Introduction to The Sickle Cell Society

The Sickle Cell Society was first set up as a registered charity in 1979. It was formed by a group of patients, parents and health professionals who were all concerned about the lack of understanding and inadequacy of treatment with sickle cell disorders.

Mission

Our mission is to enable and assist individuals with a sickle cell disorder to realise their full economic and social potential. This is achieved by improving opportunities for sickle cell affected individuals and families by raising public awareness through education, advocacy together with the provision of direct welfare services, assisting in research and lobbying.

Vision

Our vision is to be the most successful sickle cell organisation nationally with a wide network of well-informed, committed and active supporters working at local, national and international levels.

Objectives

The main objectives of The Society are:

1. the relief of persons living with sickle cell disease;

2. 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 disease;

3. the provision of facilities for recreation or other leisure time occupation for such persons and for such immediate members of their families having need of such facilities by reason of their youth, age, infirmity, or disablement, poverty or social economic circumstances with the object of improving the conditions of life for such persons;

4. to advance public education in sickle cell disease by carrying out or assisting in carrying out research into the causes, effects and treatment of sickle cell disease and to disseminate useful results of such research.
Activities and Services

The activities and services we provide are:

1. The Ralma Faulkner Welfare Fund - provides welfare benefit to individuals with sickle cell disorder in the form of household items such as carpets, beds and washing machine.
2. Bryan Jones Educational Fund - supports individuals who miss out on schooling and require IT support or who are undertaking university or college course.
3. Annual Children's Holiday - 30 children aged between 7 and 17 are taken on a one week holiday free of charge from which both the child and carer benefit. We also provide several day trips throughout the year.
4. Health Education/Information program provides:
   a. Leaflets, exhibitions, books, videos and CD's
   b. Conferences seminars, workshops and partnership working
   c. Talks and training
   d. Internet web-site and e-mail services
5. Outreach program provides direct services such as advocacy, information and advice, support, respite care and access to welfare benefits.
6. Assisting research into treatment, by managing patient's involvement.
7. Assisting to steer statutory programmes of the government, such as NHS Screening Programmes
8. Developing strategic collaborations and partnerships both nationally and internationally

Sickle Cell Disorders

Sickle Cell Disease is the most common inherited blood disorder in the country. It is estimated there are between 12,500 and 15,000 people living with sickle cell disease and 380,000 people are carriers of the gene in England. The Screening Programme identifies 20,000 babies who carry the gene and 350 babies are born with sickle cell disease every year (National Screening Committee for Sickle Cell and Thalassaemia 2012).

In England, 1 in every 1,900 births is a child born with sickle cell disease. 1 in every 70 births of all babies will carry the relevant gene. 1 in 7 Black African, 1 in 8 Black Caribbean and 1 in every 450 White British new-borns carries a sickle cell gene (National Screening Committee for Sickle Cell and Thalassaemia 2012).

Sickle cell is a disorder of the haemoglobin in the red blood cells. There are over 300 different types of haemoglobin. Haemoglobin is the substance in red blood cells that is responsible for the colour of the cell and for carrying oxygen around the body. People with sickle cell disorder are born with the condition. It is not contagious and can only be inherited from both parents.

The main symptoms of sickle cell disorder are anaemia and severe pain. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then, stick together, causing blockages in the small blood vessels. These painful
episodes are referred to as sickle cell crisis. They can last for a few hours, a couple of days or up to a couple of weeks.

Sickle cell sufferers are often admitted to hospital when they have a crisis. They are given strong painkillers such as pethadine and morphine to control the pain. Over time sickle cell sufferers can experience damage to internal organs such as the liver, kidney, lungs, heart and spleen. Due to organ damage life expectancy of people with sickle cell disorders is mid-40s, although with modern treatments patients can survive into their 50s. Sadly death can also result from complications of the disorder.

Children with sickle cell disorder are more likely to have strokes than those without the disease. The risk of stroke is highest in the most commonly detected type of sickle cell disease which is sickle cell anaemia (HbSS). The risk of stroke in children with sickle cell disorder is greatest between the ages of 2 and 16. About 10% of all children with sickle cell disorder will have a stroke by the time they are 20 years old. Stroke recurrence is also a major concern for children and their families. Stroke recurs in over 60% of children with sickle cell disorder (Sickle Cell and Stroke, The Stroke Association 2009).

