

OSCAR'S STORY:



The History of Sickle Cell in Leicester

Simon M Dyson

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Sickle Cell: A Personal Experience

“I was first told about sickle cell anaemia when I was five years old. I went into hospital with pains in my back. I didn't know what had happened. I was feeling all this pain and I didn't know how to cope with it. And there was nobody to tell me what to do. As I grew older it became a lot worse. Just imagine, I would either be sleeping or at a party or doing anything, watching television, and all of a sudden this pain would start in my back or in my arms or in my legs. And this excruciating pain would get worse and worse. And by the time you get to hospital, you're in so much pain that sometimes you had to lie there and take it, or end up crying. And it wasn't until I met OSCAR that I learned how to deal with it. With having so much pain, you don't know what to do. There was nobody to tell me or my mother what to do, how to cope with it, what to do in winter, how to prevent having a crisis.

This went on for years and years, even at school. I remember at school that we sometimes had to go out on the playing field in the middle of winter, playing football. And even though I told the teachers that I shouldn't be playing this game, one because it's too exhausting for me and secondly, it's too cold, they wouldn't believe me. And the reason for that was because we didn't have any community support there. There wasn't any information about sickle cell anaemia.

The thing about sickle cell anemia is the unpredictability of it. It's so hard to put over to you. But I remember one time when I was about eighteen and I was at home and the pain started. First of all it started slowly, and then the next thing you know, you're on the floor crawling around in pain. You're on your hands and knees and you're in that position for a minute, but that's no good because the pain is too strong. So you stand up. And when you stand up you're twisting around and turning around in pain, and that's no good. And you have to wait for the doctor to come which could be a couple of hours or even longer. And then when he does come, he doesn't know what to do. He asks you, where's the pain, and you tell him. And he says, well I really don't know what to do, I'll send you to the hospital. Which means you have to phone the ambulance, which could take another half an hour. And then you go into casualty and you find yourself dealing with a doctor who really doesn't know what to do. I remember a doctor who had to go and look in a book to find out how to treat sickle cell anaemia. Imagine, with all that pain, you have to deal with that. And my mother never had any support at all. I mean she was just told that I'd got sickle cell anaemia and that's it. When we were younger, when I had pains in my belly, she would rub it with vaseline, and just keep rubbing until the pains went away. And I would just lie in bed for hour after hour in all that pain until I fell asleep. And the thing about the pain, it could last for about one hour, or it could last for a week or two weeks. And you never know when it will end. And all you can do is pray for when it ends, or when you can get into hospital or get an injection to take away the pain.

This is why I am here today to prove to you that we need community support; we need understanding; and we need other sickle cell sufferers not to be ashamed of the fact that they have sickle cell. They need to come out and for all of us to get together to share experiences about how to cope with it, how to deal with it, and to really support one another. Because, at the moment, I'm the only one who has ever talked about sickle cell in Leicester. And I wish that there were others out there who could do the same. Sometimes it's not even about the sickle cell sufferer, it's their parents or their friends who don't want them out there talking, because somehow it looks bad on them. And I'm saying to them, I want you out here with me for us to go forward. Because it's for our children, and our children's children, that we need community support.”

[Richard Fenton, 24th September 1988]

Acknowledgements

I would like to thank Leicester Organization for Sickle Cell Anaemia Research (OSCAR) for providing me with the opportunity to write their history. I am proud to say that it is also part of my own history and that of my family, since the evening I first met the members of Leicester OSCAR in 1986 when attending a meeting of a new initiative, the Leicester Community Health Forum, at the Leicester Rights Centre. I was able to support the initial activities of Leicester OSCAR while working as a health promotion officer for Leicestershire Health between 1985 and 1990, helping to organize the various seminars and conferences in 1988, 1989 and 1990. I was later able to speak at OSCAR conferences including those in 1995, 2002 and 2007. Later Leicester OSCAR were able to help me in my academic career in supporting my work looking at community knowledge of sickle cell; researching ante-natal screening and sickle cell, and surveying the experiences of young people with sickle cell in schools. I have had the honour of being invited to take part in many of their activities in the years since they were founded in March 1985, and know how much of their own time and energy OSCAR members have given in the absence of a funded community development worker. I hope that this book will serve to acknowledge OSCAR's role in the early history of sickle cell in Leicester, but that the book will also encourage the younger generation of people living with sickle cell and their families to join Leicester OSCAR, and to continue the good work that Leicester OSCAR has begun.

