect of the charity, or
- the financial statements do not accord with the accounting records, or
- certain disclosures of trustee's remuneration specified by law are not made, or
- any information or explanation to which we are entitled has not been afforded to us

PKFlUH) LG

Richard Faulkner (Senior Statutory auditor)
For and on behalf of PKF (UK) LLP, Statutory auditor
Guildford

Date 25 10.11

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING THE INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2011

	<u>Notes</u>	Unrestricted Funds £	Restricted Funds £	Total <u>2011</u> £	Funds 2010
INCOMING RESOURCES					
Income resources from generated funds: Voluntary income		2.455			
Membership subscriptions Donations, legacies, grants and similar		2,175	•	2,175	2,795
ıncome	2	69,729	269,671	339,400	360,435
Activities for generating funds Advertising, promotions & fundraising		41,260	•	41,260	29,084
Investment income	3	1,921	-	1,921	2,045
Total incoming resources		115,085	269,671	384,756	394,359
RESOURCES EXPENDED					
Costs of generating funds Fundraising costs	4	15,214	-	15,214	13,560
Charitable activities	4	87,192	327,833	415,025	350,194
Governance costs	4	35,569		35,569	19,618
Total resources expended	4	137,975	327,833	465,808	383,372
Net incoming/(outgoing) resources before transfers		(22,890)	(58,162)	(81,052)	10,987
Transfer between funds		(13,705)	13,705	-	-
Net movement of funds in year		(36,595)	(44,457)	(81,052)	10,987
Total funds brought forward		264,438	101,419	365,857	354,870
Total funds carried forward		227,843	56,962	284,805	365,857

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 18 to 27 form part of these financial statements

Company Number: 2840865

THE SICKLE CELL SOCIETY

BALANCE SHEET AS AT 31 MARCH 2011

		<u>201</u>	<u>I</u>	<u>201</u>	0
	Notes	£	£	£	£
TANGIBLE FIXED ASSETS					
Tangible assets	8		7,062		7,988
CURRENT ASSETS					
Stocks		4,645		1,825	
Debtors and prepayments	9	22,798		27,340	
Cash at bank and in hand	11	340,147		369,825	
		367,590		398,990	
CREDITORS (amounts falling due					
within one year)					
Creditors	12	89,847		41,121	
Net current assets					
			277,743		357,869
Total assets less current liabilities			284,805		365,857
REPRESENTED BY			<u> </u>		
Unrestricted funds	13		227,843		264,438
Restricted funds	13		56,962		101,419
			284,805		365,857

These financial statements 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 in accordance with the Financial Reporting Standard for smaller entities (effective April 2008)

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

and signed on its behalf by

Anne Welsh BSc MSc

In Junior Kebbay

Chairperson

The notes on pages 18 to 27 form part of these financial statements

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

ACCOUNTING POLICIES

a) Accounting convention

The accounts have been prepared under the historical cost convention and in accordance with the Companies Act 2006 and follow the recommendations in Accounting and Reporting by Charities Statement of Recommended Practice (SORP) revised 2005. The accounts have also 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 in accordance with the Financial Reporting Standard for small entities (effective April 2008)

b) Stock

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

c) Capital grants

Capital grants received for the purchase of equipment and other fixed assets are treated as restricted funds in the Statement of Financial Activities and are recognised in the year in which they are receivable

d) Revenue grants

Revenue grants are recognised in full in the Statement of Financial Activities in the year in which they are receivable

e) Donations

Donations and similar income are accounted for in the year in which they are receivable

f) 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

g) Legacies

Legacies are accounted for on a receivable basis

h) Resources Expended

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

Charitable expenditure 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

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

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

1. ACCOUNTING POLICIES (CONTINUED)

h) Resources Expended (continued)

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 4

1) Leased assets

Assets held under lease arrangements that transfer substantially all the risks and rewards of ownership to the Society are capitalised. The capital element of the related rental obligations is included in creditors. The interest element of the rental obligations is charged to the Statement of Financial Activities on a straight line basis. Rentals in respect of all other leases are charged to the Statement of Financial Activities.