**Our Key Achievements and Partnership Work**

1. Understanding the Contribution of Sickle Cell and Thalassaemia Nurses Study was published in July 2012. The NHS Sickle Cell & Thalassaemia Screening Programme was funded by Roald Dahl's Marvellous Children's Charity to carry out the study in collaboration with a Working Group which The Sickle Cell Society was part of.

2. In June 2012 NICE Clinical Guidelines 143, Management of an acute painful sickle cell episode in hospital was produced. NICE clinical guidelines are recommendations for the treatment and care of people with specific diseases and conditions in the NHS in England and Wales. The Sickle Cell Society was a key stakeholder in the development of the clinical guidelines which involved active membership of the guideline development group. The members provided expert advice, guidance and vital patient based evidence to help develop the guidelines.

3. Department of Health Commissioning Framework for Haemoglobinopathies released in July 2011, which is a guide to effectively commissioning high quality Sickle Cell and Thalassaemia services. The Sickle Cell Society was a stakeholder and provided members to join the expert working group. The members provided expert advice, guidance and helped deliver a User Workshop held in London on 30th March 2011.

4. A Nurses Competencies Framework was produced by the NHS Sickle Cell & Thalassaemia Screening Programme to educate nurses caring for people affected by Sickle Cell Disease and Thalassaemia in April 2011. Professor Elizabeth Anionwu CBE, Patron and Founder of the Society chaired the working group.

5. In January 2011 The Sickle Cell Society was one of the first organisations to successfully complete Information Standard Accreditation. The scheme was developed by the Department of Health to help the public identify high quality evidence-based health and social care information.
6 From 2010 to 2011 The Society worked with the Department of Health’s Advisory Committee on the Safety of Blood, Tissue and Organs (SaBTO) to represent patients with sickle cell disease.

7 The Society worked on a CLAHRC project in partnership with Brent PCT, Brent Sickle Cell & Thalassaemia Centre and the Harness Cluster to deliver a research project from 2010 to 2011. The project aimed to work with service providers including GP’s, practice nurses and community matrons to educate them about sickle cell disease, encouraging them to involve patients and carers to develop primary care services to reduce emergency hospitalisation and repeat admission for patients.

8 The Society is working with The UK Forum on Haemoglobin Disorders to promote the Department of Health’s National Haemoglobinopathy Registry which is an important initiative to document service need and has become central to commissioning services. The Society has actively been involved to inform patients and encourage them to consent to the register.

9 Paediatrics Standard of Care for Children with Sickle Cell Disease 2nd Edition published in October 2010 in collaboration between clinicians, patients, the Department of Health, NHS Sickle Cell & Thalassaemia Screening Programme and UK Forum on Haemoglobin Disorder.

10 The Society in partnership with the Department of Health, NHS Sickle Cell and Thalassaemia Screening Programme developed the Transcranial Doppler (TCD) Scanning for Children with Sickle Cell Disease in 2009 for clinicians on delivering TCD scanning for children with sickle cell disease.

11 From 2009 to 2012 was commissioned by the Department of Health to deliver a National Support Care Advisor project which entailed working with local commissioners to implement the Adult Standards and replicate the Regional Care Advisor Project in their local areas. The Society is currently working to ensure the future sustainability of the project.

12 A national peer review programme has been developed by the UK Forum on Haemoglobin Disorders in 2009 which will inform clinicians, patient groups and commissioners about the functioning of the clinical networks. The Society has supported this important review programme by managing patient’s involvement and ensuring patient’s views and needs are met. Members of the Sickle Cell Society were part of the review panels which inspected the various hospitals.

13 Awarded a Runners-Up 2009 GlaxoSmithKline IMPACT Award. IMPACT Awards is designed to recognise and reward charities that are doing excellent work to improve people’s health. They are funded by GlaxoSmithKline and managed in partnership with The King’s Fund.

14 In July 2008 The Sickle Cell Society produced the Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK in collaboration between clinicians, patients, the Department of Health, NHS Sickle Cell & Thalassaemia Screening Programme and UK Forum on Haemoglobin Disorders. These standards have been used internationally by other sickle cell organisations based in EU, Middle East, USA and Africa.

