2840865

THE SICKLE CELL SOCIETY

(A Company limited by guarantee and having no share capital)

REPORT AND ACCOUNTS

31ST MARCH 2005

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COMPANIES HOUSE 18/01/2006

LEGAL AND ADMINISTRATIVE DETAILS

PATRONS:

Floella Benjamin OBE

The Rt Hon Paul Boateng MP

Mr Derrick Evans Mr Lenny Henry CBE Mr Clive Lloyd OBE Mr Trevor Phillips OBE

TRUSTEES-DIRECTORS: Mr Linserd Miller MCIH

- Chairman

Mrs Marvelle Brown

- Company Secretary

Mr Neville Samuda

Ms Fortune Esimaje ACMA - Treasurer Mrs Sherlene Rudder MBE - President Mr Michael Asampong - to July 2004

Dr Lorna Bennett

Mr Bruce Cheltenham JP

Ms Edith Chikago Mrs Gloria Maughan Mr John Mozie Dr Philip Nortey

Mr Chuma Omenukwa Mr Anthony Sandiford

- to July 2004

Dr Joan St John

Ms Beverley Thomas-Daniel

CO-OPTED MEMBERS:

Ms Edith Chikago

- to July 2004

Mr Cecil Etienne

Mr Tony Harris

- from July '04 to Jan '05

- to July 2004 Ms Shade Kilani - to July 2004 Mr John Mozie - to July 2004 Mrs Millicent Simpson

EXECUTIVE DIRECTOR: Dr Asa'ah Nkohkwo FRSH

STAFF 2004/05:

Mr Vincent Cox

Direct Services Mgr./Deputy Director

Regional Care Advsior (Mcr/L'pool) Mr Antony Mason Mrs Cecilia Shoetan Regional Care Advisor (London NE) Ms Jan Tatham (fro May'05) Regional Care Advisor (Bristol-Cardiff) Regional Care Advisor (London South) Ms Iyamide Thomas Health Educ/Information Officer

Mrs Barbara Brewster (vacant new post) Health Education Researcher Mrs Comfort Ndive Community Link Worker Volunteers Co-ordinator Mr Noel Fearon

Support Services to April 2005 Ms Barbara Phillips Ms Lorna Fletcher Support Services from June '05

Ms Miriam Williams Support Services

Mr Mark James ACCA Accounts Consultant (P/T) ICT Consultant (P/T) Mr Rizwan Mahmood Mrs Stephanie O'Sullivan FInstF **Fundraising Consultant**

LEGAL AND ADMINISTRATIVE DETAILS (CONTINUED)

REGISTERED ADDRESS:

54, Station Road

London NW10 4UA

Tel. 020 8962 7795

www.sicklecellsociety.org.uk

REGISTERED CHARITY NUMBER: COMPANY REGISTRATION NUMBER:

1046631 2840865

AUDITOR:

Pridie Brewster

Chartered Accountants

Carolyn House

29-31 Greville Street London EC1N 8RB

LEGAL ADVISOR:

Mr J Ritchie, Solicitor

Brent Community Law Centre

389 High Road Willesden London NW10

BANKER:

National Westminster Bank

Park Royal Branch
1 Abbey Road
London NW10 7RA

MEDICAL ADVISORS:

Dr Nellie Adjaye

Consultant Paediatrician

Mid Kent Healthcare NHS Trust

Prof. Sally Davies

Department of Haematology

Central Middlesex Hospital, London.

Director, R&D, DOH.

Dr Mark Layton

Consultant Haematologist

Hammersmith Hospital, London

Dr Adrian Stephens Rtd Consultant

Department of Haematological Medicine

Kings College Hospital, London.

Dr Iheanyi Okpala

Consultant Haematologist St Thomas' Hospital, London.

Dr David Rees

Consultant Haematologist

Kings College Hospital, London.

Dr Mary Petrou

Director, Perinatal Centre UCL Hospital, London.

TRUSTEES' REPORT

The Trustees have pleasure in presenting their report and audited financial statements for the year ended 31st March 2005.

These statements relate to the funds of the Society, its decentralised Sickle Link and Regional Support Care projects, as well as the tripartite Sickle Cell Anaemia Detector (SCAD) research project.

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 its oxygen it loses its flexibility and uniform roundness adopting a sickle shape. 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 with a sickle cell disorder. 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 frequently as cells that are sickling (changing shape) within the spleen are rapidly destroyed.

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 are disabled. There is no easy cure and death is sometimes a further consequence of these complications.

OUR 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 of the members 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 Cell 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 (CONTINUED)

CHARITY OBJECTIVES

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 Projects
- 3. Regional Advocacy & Support Advise 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

STRUCTURE

The Memorandum and Articles, as amended in 2002, allow 14 individuals from the membership to be elected on to the Board each year at the Annual General Meeting, to serve for 2 years.

The Board meets monthly. The meetings are complemented by sub-committees, and ad-hoc working groups. These Committees have delegated powers. Management committee meetings are open to members on prior notification to the Company Secretary or Chair.

The Executive Director (heading a team of paid staff, in addition to a pool of volunteers) provides strategic support to the Board and is responsible for the day-to-day operational activities of the organisation. The Director also has line managerial responsibility for all decentralised projects.