j) 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

k) 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

l) 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

m) Designated funds

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

n) Grant income

Grant income is recognised on a receivable basis when the granting organisation is committed to payment

o) Donations in kind

Donations in kind are included in the accounts at market value

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

1. ACCOUNTING POLICIES (CONTINUED)

p) 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

2. DONATIONS, LEGACIES, GRANTS AND SIMILAR INCOME

	Unrestricted	Restricted	Total 2011	<u>2010</u>
	£	£	£	£
Donations	69,729	-	69,729	113,926
Grants	-	269,671	269,671	246,509
	69,729	269,671	339,400	360,435
3. INTEREST RECEIVAB	LE		············	
			<u> 2011</u>	<u>2010</u>
			£	£
Bank and COIF d	eposit interest		1,921	2,045

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

Costs directly allocated to activities	Basis of allocation	Fotal	London	DOIL	DOH Carer's Project	Jeans for Genes	Roald Dabi Grant	Kings College Fund	CLARHC Project	Childrens	General Charitable Activities	Governance Costs	2010
		ધ્ય	બ	ધ્ય	ч	¥	4 1	44	44	ધ્ય	બ	u	ţ
Staff costs (Note 5)	Direct	284,954	57,659	70 508	16,440	,	25,213	41,121	3,384	•	60,129	10,500	218,431
Anniversary Merchandise	Direct	, 64	173 C	. 000	. 65	•	. [5]	,000 6	. 154	•	. 744	•	4,300
Vinting and publications	No of expected income	0,439	195,2	006.1	404	• 1	1.7.1	2,000	104		0320		11,423
Wellate Oranis Children's Holiday	Diest	16 294		, ,					. ,	16.294	,	•	10,663
Bryan Jones Fund	Direct	1.896	•	•	•	•	•	•	•	,	1,896	•	3,505
Novartis Scholarship	Direct	5,000	•	•	1	•	•	•	,	•	5,000	•	5,000
SCAD	Direct	•	•	• ;	• ;	•	• ;	• !	• !	•	,	•	3,490
ICT Support	% of expected income	7,890	2,454	1,820	392	•	1,160	1,917	147	•	. 090	•	4,783
Kemembrance Service	Direct	0,050	, ,		• •						050,1	10.653	11.470
Awareness & Conference	Direct	40,4	412	88	1.859	•		3.738	•	•	5,357	,	10,423
Cost of Fundraising	Direct	2,160	•	'	•	•	2,025	•	562	•	2,160	•	1,923
Volunteering Strategy	Direct	4,791	•	٠	•	4,791		•	•	•	• ;	•	4,152
Payroll Giving	Direct	13,054	•	•	•	•	Ī	•	•	•	13,054	•	11,828
		379,621	980'59	74,316	19,100	4,791	29,609	48,776	4,247	16,294	98,249	21,153	314,800
Support costs allocated to	:	!									•		,
Recruitment	Direct	2,643	• •	• ;	' (•		•	ı	•	2,643	•	3,631
Staff cost - training	Direct	1,765	238	781	270	•	61.	. 631	. 651	•	357	•	4.0.4
I ravel & subsistence	DIRECT Disease	1,555 595 C	7,480	4,136	•	• (cc ·	£61) + [•	, oc	7 283	1,1
Subscriptions	Direct	30									30		502
Establishment costs	Direct & % of income	3,041	946	101	151	٠	447	739	57	•	;	•	4,021
Telephone & Fax	% of expected income	7,857	2,444	1,813	390	•	1,155	1,908	147	•	•	•	7,123
Postage & Stationery	% of expected income	11,145	3,466	2,571	554	•	1,639	2,707	208	•	٠,	•	8,968
Ketresnment Insurance	Direct % of expected income	4.44 1.44	1381	1.024	22.1		653	1,079	83 '	, ,	70		4,214
Cleaning	% of expected income	2,547	792	588	126	•	374	619	48	•		•	2,342
Repair & Maintenance	% of expected income	3,626	1,128	836	180	٠	533	881	89	•	•	•	5,116
Bank Charges & Interest	Direct	169	•	•	•	•	• ;	•	• •	•	697	•	575
Depreciation & Loss on	% of expected income	2 126	908 C	490	106	•	313	516	130	•	, ,	•	2,747
Audit & Accountancy	Direct	8,903	,	, ,	3	٠			<u>.</u>	•	•	8,903	9,084
Legal & Professional Fees	Direct	16,509	•	•	780	•		9,100	3,399	•	•	3,230	147
License and Support	% of expected income	3,744	1,18 1,18	86	186	ı	188	606	70	•	•	•	2,652
Youth Training	Direct	86,187	17,006	15,537	3,332		6,929	20,412	4,399		4,156	14,416	68,572
Total Cost of Charitable Activities	tivities	465,808	80,092	89,853	22,432	4,791	36,538	69,188	8,646	16,294	102,405	35,569	383,372