Simon Dyson, July 11th 2008

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What is Sickle Cell?


What are Sickle Cell Disorders?

Sickle cell disorders (SCD) are serious inherited blood conditions that can affect peoples of many different ethnic origins, but mainly affect people of African, Caribbean, Middle Eastern, South Asian and Mediterranean descent. Sickle-cell anaemia is the most common of these sickle cell disorders, which are associated with episodes of severe pain called sickle cell painful crises. People with sickle-cell anaemia have a type of haemoglobin (called haemoglobin S (HbS) or sickle haemoglobin) which differs from usual adult haemoglobin (haemoglobin A or HbA).

What is haemoglobin?

Haemoglobin is the substance in our red blood cells that gives blood its red appearance. One function of haemoglobin is to transport oxygen from the lungs to the rest of the body. The transfer of oxygen takes place in the narrow blood vessels called capillaries. These may be no more than the width of a red blood cell. In people with usual adult haemoglobin (haemoglobin A), the red blood cells remain round and flexible to enable them to squeeze through the capillaries.

How does sickle haemoglobin affect people?

In people with sickle haemoglobin (haemoglobin S), when the haemoglobin gives up its oxygen, the haemoglobin stacks up into long rigid chains inside the cells. These chains distort the cell wall into odd shapes - often like the shape of the old-fashioned farming implement called a sickle . Such sickle-shaped cells are not as flexible and may become stuck in the narrow blood vessels. When this happens, that part of the body becomes deprived of oxygen. The result is mild, moderate or excruciating pain in the part of the body affected, with the possibility of permanent damage to the tissue.

How is sickle cell anaemia treated?

The current treatments for sickle-cell anaemia are drugs to try to reduce the frequency with which sufferers experience the painful crises, painkillers to reduce the pain of the crises, and fluids to help keep the person well hydrated. There may also be blood transfusions for particular types of crises where the production of new blood cells (which takes place in the bone marrow) suddenly stops. Blood transfusions may also be given regularly to those children with sickle cell disorder who are found to be at greater risk of having a stroke.

How can the symptoms of sickle cell disorders (SCD) be prevented?

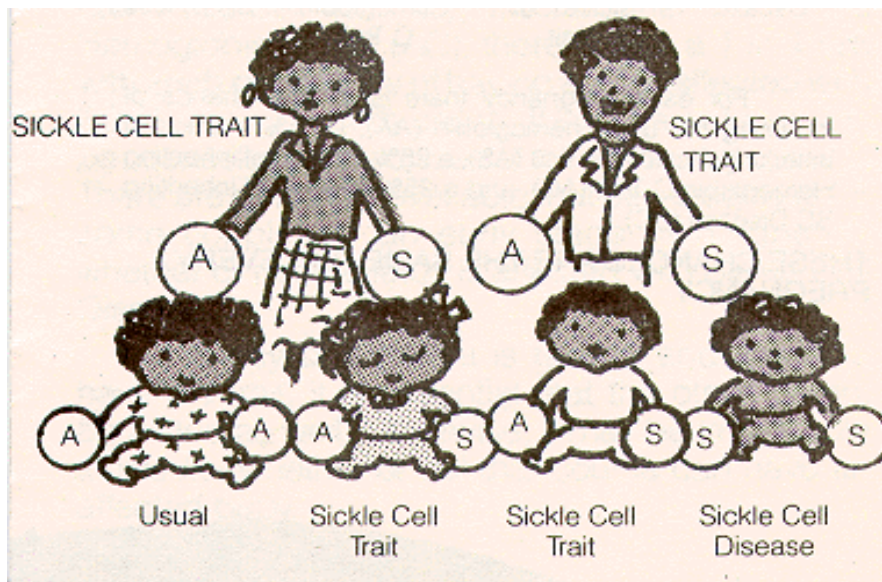
Penicillin is given daily to try to prevent infections which, especially for the first seven years of life, could be life threatening for children. A full and up-to-date set of vaccinations is also vital for people with SCD. Folic acid supplements are given to promote the production of red blood cells. Certain factors have been identified as more likely to precipitate a painful sickle cell crisis. These include infections, cold and/or damp conditions, pollution, dehydration, strenuous exertion, stress, sudden changes in temperature, alcohol, caffeine, and smoking. Advice to people living with a sickle cell disorder on preventing crises includes keeping warm, eating healthily, taking moderate exercise, taking plenty of fluids, avoiding smoking and alcohol, keeping up to date with medications and vaccinations, and trying to live a stress free life.