15 All Party Parliamentary Group on Sickle Cell and Thalassaemia (APPG) was formed in 2008, chaired by the Shadow Minister for Public Health Diane Abbott MP.
Since its inception The Society has worked with the APPG to address important issues that affect patients to help change national policies.

16 National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD), A Sickle Crisis? Report was published in 2008. The key outcomes from the Regional Care Advisors Project (RCAP) were used to inform the content and recommendation for this important report.

17 Since 2007 The Society has supported Jeans for Genes to produce genetic educational resources for schools and the general public to raise awareness of sickle cell disease.

18 From 2006 to date The Society has worked in partnership with the De Montfort University on social policy and research. During that time we have worked closely with them on the production and dissemination of the Guide to School policy for Sickle Cell Disease which was adopted by the Department for Education.

19 The Sickle Cell Society started its first prescription lobbying in 2005 by submitting a petition for free prescription for patients living with sickle cell disease. In response to Professor Ian Gilmore’s (PRCP) enquiry the petition was revived and resubmitted in 2008.

20 The Sickle Cell Society developed a model of care over a three year period from 2004 to 2007 which is the Regional Care Advisors Project (RCAP). This model was based on addressing those determinants of health and social care which need to be addressed in order that the people affected by sickle cell disorders can have the best quality of life (Dahlgren and Whitehead 1993). The model has been endorsed by the Department of Health’s Chief Medical Officer, Professor Dame Sally Davies, as well as Lord Earl Howe, Parliamentary under Secretary of State for Quality (Lords).

21 As a result of lobbying over the years a national NHS Sickle Cell & Thalassaemia Screening Programme was developed in 2001 as an outcome of the NHS Plan 2000. The Sickle Cell Society has supported and advised the programme as a principal user group, helping with outreach, community education activities and media work since inception to date.

22 Since 2000 to present The Sickle Cell Society has been working with the National Health Service Blood and Transport to raise awareness and encourage people to donate blood within the BME community as well as working on issues regarding blood safety.

23 Since 1995 to date The Sickle Cell Society has supported and advised the multi-disciplinary professional group (paediatricians, haematologists, doctors, clinical nurse specialists, nurse counsellors, psychologists) the UK Forum on Haemoglobin Disorders as a principal user group.
Video Links

1. Iyamide Thomas, Regional Care Advisor for the Sickle Cell Society

   Iyamide talks about the social and physical issues of living with sickle cell disease and the work the Sickle Cell Society undertakes.

   http://www.youtube.com/user/haemscreening#p/u/4/D4NI7-_FhGI

2. Sickle cell - Personal experiences: Junior

   Junior gives his personal account of what it means to live with sickle cell, discussing both the physical and personal aspects of living with the disease.

   http://www.youtube.com/watch?v=HHpZcJRu5s8

3. Sickle Cell - Personal experiences: Oliver and Hannah

   Oliver and Hannah are both carriers of the sickle cell gene and have a teenage daughter with the disease. They describe how they felt when they discovered they were at risk of having children with sickle cell disease and their experience of raising a child with the disease.

   http://www.youtube.com/watch?v=V2q2_ygbTqM&feature=related

4. Sickle Cell - Personal experiences: Pamela

   Pamela Gyebi-Ababio, 18, has sickle cell anaemia. In this video, she and her parents talk about family life with the condition, and how Pamela won't let it stop her achieving her dreams.

   http://www.nhs.uk/Livewell/Blackhistorymonth/Pages/VideoPamelaGyebiAbabio.aspx

5. The Family Legacy

   The Family Legacy is an emotional three-part drama which explores the impact that the birth of a child with sickle cell disease has on four generations of the same family. As they struggle with the decisions and overcome their misconceptions and superstitions, they come to understand what the baby will mean for each of them. The story is drawn from the real-life experiences of people living with sickle cell disease and their carers.

   http://sct.screening.nhs.uk/familylegacy

   For further enquiries regarding The Family Legacy please contact Iyamide Thomas on 07841 558 611 or email iyamide.thomas@sicklecellsociety.org