TRUSTEES' REPORT (CONTINUED)

TRUSTEES

The Trustees of the Society are also the Directors of the Company. The following served during the year:

Mr Michael Asampong

Dr Lorna Bennett

Ms Marvelle Brown

Mr Bruce Cheltenham JP

Ms Edith Chikago

Ms Fortune Esimaje ACMA

Mrs Gloria Maughan

Mr Linserd Miller MCIH

Mr John Mozie

Dr Philip Nortey

Mr Chuma Omenukwa

Mrs Sherlene Rudder MBE

Dr Joan St John

Mr. Neville Samuda

Mr Anthony Sandiford

Mrs Beverley Thomas-Daniel

REVIEW OF ACTIVITIES AND DEVELOPMENT DURING THE YEAR

EDUCATION / INFORMATION & AWARENESS:

The review of the Society's information materials continued during the year with dissemination of the new publications produced earlier thanks to part-funding from the DoH, and in partnership with Newham Local Authority.

- Understanding Sickle Cell (audio tape)
- Talking about sickle cell (DVD and videotape)

Two new products were added:

• Claim it Right – A self-help guide to claiming disability living Allowance for adults and children with sickle cell disorders.

The Sickle Cell Society had long recognised that the symptoms and consequences of having a sickle cell disorder can create substantial care or supervision needs or mobility problems for those affected. Lloyds TSB bank awarded funding, jointly, to the Sickle Cell Society and the Disability Alliance to produce a 27-page booklet about Disability Living Allowance, specifically geared for individuals with sickle cell disorder.

TRUSTEES' REPORT (CONTINUED)

• Finding Your Way Around the Benefits System – An information leaflet.

This booklet was also produced in collaboration with the Disability Alliance and includes useful information about Income Support, Incapacity Benefit, Attendance Allowance, and child tax credits.

The Society remains the first point of call to the public for information. During the year, the Society provided information, advice and referral service in response to 2000 (1,605 in 2004) letters and email requests, and 3,500 (2,306 in 2004) telephone calls. 9000 (12000 in 2004) newsletters (Sickle Cell NewsReview & Sickle Scene for younger readers) were circulated. 500 copies of a special review marking the 25th Anniversary were distributed. The Society continued work with the media (TV, mass media and print press).

The Society is represented by the Director on the steering group of the Government's on-going NHS Screening Programme for Sickle & Thalassaemia, and the National Confidential Enquiry into Patients Outcomes & Deaths, (from Sickle Cell & Thalassaemia), funded by the National Institute for Clinical Excellence (NICE).

The Sickle Cell Society has maintained its external training activities during the year and has continued to deliver seminars on sickle cell disorder to as diverse an audience as schools, colleges, university hospitals, churches, and the Soroptimists International (Women Fellowship) in London and the South-East.

TRUSTEES' REPORT (CONTINUED)

25th Anniversary Celebrations

Over 200 guests attended a reception at the House of Commons on the 21st May 2004 to launch a year-long programme marking the 25th Anniversary of the Sickle Cell Society. The launch was hosted by a patron of the Society, The Rt Hon Paul Boateng MP, Chief Secretary to the Treasury.

The successful launch was followed during the year by a number of other awareness-raising events. The highlight of the 25th AGM, held on the 3rd of July 2004 at the Commonwealth Centre in Kensington London, was a memory lane tracing by two key founders, the President Mrs Sherlene Rudder MBE and Professor Elizabeth Anionwu CBE. A major milestone was the launch of the Society's free-phone helpline (0800 001 5660), a unique public service thanks to sponsorship by You Telecoms Ltd. As promotion gains momentum, we look to improve the service take-up, presently at about 30 callers a month. (See table below).

TWENTY FIVE YEARS OF THE SICKLE CELL SOCIETY

TWENTY FIVE YEARS OF THE SICKLE CELL SOCIETY
Formation of Sickle Cell Society - Founder members Ms. Elizabeth Anionwu and Mrs Sherlene Rudder
First Sickle Cell Society News Letter printed
Donated £1,800 to Central Middlesex Hospital to purchase screening equipment
£5,000 donated to Willesden General Hospital for the purchase of a computer.
1st Fundraising Gospel Concert held at Brent Town Hall, Wembley. Lenny Henry becomes a Patron of the Sickle Cell
Society
1st London to Brighton Bike Ride in memory of Geoff Johnson who dies on May 23rd and whose 4-year old daughter had
sickle cell disease.
Presented two 'on-demand' analgesia computer pumps
Sickle Cell Conference chaired by Lord Pitt, with participants from various Health authorities and sickle cell centres.
The Lenny Henry Gala Concert organised by the Rotary Club held at the Hippodrome, Birmingham: fund-raising on behalf
of the Sickle Cell Society raises £20,000 Floella Benjamin Achievement Award started.
The first holiday for children with sickle cell disease to Bognor Regis
The Sickle Cell Society and SCAR jointly advertise for applications for research grants. Professor Stuart from Birmingham
and Dr. Tuck for the Royal Free Hospital were selected.
Sickle Cell Society Symposium on education and employment at Northwick Park Hospital, Harrow, Middlesex.
Donation of four Graseby infusion pumps (£700) to the N. Middlesex Hospital
4 marathon runners raised £4,000 for the Sickle Cell Society
1st National Sickle Cell Conference at Aston University
Launch of the booklet "Living with Sickle Cell Pain"
Founder member, Mrs Sherlene Rudder receives MBE
The Society's Ralma Faulkner Welfare Fund established in addition to the Bryon Jones Educational Fund; Publication of two
booklets: Introduction to the Sickle Cell Society and A Brief Guide to Sickle Cell Disorders.
Launch of Hackney Sickle Link – a support service to support families affected by sickle cell disease.
Launch of Sickle Cell Society web-site: www.sicklecellsociety.org
20 th Anniversary Ball
Launch of Sickle Cell Awareness Programme at Jamaica Blue Café, London
Launch of booklet Get Tested & Have a Healthy Baby by Sherlene Rudder MBE
Mr Trevor Philips OBE and cabinet member Mr Paul Boateng MP become patrons, joining Lenny Henry CBE, Clive Lloyd
OBE, Floella Benjamin OBE and Derrick Evans.
Visit to the society's headquarters from Cherie Blair. Society's 24th AGM - The Great Debate: has there been a rapid
improvement in services for sickle cell?
Launch of the Silver Anniversary of the Sickle Ceil Society at the Terraces Pavillion, Houses of Parliament, hosted by Rt
Hon Paul Boateng MP.
Launch of the 5-region Regional Support Care Advice project, funded by the Community Fund of the Big Lottery Fund,
building on the Hackney, Lambeth and Brent community Links.
Launch of the NHS Sickle Cell and Thalassaemia Screening Programme with the Society's support on the programme
Steering Group and media personalities.
Launch of the Society's free-phone nation-wide helpline, (0800 001 5660), sponsored by You-Telecoms, at the 25th AGM,
Commonwealth Centre, London.
Launch of the Sickle Cell Anaemia Detector clinical trial in collaboration with Nottingham University and Imperial College
London, a major R&D funded by the Big Lottery Fund.
The Sickle Cell Society's Campus Tour is initiated