How does someone get sickle cell anaemia?

Sickle cell anaemia is inherited, that is passed on through the family genes. It is **not** an infectious disease. It **cannot** be caught like coughs or colds. People who are sickle cell carriers (sometimes referred to as having sickle cell trait) have genes associated with both adult haemoglobin (haemoglobin A) and with sickle haemoglobin (haemoglobin S). Sickle-cell carriers are usually perfectly healthy themselves, and may not know they have sickle cell trait unless they have a blood test.

If someone is a carrier they cannot then go on to have sickle cell anaemia itself. If both partners have sickle-cell trait (haemoglobin AS), then **in each pregnancy** there is a one in four chance that they will have a child with sickle-cell anaemia (haemoglobin SS); a one in four chance they will have a child with usual haemoglobin (haemoglobin AA); and a one in two chance that they will have a child with sickle-cell trait (haemoglobin AS).

The pattern of inheritance for sickle cell anaemia where both parents are sickle cell carriers



(Courtesy: New York State Department of Health)

There are about 250,000 sickle cell carriers in the UK with around 15,000 people living with a sickle cell disorder. Around one in every 1,230 children born in England has a sickle cell disorder (SCD).

How can educational arrangements affect people with sickle cell disorders (SCD)?

In view of the types of hard manual work ill-suited to those with SCD, it becomes doubly important for those with SCD to receive a good education and sound careers advice.

- *School absences:* If schools/colleges do not have strong supportive frameworks on sickle cell to reduce school absences, then studies have suggested that a pupil with SCD could miss up to six weeks of schooling a year, most often associated with experiencing painful crises.
- *Dehydration:* avoid placing the pupil with sickle cell in conditions likely to lead to dehydration.

Have a ready supply of fresh drinking water (not fizzy drinks or caffeinated drinks) available. Do not restrict drinking water in class nor toilet breaks as part of school rules.

- *Lowered resistance to infection:* avoiding overcrowded classrooms; ensuring hygienic school environment; enabling safe storage and dispensing of any antibiotic drugs prescribed for the young person with sickle cell.
- *Susceptible to changes in temperature:* avoiding activities that require outdoor work in cold or damp conditions; avoiding both over-heating and under-heating of classrooms, especially mobile classrooms; maintaining good ventilation of study areas. Allow coats to be worn in class, and permit the child to stay inside at break in cold or wet and windy weather.
- *Physical Exertion:* avoid hard, physical exercise involving strenuous exertion that could precipitate a sickle cell crisis. Encourage moderate exercise.