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

5.	STAFF COST AND NUMBERS	<u>2011</u>	2010
		£	£
	Wages and salaries	242,091	186,962
	Social security	22,456	16,012
	Pension	20,407	15,457
		284,954	218,431

The average number of employees during the year was 8 (2010 7)

No employee earned more than £60,000 per annum (2010 N11)

No remuneration has been paid to the Trustees other than the reimbursement to them for their travel and training expenses totalling £2,283 (2010 £1,511), incurred when attending meetings or other Society business and £3,399 in professional fees (2010 nil)

6. INCOMING RESOURCES FOR THE YEAR

Is stated after charging	<u>2011</u> £	2010 £
Depreciation on owned assets	2,126	2,747
Auditors' remuneration (including VAT)		
Audit fees	6,025	5,775
Accountancy and other services	2,878	3,309
Equipment rental	7,415	9,466

7. **TAXATION**

The Society does not pay corporation tax due to its charitable status

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

8. TANGIBLE FIXED ASSETS

9.

10.

	Eq	ture and uipment £
COST		
At beginning of year	103	490
Additions at cost		200
At end of year	104	690
DEPRECIATION		
At beginning of year	95,	502
Charge for year	2,	126
Depreciation at end of year	97,	628
NET BOOK VALUE		
At 31 March 2011	7	062
At 31 March 2010	7,	988
All of the above assets were used for direct charitable	purposes during the year	,
DEBTORS		•
DEDIVES		
DEDIONS	<u>2011</u>	<u>2010</u>
DEDIORS	2011 £	
	£	<u>2010</u> £
Grants and donations receivable (Note 10)	· · · · · · · · · · · · · · · · · · ·	<u> 2010</u>
Grants and donations receivable (Note 10)	£ 16,135	2010 £ 25,966
Grants and donations receivable (Note 10) Prepayments GRANTS RECEIVABLE	£ 16,135 6,663 22,798	2010 £ 25,966 1,374 27,340
Grants and donations receivable (Note 10) Prepayments	£ 16,135 6,663 22,798	2010 £ 25,966 1,374 27,340 2010
Grants and donations receivable (Note 10) Prepayments	£ 16,135 6,663 22,798	2010 £ 25,966 1,374 27,340
Grants and donations receivable (Note 10) Prepayments GRANTS RECEIVABLE	£ 16,135 6,663 22,798	2010 £ 25,966 1,374 27,340 2010
Grants and donations receivable (Note 10) Prepayments	£ 16,135 6,663 22,798 2011 £	2010 £ 25,966 1,374 27,340 2010 £

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

11. CASH AT BANK AND IN HAND

11.	CASH AT BANK AND IN HAND		
		<u>2011</u>	<u> 2010</u>
		£	£
	Cash in hand	113	352
	NatWest Bank Accounts	97,553	68,878
	COIF Charities Deposit Fund	242,481	300,595
	<u>-</u>	340,147	369,825
12.	CREDITORS (amounts falling due within one year)		
		2011	<u>2010</u>
		£	£
	Other creditors	60,888	33,072
	Accruals and deferred income	28,959	8,049
		89,847	41,121

13. ANALYSIS OF CHARITABLE FUNDS

	Balance				Balance
	l Aprıl	Incoming	Outgoing	Transfers	31 March
	2010				2011
	£	£	£	£	£
Restricted funds					
Children Holiday scheme	-	848	(16,294)	15,446	-
Roald Dahl Foundation	10,396	37,000	(36,538)	-	10,858
Sickle Link projects					
- Greater London	3,260	-	-	-	3,260
Hammersmith & Fulham	3,000	-	-	-	3,000
Jeans for Genes	24,122	-	(4,791)	-	19,331
Department of Health	867	-	-	-	867
DoH – NCA Advisor	32,850	58,046	(89,853)	(1,043)	-
DoH – Reaching Out to Carers	-	25,000	(22,432)	-	2,568
Regional Care Advice Projects					
Big Lottery Fund	698	-	-	(698)	-
The Welcome Trust	3,633	-	-	-	3,633
Member of Parliament grant	465	-	-	-	465
Roald Dahl (welfare grants)	90	-	-	-	90
Kings College	10,806	61,119	(69, 188)	-	2,737
London Council	11,232	78,259	(80,092)	-	9,399
NIHR CLAHRC Project	-	9,400	(8,646)	-	754
Restricted funds carried					
forward	101,419	269,672	(327,834)	13,705	56,962