TRUSTEES' REPORT (CONTINUED)

Other major events during the year included:

- o a congregation of over 100 attended our annual Service of Remembrance & Thanksgiving, hosted at the St Stephen's & St John's Church, Rochester Row, Westminster on Sunday, 4th July 2004. The Reverend Tunde Roberts delivered the sermon at the service attended by an array of London mayors, members of the public, the Society, the Barbados Overseas Nurses Choir and the Willesden Seventh Adventist Church Choir;
- o an educational tour of university campuses led by Dr Simon Dyson of De Montfort University, Leicester;
- o the children's annual week-long holiday to Buckinghamshire held in August;
- o the Jeff-Johnson Memorial London Bike Ride held in September;
- o the KICC Walk of Champions held at the Hackney Marsh in October, organised by the Kingsway International Christian Centre, London, who adopted the Society as the Charity of the Year. The sponsored Walk raised over £ 40,000 for the Society, a cheque for which was presented by the KICC's Senior Pastor Matthew Ashimolowo, to Mr Linserd Miller, Chairman of the Society, at a congregation service in January 2005. Apart from staff of the Society, also in attendance at the cheque presentation were Mr Trevor Phillips OBE, Chair of the CRE and Patron of the Society and Miss Simone Stuart, celebrity singer and supporter of the Society.

(also, see later section on "Engaging Service Users with Providers).

TRUSTEES' REPORT (CONTINUED)

Internet Web-site & General Information Communication Technology

Our revamped website, <u>www.sicklecellsociety.org</u>, continued to register a high level visitor activity, (over 20,000 hits a day or over 300 actual visitors daily).

The redefinition of the Society's ICT network continued with the purchase of new ICT stock of PCs and other equipment.

DIRECT SERVICES

Sickle Link Projects:

Brent Council funding having run out, the Trustees have continued to maintain current levels of adult home support care service for **Brent Sickle Link** from the Society welfare funds. Thanks to the grant from the Roald Dahl Foundation, community respite and link services are presently being developed for families with children in Brent. The new Volunteers Coordinator is making maximum use of the concept of Structured Volunteering to extend the reach of the funding, so as to benefit as many youngsters as possible. The challenge of relying on the availability of volunteers to deliver the project to children continued throughout the year with an extended feasibility, as directed by the changing needs of the youngster clients.

The Hackney Sickle Link Sure Start project started in 2004 ended in the Autumn. The Hackney Council funded Carer Support Grant scheme remains at capacity with 10 clients and 5 police-screened and trained volunteer carers providing respite care and carrying out hospital visiting initially for children and now for adults. The FastForward project (European Community Fund) working with 10 young sickle cell service users in the production of a newsletter for their support group also ended in the Autumn.

Lambeth Outreach, the Lambeth Council-funded community link support service for sickle-cell sufferers maintained capacity with 7 service users and 5 screened and trained volunteer support carers.

Regional Support Care Advisors Project.

The Society's long-planned Regional Support Care Advisors project entered the implementation phase by the end of the financial year. The project partitioned London into three geographical regions. Two further regions cover Manchester-Liverpool and Bristol-Cardiff. Regional Care Advisers for London and the Manchester-Liverpool regions were recruited and introduced in the Autumn. The RCA for Bristol-Cardiff was recruited in March, with a start date scheduled for May 2005.

It is envisaged that the success of the project will eventually attract sufficient funding to enable a full nation-wide coverage within the next couple of years.

TRUSTEES' REPORT (CONTINUED)

Focus AR 2003-04: ENGAGING SERVICE USERS WITH PROVIDERS

The Society embarked on three key user-provider engagement exercises to shape not only its work, but that of the providers of NHS clinical haematology.

o The Regional Care Project (RCP) & Health Impact Assessment (HIA)

Two major Health Impact Assessment workshops, (each numbering over 30 participants), were organised in December '04 (Hackney London) and January '05 (Manchester). Engaging stakeholders (service users and healthcare professionals), the HIA workshop employed the WHO's Gothenburg Consensus of 1999 to influence the implementation of the project, according to the needs of the service users. The HIA will thus also serve as the basis for evaluating the regional care project, over the next three years, on the wider determinants of the public health of those affected by sickle cell disorders.

o The Science of Sickle Pain Management

Funded by the Welcome Trust, the Society organised two workshops to address the increasing complaints we receive from our client group, with regards to their experience of sickle-cell pain management, when they attend NHS clinical haematology departments and wards. The first workshop in February, held in Hackney, focused on service users and crystallised their concerns. These concerns formed the focus of the subsequent Doctors Workshop held at our head office a week later in March, attended by 10 top practising NHS consultant haematologists.