Schools and local education authorities can help by:

- *Policy:* Developing comprehensive policies covering children with SCD at schools and colleges.
- *Awareness:* Ensuring all teachers who teach a child with SCD are aware of the condition. Ensure they know what to do if the child has a painful crisis, how to recognize signs and symptoms of a stroke in young people with SCD, and that they learn to listen to the child if the child says they are feeling unwell.
- *Medicines:* Making arrangements for the safe storage and dispensing of any medications at school.
- *Rest Room:* Ensuring the availability of a safe area for a pupil with SCD to recover and take time out from activities. They may be able to return to study later in the day.
- *Challenging Discrimination:* Ensuring that sickle cell is discussed as part of the Personal, Social and Health Education curriculum, and making sure that teachers and other pupils are challenged on any discriminating views they may hold about SCD.
- *Curriculum:* Ensuring that sickle cell is covered as part of the curriculum of the school or college. It can be used as an example of genetic inheritance in biology, of probability in mathematics, of the historical spread of the sickle cell gene for geography and history. As a topic, it can also be the source of inspiration for arts, drama and music.
- *Educational Opportunity:* Making arrangements for tuition if a child is absent, whether for a few days or a few weeks. Teachers spending dedicated time with the child who has missed school is preferable rather than leaving the child to copy up notes that may mean little to them.

How can employers affect sickle cell?

One of the biggest problems is that employers may not distinguish between being a carrier for sickle cell (having sickle cell trait) and having a sickle cell disorder, the full chronic illness. It is important for employers to recognize that there are no jobs, including strenuous manual jobs, which cannot be safely undertaken by people with sickle cell trait.

In cases where the employee has sickle cell anaemia itself, there are many arrangements that an employer should consider in order to conform the requirements of the 1995 Disability Discrimination Act. The following effects of sickle cell disorders can be minimized by any responsible employer:

- *Physical Exertion:* avoid hard, physical work involving strenuous exertion (since this is the very basis of some manual jobs this has implications for the education and the careers advice a sufferer receives).
- *Stress:* avoid emotional stress or intense mental strain.
- *Dehydration:* avoid placing the person with sickle cell in conditions likely to lead to dehydration. Have a ready supply of fresh drinking water (not fizzy drinks or drinks with caffeine) available. Do not restrict/monitor toilet breaks as part of work conditions.

- *Lowered resistance to infection:* avoiding overcrowded work areas; ensuring hygienic work areas; ensuring that other employees take time off when ill.
- *Susceptible to changes in temperature:* avoiding roles that require outdoor work in cold or damp conditions; avoiding both over-heating and under-heating of offices; maintaining good ventilation of work areas.

In addition the good employer could enable more people with sickle cell disorders to undertake constructive work by:

- *Appropriate leave:* Recognizing that a person with SCD may need to attend hospital for regular monitoring and health checks.
- *Job Flexibility:* Consider use of flexi-time and job sharing to enable recruitment and retention of workers with sickle cell disorder.

How can housing affect sickle cell?

Those living with sickle cell anaemia can be helped by a local housing department that is attuned to the particular needs associated with sickle cell.

- *Physical Exertion:* avoiding unnecessary physical exertion means that accommodation should be on ground floor level and not in high rise flats. Those with Haemoglobin SC disease in particular are liable to suffer from problems with the hip joints. All those with SCD are advised against excessive exertion.
- *Dehydration:* avoid placing the tenant with sickle cell in conditions likely to lead to dehydration.
- *Lowered resistance to infection:* avoiding overcrowded housing conditions; avoid exposure to damp housing (associated with fungal spores and respiratory infections); avoid infestations of rodents, cockroaches and other pests associated with increased infections.
- *Susceptible to changes in temperature:* provide housing that is free from damp, is well heated and well ventilated.
- *Single bedroom:* Some young people with sickle cell anaemia have regular blood transfusions to avoid strokes, and in such cases they usually also require a drug, given for 10-12 hours a day, often overnight with the child sleeping with the needle in their body. Such children would need a single bedroom.