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

13. ANALYSIS OF CHARITABLE FUNDS (continued)

		Movemen	t in Funds		
	Balance I Aprıl 2010	Incoming	Outgoing	Transfers	Balance 31 March 2011
	£	£	£	£	£
Restricted funds b/fwd	101,419	269,672	(327,834)	13,705	56,962
Unrestricted funds General fund	264,438	115,084	(137,974)	(13,705)	227,843
Total funds	365,857	384,756	(465,808)	-	284,805

Section 37 Statement

Grant income of £78,259 was received in 2010/11 from London councils to address poverty alleviation in our target community in London. The note above and the resources expended note (note 4) illustrates how these funds have been used for the purposes intended with £9,399 carried forward to be utilized in future periods.

Restricted Funds

The purpose of each of the restricted funds is as follows

Roald Dahl Foundation funding is for the Befriending project

Greater London Sickle Link

The funding is for an administrative support post

Department of Health

The funding is for the Information Officer's post

DOH - NCA Advisor

The funding is for the post of Comprehensive Care Advisor

Hammersmith & Fulham Local Authority

To support the volunteering work benefiting the London Borough of Hammersmith & Fulham

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

13. ANALYSIS OF CHARITABLE FUNDS (continued)

Jeans for Genes Campaign

To support the recruitment and development of a pool of volunteers to support our practical community service to those living with sickle cell disease

The Wellcome Trust funding is applied to the doctors-patients engagement initiative

Kings College

To support the community engagement effort of the society, which enables the successful implementation of the NHS Sickle Cell & Thalassaemia screening programme, run from King's College at Guy's Hospital, London

London Council

Grant awarded to specifically address poverty alleviation in our target community in London

14. UNRESTRICTED DONATIONS, LEGACIES AND FUNDRAISING

Receipts of £500 and Over

Payroll Giving

Online Giving - Including External Fundraising

EPAL Pensions Administrator re Miss Olabowale Duroshola

BBC - Celebrity Mastermind (Levi Roots)

Mayor of Rugby Borough Council, Councilor Don Williams

Emma Quarshie - TASC - Datchet - Berks

Future & Planners Limited - Cheryl Saunders Atkinson & Keith Dublin

ASDA Foundation Charity - Susan Hughes

Daniel Chandler in memory of Michael Mensah

Tennis Tournament - Sophie Barnes

Fundraising Dinner and Dance - Tony Excel

Genesis Housing Group

GSK Stevenage Golf Society - Dr Bams Abila

St James' Catholic High School - Niamh Arnull

Hospital Saturday Fund

Sainsbury Plc - Hendon Branch

Lucreta La Pierre

GSK Sports & Social Club

Gospel Concert - Judith Spence

Black Solicitors Network - Cordella Bart-Srewart

Collonade Lodge - Paul Benscher

Simone Kadijat

Islington Arts & Media School

L'Oreal (UK) Limited - Bury Branch

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2011

15. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted £	Restricted £	Total funds £
Tangible assets	7,062	-	7,062
Current assets	310,625	56,962	367,590
Current liabilities	(89,847)	-	(89,847)
Net assets at 31 March 2011	227,840	56,962	284,805

16. TRANSFER BETWEEN FUNDS

During the year the Trustees agreed a transfer of £13,805 (2010 £1,497) from Unrestricted Funds to make good the deficits on the Restricted Funds

17. LEASING COMMITMENTS

The Society is committed to make the following payments within the next year under operating leases for equipment -

I' P	<u>2011</u>	<u>2010</u>
Commitments expiring	£	£
Within 1 year	-	302
Within 2 to 5 years	8,478	7,214
	8,478	7,516