The findings from these workshop will form the basis of a presentation and debate at the general meeting UK Forum for Haemoglobinopathy scheduled for May 2005. A motion for the review of current guidelines and audit of related protocols for sickle cell pain management in the NHS will be tabled by the Society.

o Sickle Cell Anaemia Detector (SCAD) Project: a unique collaboration

Aims of SCAD

The project is a unique collaboration between the University of Nottingham, Imperial College and the Sickle Cell Society. The aim is to try to develop a new clinical instrument to monitor disease severity. This is to be supported by a study of patients' experiences of existing services (including perceived gaps & deficiencies), their relationships with doctors & nurses and the likely acceptance of this monitor. In this way we hope to anticipate the longer-term potential of the monitor as an aid for clinical assessment.

SCAD & the problem facing doctors and patients

Because SCD is incurable the purpose of therapies is to improve the quality of life for patients by managing the disease. However therapies are hampered by the absence of objective and precise measures of the disease level. Doctors and nurses can only use self-assessment of pain by patients as guidance because there is no monitor to reveal what is happening inside the red blood cells. As a result the effectiveness of disease management is diminished and patient suffering is increased. For the same reason the development of new treatments is thwarted. Moreover the difficulty of self-assessment of pain has increasingly hampered relationships between doctors and the patient community - relationships that are now continually monitored by the Sickle Cell Society.

TRUSTEES' REPORT (CONTINUED)

The SCAD project

The Applied Optics Group in the School of Electrical and Electronic Engineering, Nottingham, is developing the instrument in collaboration with haematologists and clinical scientists at Imperial College. The proposed technique relies on imaging of individual red blood cells *in-vivo* as they flow through the microcirculation (very small blood vessels just under the surface of the skin) in patients with SCD. The aim is to measure some of the physical properties of red blood cells and then relate these to the severity of the disease (using existing & rather crude definitions). If this can be done then the instrument's proof of concept will have been established and further refinements are then possible.

Development of the instrument is taking place at Nottingham alongside investigations at Imperial College (at Hammersmith and Central Middlesex Hospitals). These are to determine of the best method of patient examination (using currently available instruments as proxies for the new technique). Two of our medical advisers (Dr Mark Layton and Professor Sally Davies) are clinical researchers for the project.

The Sickle Cell Society will study patients' experiences of existing services (including perceived gaps & deficiencies), their relationships with doctors & nurses and the likely acceptance of this monitor. In this way we hope to anticipate the longer-term potential of the monitor as an aid for clinical assessment.

The phase 1 project, lasting 18 months, is funded by a grant of £237,000 from the Research Grants Division of the Big Lottery Fund.

The Rt Hon Paul Boateng MP, Chief Secretary to the Treasury and Patron of the Society, launched the project on April the 1st, 2005, at the Central Middlesex Hospital, Park Royal, Brent, London. In attendance were representatives of this unique tripartite project, the Big Lottery Fund and service users. Mr Trevor Phillips OBE, another Patron of the Society, had earlier supported the case for the project endorsing the bid to the Big Lottery Fund.

THE RALMA FAULKNER WELFARE FUND

This fund provides welfare benefit to individuals with a sickle cell disorder in the form of household items such as carpets, curtains, beds and washing machines. The fund spent £10,695 (£13,135 in 2004) supporting individuals with a disorder. Again, the regional spread of beneficiaries reflected the entire country.

THE BRYAN JONES EDUCATIONAL FUND

During the financial year to March 2005, this fund distributed £700 (£1,947 2004) in support of individuals with a sickle cell disorder who miss out on schooling, require IT support or who are undertaking a university or college course.

TRUSTEES' REPORT (CONTINUED)

PARTNERSHIPS & NETWORKING

The Society's national networking included active membership to the Long-term Medical Condition Alliance, the Health Coalition Initiative, the UK Forum for Haemoglobinopathies, the National Council for Voluntary Organisation (Health Electoral College), the Newborn Screening Centre Board, the NHS Sickle Cell & Thalassaemia Screening Steering Group. The Director remained on the Patients Editorial Panel of the BMJ. The Director and Dr Lorna Bennett, a Trustee, maintained the Society's membership on the Pan-European Blood Safety Alliance. The Director was eventually elected onto the 5-man Board of the PBSA at the sitting in Vienna in February 2005.

Work on the Sickle Cell Anaemia Detector collaborative research project has already been discussed above.

PUBLIC RELATIONS

The Society continued to enjoy a raised profile through the patronage of eminent personalities including, the Rt Hon Paul Boateng MP (Chief Secretary to the Treasury) and Mr Trevor Phillips OBE, Chairman of the Commission for Racial Equality, (formerly, Chairman Greater London Assembly), Mr Lenny Henry CBE, Mr Clive Lloyd OBE, Mr Derrick Evans (alias Mr Motivator) and Floella Benjamin OBE.

Medical Advisors

The Society maintained a top-level team of consultants as a pool of Medical Advisors: Dr Iheanyi Okpala (St Thomas' Hospital); Dr David Rees (King's College Hospital) and Dr Mary Petrou (UCLH, London). Professor Sally Davies (Central Middlesex Hospital and the DoH); Dr Nellie Adjaye (Kent Community NHS Trust) and Dr Mark Layton (Hammersmith Hospital). Dr Adrian Stevens continues to serve though retired from active NHS in June 2003.