Local government housing authorities can help by:

- *Policy:* Developing comprehensive policies covering tenants with SCD.
- *Awareness:* Ensuring all housing officers are aware of the condition and what factors need to be addressed to meet the housing needs of people with SCD.
- *Overcrowding:* Avoid placing families with a member with SCD in stressful and/or overcrowded housing conditions.
- *Amenities:* Ensure that the family has access to an indoor toilet; to their own bathroom; and for the person with SCD their own bedroom. Ambulance personnel must have easy access to the home for any occasions when the person with SCD experiences a painful crisis requiring hospitalization. This suggests the need for a ground floor not a high rise flat and for easy access to a telephone.

The History of Leicester OSCAR 1985-2008

Introduction

The Organization for Sickle Cell Anaemia Research (UK) was founded in 1975 by Neville Clare, a person living with sickle cell disorder in London. In 1977 a self-help group was founded in Birmingham by another person with sickle cell disorder, Don Smith. Both branches were independent of each other not knowing of the other's existence until late 1977. In 1978 Sickle Cell Anaemia Birmingham 1 (SCAB-1) was formed. In 1981 the Birmingham group also took on the name OSCAR. Both groups served and supported the same cause and both subsequently expanded. The organization established itself with the aims of providing as much information as possible about sickle cell disorders, bringing people together who have a common interest in sickle cell anaemia such as people living with sickle cell, carers and professionals. In time other branches of OSCAR were established in Sandwell, Dudley, Bristol, Nottingham, Reading, Croydon, Brent, Lambeth and, of course, Leicester. The Leicester OSCAR branch was founded on 23rd March 1985 and has since campaigned at local and national level for greater awareness amongst doctors, social workers, teachers, employers and the community at large.

OSCAR nationally did not have an easy time in the early days. Right-wing groups were inciting racist hatred and OSCAR had to keep a lower profile than it might otherwise have done for fear of playing into the hands of such groups. For example, the National Front published an article accusing the black population of “spreading” sickle cell disease in Britain. We need to remember that as late as 1974 in Leicester East the National Front won 7.5% of the vote at the general election. This meant that the black community was reluctant to publicize a disorder that might be used to further discriminate against them. To be an OSCAR advocate in the early days was therefore also to show political bravery as well as community spirit.

The following account describes the struggles and achievements of the local branch of OSCAR between 1985 and 2008, documenting the activities undertaken by the group in each year since OSCAR’s formation until the present day. In order to give the reader some sense of the historical context of the work of the group, each year is divided into three sections organized under the following symbols:

 **World events, especially those affecting the black and minority ethnic communities in Britain.**

 **Events or circumstances in the wider world of sickle cell, both nationally and internationally.**

 **The particular activities and achievements of Leicester OSCAR for that year.**

Bear in mind as you read that this is a voluntary group who do not have any regular source of funding other than what they raise by raffles, dinner-dances, and donations from individuals and the like. All Leicester OSCAR’s activities to date have been undertaken by voluntary efforts, by people giving their time to the cause freely. As such it is perhaps not surprising that there are years when activities are extensive, frenetic even, and other quieter years. But remember as you read that Leicester OSCAR is a group comprised only of volunteers. Imagine what they could achieve with a funded worker!

1985



This was the year that the British government struck a blow against the emerging multi-ethnic society by withdrawing from the United Nations Education Social and Cultural Organization UNESCO; the year that frustrations with high rates of unemployment and discrimination boiled over in Handsworth and Toxteth; the year when, with 3,000 black members in the National Union of Mineworkers, the year-long miners' strike ended. 1985 also saw Bernie Grant appointed as Britain's first black council leader in Haringey, North London.