SPONSORSHIP HIGHLIGHTS

Thanks to Endemol-UK, Romeo, a colleague of Harvey of Rap music group, So Solid Crew, also represented the Society at the 2004 edition of The Games, a made-for-TV celebrity Easter pentathlon screened on Channel 4. Romeo also raised over £12,000 for the Society, designated for the Children Summer Holiday project. Yet another connection of the music group, Lisa Mafia, was selected for the 2005 edition, again representing the Society.

Pharma giant, Wyeth Labs Ltd, sponsored the launch of the 25th Anniversary programme at the House of Commons on the 21st May 2004, with a £5,000 unrestricted donation.

As stated previously, another milestone was reached when, at the 25th AGM in July, the Society announced a free telephone helpline (0800 001 5660) sponsored by You Telecoms Ltd.

EVENTS & ACTIVITIES

As stated previously, over 200 delegates attended the launch of our 25th Anniversary programme at the House of Commons on 21st May 2004. The event was hosted by the Rt Hon Paul Boateng MP, a Patron of the Society.

TRUSTEES' REPORT (CONTINUED)

Over 100 delegates attended the Society's 25th Annual General Meeting on Saturday, 2nd July 2004 at the Common Wealth Institute in Kensington. The highlight of afternoon was a memory lane tracing by two founder members of the Society as stated earlier. The Society also announced the free helpline numbe (0800 001 5660). The Director of You Telecoms, Mr Mark Hayles, addressed the meeting on his company's sponsorship of the helpline.

The AGM was followed the next day by a service of Thanksgiving & Remembrance as detailed previously. Rebecca Gordon, aka Miss Jamaica-UK and Victor, a celebrity from Channel 4 Reality TV programme Bi Brother were Guests of Honour at the 18th annual Jeff Johnson Memorial Bike Ride on Sunday, 6t September 2004, at the Wandle Recreation Centre in Wandsworth. 99 cyclists participated including mer women and children.

Reserves policy

The charity retains at all times sufficient reserves to cover its operational overheads and to continue as going concern.

Risk management policy

The charity always ensures it has sufficient funds in hand to meet any major crisis and presently has the matter well within safety margins.

TRUSTEES' RESPONSIBILITIES

Company law requires the trustees to prepare financial statements for each financial period, which give true and fair view of the state of affairs of the charity and of the surplus or deficit for that period. preparing these financial statements, the trustees are required to:

Select suitable accounting policies and they apply them consistently

Make judgements and estimates that are reasonable and prudent

Prepare the financial statements on the going concern basis unless it is inappropriate to presume that t charity will continue in operation

The trustees are responsible for keeping proper accounting records, which disclose with reasonable accura at any time, the financial position of the charity. They are also responsible for safeguarding the assets of t charity and hence for taking reasonable steps for the prevention and detection of fraud and oth irregularities.

This report has been prepared in accordance with the special provision of Part VII of the Companies A 1985 relating to small companies.

AUDITORS

The auditors, Pridie Brewster, Chartered Accountants, are willing to continue in office, and a motion their re-appointment will be put before the next annual general meeting.

Finally, the Trustees would like to record their appreciation for the hard work put in by the staff a volunteers to ensure a very productive year at the Society.

BY ORDER OF THE TRUSTEES

LINSERD MILLER Chair 14 JULY 2005

INDEPENDENT AUDITORS' REPORT

TO THE MEMBERS OF THE SICKLE CELL SOCIETY

We have audited the accounts of The Sickle Cell Society for the year ended 31st March 2005 which comprise the Statement of Financial Activities, the Balance Sheet and related notes. These financial statements have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective June 2002), under the historical cost convention and the accounting policies set out therein.

This report is made solely to the Trustees. Our audit work has been undertaken so that we might state to the Trustees 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 Trustees for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

The trustees' responsibilities for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards are set out in the Statement of Trustees' Responsibilities.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and United Kingdom Auditing Standards.

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Companies Act 1985. We also report to you if, in our opinion, the Trustees' Annual Report is not consistent with the financial statements, if the charity has not kept proper accounting records, if we have not received all the information and explanations we require for our audit, or if information specified by law regarding trustees' remuneration and transactions with the charity is not disclosed.

We read other information contained in the Trustees' Annual Report and consider whether it is consistent with the audited financial statements. We consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the financial statements. Our responsibilities do not extend to any other information.

Basis of audit opinion

We conducted our audit in accordance with United Kingdom Auditing Standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

INDEPENDENT AUDITORS' REPORT

TO THE MEMBERS OF THE SICKLE CELL SOCIETY

Opinion

In our opinion the accounts give a true and fair view of the state of the charity's affairs as at 31st March 2005 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended and have been properly prepared in accordance with the Companies Act 1985.

PRIDIE BREWSTER
CHARTERED ACCOUNTANTS
REGISTERED AUDITORS

22/7/2005

Carolyn House 29-31, Greville Street London EC1N 8RB

STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 31ST MARCH 2005

					\mathcal{A}	
		Unrestricted	Designated	Restricte	d Tot	al Funds
	<u>Notes</u>	<u>Funds</u>	<u>Funds</u>	<u>Funds</u>	<u> 2005</u>	<u>2004</u>
		£	£	£	£	£
INCOMING RESOURCES						
Membership subscriptions		2,569	-	-	2,569	2,100
Activities for generating funds	2	93,205	-	-	93,205	44,959
Donations, legacies, grants and similar						
income	3,16	84,306	-	261,978	346,284	237,529
Interest receivable		3,539	-	-	3,539	3,706
Other income		2,889	-		2,889	2,551
Total incoming resources		186,508	-	261,978	448,486	290,845
Less cost of generating funds		259	-	-	259	4,793
Net incoming resources available for charitable expenditure Charitable expenditure		186,249	-	261,978	448,227	286,052
Costs in furtherance of the charity	4	28,463	_	220,950	249,413	202,481
Managing and administering the charity	5	136,827	-	11,731	148,558	109,822
Total charitable expenditure		165,290	-	232,681	397,971	312,303
Total resources expended	6	165,549	-	232,681	398,230	317,096
Movement in total funds for the year: - Net (expenditure)/ income for the year	7	20,959	-	29,297	50,256	(26,251)
Transfer between funds Total funds brought forward	15,19	(5,100) 7,442	11,800	5,100 85,630	104,872	131,123
Total funds carried forward		23,301	11,800	120,027	155,128	104,872

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

The notes on pages 16 to 25 form part of these financial statements.

BALANCE SHEET

AS AT 31ST MARCH 2005

		2005		<u>2005</u> <u>20</u>		2004	• -
	Notes	£	£	$\underline{\mathbf{f}}$	Ŧ		
TANGIBLE FIXED ASSETS	10		22,176		15,629		
Tangible assets	10		22,170		15,027		
CURRENT ASSETS			•				
Stocks	1b	7,507		8,286			
Debtors	11	87,674		33,700			
Cash on deposit	13	80,939		78,361			
Cash at bank and in hand	13	-		6,856			
Note that the second of the se	* ** ** **	176,120	e e e	127,203	·		
CREDITORS (amounts falling due							
within one year)	14	43,168		37,960			
Net current assets			132,952		89,243		
Total assets less current liabilities	18		155,128		104,872		
REPRESENTED BY							
Unrestricted funds	18		23,301		7,442		
Designated funds	18		11,800		11,800		
Restricted funds	15,18		120,027		85,630		
			155,128		104,872		
							

These financial statements have been prepared in accordance with the special provisions of Part VII of the Companies Act 1985 relating to small companies and with the Financial Reporting Standard for smaller charities.

The accounts were approved by the Board on 14 07 05 and signed on its behalf by:

Chair

FORTUNE ESIMAJE

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

ACCOUNTING POLICIES

a) Accounting convention

The accounts have been prepared under the historical cost convention and in accordance with the Companies Act 1985 and follow the recommendations in Accounting and Reporting by Charities: Statement of Recommended Practice (SORP) issued in October 2000.

b) Stock

Stocks of T-shirts 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.

d) Revenue grants

Revenue grants are accounted for on an accrual basis.

e) Donations

Donations and similar income are accounted for on a receivable basis.

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 residual value of each asset over its expected useful life, as follows:

Fixtures, fittings & equipment - 25% straight line

g) Legacies

Legacies are accounted for on a receivable basis.

h) Charitable expenditure

A substantial proportion of overhead expenses are incurred in providing charitable services. Consequently an apportionment of these expenses has been made to support costs on the basis of charitable purpose salaries compared to total salaries.

i) Leased assets

Assets held under lease arrangements that transfer substantially all the risks and rewards of ownership to the company 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 so as to produce a constant periodic rate of charge. Rentals in respect of all other leases are charged to the Statement of Financial Activities.

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

1. ACCOUNTING POLICIES (CONTINUED)

i) Pension costs

The Society operates a defined contribution pension scheme. The pension costs charge represents contributions paid during the year.

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.

1) Unrestricted funds

Unrestricted funds are donations and other income receivable or generated for the objects of the charity without further specified purpose and are available as general funds.

m) Designated funds

This is the investment property which was part of a legacy left to the Society and has been sold and the proceeds are to be used for the furtherance of the charity's objectives.

n) Grant income

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

o) Support costs

Support costs represent staff and overhead costs in support of the charity's principal activity.

p) Resources expended

Resources expended are included in the Statement of Financial Activities on an accruals basis, inclusive of any VAT which cannot be recovered.

Certain expenditure is directly attributable to specific activities and has been included in those cost categories. Certain other costs, which are attributable to more than one activity, are apportioned across cost categories on the basis of an estimate of the proportion of time spent by staff on those activities.

q) Donations in kind

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

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

2.	INCOME FROM ACTIVITIES FOR GENERATING FUNDS							
		Unrestricted	Designated	Restricted	Total 2005	<u>2004</u>		
		£	£	£	£	£		
	Advertising, promotion &	~	~	~	~	~		
	fundraising	93,205	_	_	93,205	43,630		
	Merchandise	93,203	_	_	75,205	1,329		
	Meichandise				<u>-</u>	1,529		
		93,205	-	-	93,205	44,959		
		-			=			
3.	DONATIONS, LEGACIES, O	CD ANTS ANT	SIMIT AR INICO	οMF				
J.	DONATIONS, ELGACILS,	Unrestricted	Designated	Restricted	Total 2005	<u>2004</u>		
		£	£	£	<u>10tai 2005</u> £	<u>2004</u> £		
	- The second sec		*	æ				
	Donations	69,193	-	-	69,193	86,292		
	Grants	15,113		261,978	277,091	151,237		
		84,306	-	261,978	346,284	237,529		
						<u> </u>		
1	COSTS IN FURTHERANCE	OF THE CUA	DITV					
4.	COSIS IN FURTHERANCE			Restricted	Total 2005	2004		
		Unrestricted	<u>Designated</u>	£	10tai 2005 £	2004 £		
•	000	£	£					
	Staff costs	~	-	161,541	161,541	129,472		
	Welfare	-	-	11,345	11,345	15,244		
	Remembrance Service	-	-	806	806	742		
	Bryan Jones Fund	700	-	-	700	1,947		
	Children Holiday scheme	_	-	13,123	13,123	12,746		
	Hackney Sickle Link	-	-	-	-	2,172		
	Brent Sickle Link	- ,	-	-	=	-		
	Promotion and advertising	2,849	-	8,887	11,736	8,511		
	Depreciation	3,858	-	2,483	6,341	5,260		
	Fundraising strategy	21,056	-	-	21,056	16,160		
	SCAD project	_	-	9,144	9,144	· -		
	Website costs	_	-	- -	•	3,069		
	Member of Parliament					,		
	event	_	_	4,535	4,535	_		
	Welcome Trust	_	_	1,855	1,855	_		
	Lambeth Regional Care			1,000				
	Project Project	- -	-	7,231	7,231	-		
		28,463	-	220,950	249,413	195,323		