The Runnymede Trust published a report entitled *Sickle Cell Anaemia: Who Cares?* This was written by Usha Prashar (now Baroness Usha Prashar and a former chancellor of De Montfort University in Leicester) Milica Brozovic and Elizabeth Anionwu (later awarded the CBE and now Emeritus Professor of Nursing at Thames Valley University). This was the first book or report published on sickle cell that drew attention to the lack of comprehensive services for this condition, and that the services that did exist depended on short-term Inner Area programme monies, rather than mainstream health or social services funding. The report records that in 1985 the health services in Leicester relied on information from voluntary groups such as OSCAR in providing people with written information on sickle cell. The report further records that Leicester had no in-service training on sickle cell; no information cards for sickle cell carriers; no specialist sickle cell centre; no specialist sickle cell clinics, no specialist sickle cell counsellors and kept no statistics on sickle cell.

Meanwhile also in this year, Professor Graham Serjeant of the Medical Research Council in Jamaica published the first edition of his medical book on *Sickle Cell Disease*. Professor Serjeant has helped a number of the Midlands OSCAR groups over the years by giving talks based on his lifetime of expertise, caring for patients with sickle cell anaemia in Jamaica.



Leicester OSCAR was founded by concerned members of the community on the 23rd March 1985. A number of the founder members were professionally qualified nurses who could appreciate the problems for sufferers when services were inadequately developed. OSCAR's first base was at the Leicester United Caribbean Association centre at 72, Rutland Street, in what is now the cultural quarter of the city. OSCAR's first committee included Carol King (Chair); Erdine Corbin (Vice Chair); Carole McLeod (Secretary); Winston Nurse (Treasurer); Ralph Prescod; Frank Corbin; Haskell Lane, Bernard Francis and Erskine Cave (Counsellor), and these members were later joined by Jennifer Jeffers, and Richard Fenton.

One of the first initiatives was an awareness-raising drive about sickle cell focussed on Leicester libraries. In those days before personal computers and word-processing, information sheets had to be typed by hand and photocopied. Any mistakes in drawing up the sheets had to be corrected by hand. OSCAR also handed out questionnaires designed by the Commission for Racial Equality to see how much the community knew about sickle cell and its effects, and members were met with varying degrees of embarrassment. This convinced OSCAR of the need for a group and of how much there was to be done in the years that followed.

1986



US national holiday Martin Luther King Day was observed for the first time. The black civil rights leader was only the third person to have a US holiday dedicated to him after Christopher Columbus and George Washington. Dr King was a peaceful campaigner for civil rights in the US and won the Nobel Peace Prize for his work. A date near his birthday on the 15th of January is chosen each year to celebrate his life.



An important breakthrough occurred in 1986 when, in the USA, a National Health Institute-sponsored study found that young children with sickle cell anaemia who took penicillin twice a day had much lower rates of infection than a similar group of children who received a placebo.

This year saw the death of one 'Buddy' Friend, a young African-American navy recruit. He was just about to graduate from basic training as the best recruit in class when he collapsed on the final training run. After a series of errors (being forced twice to continue before finally collapsing, an ambulance being sent away, a misdiagnosis, a hospital-acquired infection) he died in hospital. His mother Peggy Friend wrote a book to draw attention to the facts of the case. It seems that although sickle cell trait is usually harmless, and does not prevent participation in, and excelling in, physical sports, a combination of dehydration, delay in recognising heat illness caused by extreme physical exertion (as could be the case in military recruits under extreme conditions of training) and having sickle cell trait was attributed to the higher risk of exercise-related death in those who were carriers of sickle cell.

In London, one of the earliest books on sickle cell in the UK, *Living With Sickle Cell Disease* by Janet Black and Sophie Laws was published by the East London branch of the Sickle Cell Society. It covered issues concerning education, social services, employment and housing, as well as medical and health issues arising from sickle cell disorders.