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

5. MANAGEMENT ADMINISTRATION

	<u>Unrestricted</u>	Designated	Restricted	<u>Total 2005</u>	<u>2004</u>
	£	£٠	£	£	£
Rent & rates	826	_	_	826	804
Light and heat	2,099	_	_	2,099	1,616
Repair & maintenance	3,506	_	_	3,506	2,712
Cleaning	2,931	_	_	2,931	2,766
Insurance	1,306	_	1,305	2,611	3,121
General expenses	1,845	-	1,505	1,845	1,987
	·	_	_	5,768	5,098
Equipment hire Audit	5,768	-	-	3,055	3,098
	3,055 2,820	-	-	2,820	2,919
Accountancy	•	-	•		
Bookkeeping costs	5,593	-	-	5,593	6,987
Bank charges	228	-	-	228	283
Subscriptions	346	-	•	346	659
Staff salaries	82,670	-	-	82,670	49,782
Recruitment	-	-	3,132	3,132	3,605
Telephone & fax	5,021	-	1,116	6,137	4,793
Printing, postage &					
stationery and other	11,824	-	4,170	15,994	17,840
Volunteer expenses	-	-	2,008	2,008	1,564
Staff travel	1,980	-	-	1,980	1,511
Staff training	-	-	-	-	1,211
Trustees Support	1,345	-	-	1,345	508
Loss on Disposal	325	-	-	325	-
AGM	3,339	-	-	3,339	4,064
	136,827	-	11,731	148,558	116,980

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

6. TOTAL RESOURCES EXPENDED

	Staff Costs	<u>Depreciation</u>	Other Costs	<u>Total 2005</u>	2004
	£	£	£	£	£
Cost of generating funds		-	259	259	4,793
Costs in furtherance of the					
charity	161,541	-	87,872	249,413	202,481
Managing and					
administering the charity	82,671	6,341	59,546	148,558	109,822
	244,212	6,341	147,677	398,230	317,096
Wages and salaries	207,581				
Social security	29,305				
Pension	7,326				
	244,212				
					

The average number of employees during the year was 7 (2004 – 9). Pension costs for the year amounted to £7,326 (2004 - £7,979).

No employee earned more than £50,000 per annum (2004 – nil).

No remuneration has been paid to the Trustees other than the reimbursement to them for their travel and training expenses totalling £1,346 (2004 £1,707), incurred when attending meetings or other Society business.

7. SURPLUS FOR THE YEAR

	Is stated after charging:	2005 £	2004 £
	Depreciation on owned assets Auditors' remuneration (including VAT):	6,341	5,260
	Audit fees	3,055	3,150
	Accountancy and other services	2,820	2,919
	Equipment rental	5,768	5,098
8.	INTEREST RECEIVABLE	17,984	16,427
0.	I (12xdd) 1dd(2x11d2d	<u>2005</u> £	2004 £
	Bank and COIF deposit interest	3,539	3,706

9. TAXATION

The company does not pay corporation tax due to its charitable status.

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

10.	TANGIBLE FIXED ASSETS		Furniture And Equipment £
	COST		
	At beginning of year Additions at cost		71,621 12,888
			84,509
	At end of year		
	DEPRECIATION		55,000
	At beginning of year Charge for year		55,992 6,341
	Depreciation at end of year		62,333
	NET BOOK VALUE		
	At 31st March 2005		22,176
	At 31st March 2004		15,629
	All of the above assets were used for direct charitable purposes during the year.		
11.	DEBTORS		
		2005 £	<u>2004</u> £
	Grants receivable (Note 12)	£ 87,674	£ 33,700
	Glants receivable (170te 12)		
		87,674 ———	33,700
12.	GRANTS RECEIVABLE		
12.	GIGHTO IGCELT TIBBE	<u>2005</u>	<u>2004</u>
		£	£
	SCAD Healman Social Sorvings	73,734 3,940	-
	Hackney Social Services Roald Dahl	10,000	-
	Bridge House Trust	- y	13,700
	Henry Smith	-	20,000
		87,674	33,700
		7/11/2	

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

	<u> </u>	<u> </u>	<u> </u>	<u></u>			
13.	CASH AT BANK AND IN H	IAND					
						<u>2005</u>	<u>2004</u>
						£	£
	Cash in hand					-	154
	NatWest Bank Accounts					-	6,701
	COIF Charities Deposit Fund					80,939	78,361
						80,939	85,216
7.4	CDEDITIONS / All'	4	-tug to one one or				
14.	CREDITORS (amounts fallin	g aue w	ithin one year,)		2005	2004
						£	£
	Bank Overdraft - Natwest Ac	counts				5,492	-
	Other creditors					9,844	15,049
	Accruals					27,832	22,911
						43,168	37,960
15.	RESTRICTED FUNDS		D-1 1) (or E. A.		D.1. 01.
		Nata	Balance 1st		nt in Funds	Two afores	Balance 31st
		Note	April 2004 £	Incoming £	Outgoing £	Transfers £	March 2005 £
	Children Holiday scheme	19	7,200	823	13,123	5,100	L
	Sickle Link projects: - Roald Dahl-Brent Sickle	17	7,200	023	13,123	5,100	-
	Link		12,500	10,000	-	-	22,500
	- Careers Grant		56	_	56	-	_
	- Hackney Social Services		16,912	15,759	28,140	-	4,531
	- Greater London		3,260	_	_		3,260
	- Volunteering Strategy		23,279		20,071	~	3,208
	Department of Health		-	10,000	9,694	~	307
	PPP Foundation		-	26,250	30,000	-	(3,750)
	Research Regional Care Advice Project	e.	1,401	-	1,366	-	35
	- Big Lottery Fund	3	_	98,487	85,093		13,394
	City Parochial		_	2,500	2,500	-	13,374
	John Ellerman Trust		8,793	-	8,793	_	_
	Lambeth Social Services		6,625		7,703	-	10,172
	Lloyds TSB		5,604	•	5,604	-	,
	Big Lottery Fund - SCAD		-	78,734	14,209	-	64,525
	The Welcome Trust		_	3,175	1,794	-	1,381
	Member of Parliament grant			5.000	1 535		165

5,000

261,978

85,630

4,535

5,100

232,681

465

120,027

Member of Parliament grant

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

15. RESTRICTED FUNDS (CONTINUED)

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

Children Holiday Scheme

Funds receivable have been expended to facilitate holiday activities for Sickle Cell sufferers.

Hackney Sickle Link

Grant receivable from the National Lottery Charity Board and London Borough of Hackney Social Services Department is applied specifically to the operations of Hackney Sickle Link.

Brent Sickle Link

The income receivable from Brent & Harrow Health Authority is applied specifically to the operations of Brent Sickle Link.

Department of Health

The funds receivable are for a Health Education/Information officer and have been applied specifically to this work.

The Health Foundation (formerly the PPP Foundation)

The income from this fund is applied to Director's work.

City Parochial Foundation

The income from this fund is applied to the Direct Services Manager's work.

John Ellerman Trust

This grant supports the work of the Health Education/Information Officer and has been applied specifically to this work.

Lambeth Social Services

This fund has been applied specifically to our Lambeth Outreach work.

Lloyds TSB Foundation

This grant part funds our National Volunteering Strategy work.

Henry Smith Charity

This grant part funds the post of our National Volunteers Co-ordinator.

Charity Aid Foundation

This grant part funded the training of our Executive Director.

- Roald Dahl Foundation funding is reserved for the Children's aspect of Brent Sickle Link work;
- The Wellcome Trust funding is applied to the doctors-patients engagement initiative;
- The Big Lottery Fund grants are applied exclusively to the Regional Advice Support Project and the SCAD Research Project.

122,947

THE SICKLE CELL SOCIETY

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

16. DONATIONS, LEGACIES & SIMILAR INCOME OF £500 AND ABOVE

Delbanco Meyer & Company Limited	500
Hospital Saturday Fund Charitable Trust	500
Hawkeye Record Store	500
Constance (J. Sigaud)	500
Trinity School Parents Social Committee	500
Hazel Levy – Snippers 2 Rebecca – Southwark PCT	500 505
Eric Burry – Nine Elms Domino Club	563
Melissa Noel	564
B. Sagoo	591
Sylversoft Limited – Patrick Davis	600
Hastings FACE	600
At It Production	600
Credit Solutions – Naomi Peskett	633
Pricewaterhouse Coopers – Kay Marrow	635
Clive Pickering	733
Barclays – B90196085GL	733
Stephens Family Fund & Sports Day HP – Reading	882 1,000
Phil Young (Chris Ofili)	1,000
Robert & Jean White – Mambo City	1,000
Sue Bolton – Praxis (Donation fr: Bernard Horsford)	1,000
The ORR Mackintosh Foundation – Sharegift	1,000
Optimist UK	1,000
Sylversoft Limited	1,000
Relief Chest Scheme	1,081
UBSI Match Giving	1,200
Lucrea LaPierre	1,214
Sis Entertainment – Masquerade Ball Kevin Grant – Nike 10k Run	1,220
Bamjimba Productions	1,247 1,347
TSG Service Limited	1,500
L'Oreal	1,976
Andrew Gordon	2,011
Kalpa Patel	4,161
Streatham Accommodation Bureau Ltd – Evol Graham	2,250
PJH Solicitors – On behalf of Gloria Hamilton	2,500
Devon Harrison – Bequeath (Late Peter Geoffrey Strick)	3,500
NALC Area 13 Events A/C – Sharon Hariott Kerr	4,100
Gerald Akins & Co. Limited	5,000
Eddie Diaso	5,000
Wyeth Pharmaceuticals	5,000
Barclays – Estate of Late Victoria Babi Martins	8,143
Endemol UK Productions – The Games	12,050
KICC	40,808
	100.047

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31ST MARCH 2005

18. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted £	Designated £	Restricted £	Total funds £
Tangible assets	20,845	-	1,331	22,176
Current assets	50,720	11,800	118,696	181,216
Current liabilities	(48,264)	-	-	(48,264)
Net assets at 31st March 2005	23,301	11,800	120,027	155,905

19. TRANSFER BETWEEN FUNDS

During the year the Trustees agreed a transfer of £5,100 from Unrestricted Funds to make good the deficits on the Restricted Funds.

20. LEASING COMMITMENTS

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

Commitments expiring	<u>2005</u> £	2004 £
Within 1 year	2,749	-
Within 2 to 5 years	1,107	2,749
After 5 years	-	1,107
	3,856	3,856
		