In 1986 Leicester OSCAR were asked by Gill Gardner of the Leicester Rights Centre to attend a new initiative called the Leicester Community Health Forum. This was a group of community workers, voluntary groups, health promotion officers, and environmental health officers who were concerned about the effect of social conditions, such as poverty and racism, on health. At the third meeting OSCAR were invited to present the issue of sickle cell for consideration. It was at this point that I myself first met Leicester OSCAR. In May that year, a seminar was held at Moat Community College to publicize sickle cell. Speakers at the conference included Dr. Ivan Cox, a GP from Handsworth in Birmingham, one of the earliest family doctors to show an interest in the issue of sickle cell. Paul Walsh, a representative from the insurance industry, also spoke about the experience of people with sickle cell, and the difficulty and discrimination they may face in trying to obtain travel insurance, life insurance and mortgages. Paul later helped Garth Crooks with his sickle cell charity, Sickle Cell Anaemia Relief (SCAR).

In September 1986, Leicester OSCAR joined other branches of OSCAR nationally in a lobby of the House of Commons, campaigning for better services and facilities for sufferers and their families.

1987



This was the year that four Black and Asian MPs were elected to the House of Commons, including Keith Vaz (Leicester East); Paul Boateng (Brent); the late Bernie Grant (Tottenham) and Diane Abbott (Hackney). The black sociologist Paul Gilroy released his book *There Ain't No Black in the Union Jack*. The cover of the book contrasted the racist chant of the National Front, from whom the book's title is drawn, with a picture of one of the thousands of Black British servicemen who fought for Britain during the Second World War at a Remembrance Day ceremony.



The National Institute for Health in the USA recommended that all babies be tested for sickle cell at birth. Preventative treatment can commence as soon as it is known an infant has a sickle cell disorder (SCD). For the 1 in 2,340 children born in England now identified as having SCD by neonatal screening, interventions include: (1) penicillin is given daily to try to ward off infections which, especially for the first seven years of life, could be life threatening, (2) a full and up-to-date set of vaccinations, especially against flu, (3) folic acid supplements to promote the production of red blood cells, (4) health education for the carers so they can identify early signs of a sickle cell crisis, (5) health education for carers to help avoid factors more likely to precipitate a painful sickle cell crisis (infections, cold or damp conditions, dehydration, strenuous exertion, stress, sudden changes in temperature, alcohol, and smoking, including passive smoking, and (6) education for carers on how to feel the spleen to identify the type of crisis where red blood cells are trapped in the spleen causing it to enlarge.

Nationally, OSCAR produced a series of advice leaflets on Housing, Employment and Social Services. In each case there were two related leaflets, one for the service provider and one for the person living with sickle cell disorder.



Leicester OSCAR helped to run two joint seminars (with Leicestershire Health Authority's Health Promotion Department) for health workers, teachers, social workers and youth workers. The seminars were held at the old Health Promotion department at Yeoman House in Yeoman Street in the city centre. Neville Clare travelled up from London to speak about his experiences as someone who has Haemoglobin SC disease (one of the forms of sickle cell disease, and one that seems especially to lead to problems with hip pain and sometimes visual impairment). Richard Fenton spoke about his experiences as a young man living with sickle cell disorder, and Carol King spoke about the work of the Leicester OSCAR group. Carol remembers the lunch break because on one occasion the "fried" chicken they were served turned out to be chicken that was coated in breadcrumbs, but completely uncooked. And they called it a Health Promotion Department!

1988



This year marked the 150th Anniversary of the Abolition of Slavery in the Caribbean. In 1988 the Immigration Act removed the last remaining rights under British law for Commonwealth men to be joined by their wives in this country. It also restricted the right of appeal against deportation. Meanwhile at the age of eighteen Naomi Campbell became the first black woman to appear on the cover of French Vogue. It helped propel her to supermodel status. Hurricane Gilbert devastated the Caribbean island of Jamaica. That year, too, there were serious floods in Bangladesh, and a joint relief fund-raiser was held for both causes at the De Montfort Hall in Leicester.



The lengthy period in hospital associated with his sickle cell anaemia that he had experienced the previous year had led visual artist Donald Rodney to incorporate his own x-rays into his artistic work His x-ray piece *Flame of the Soul*, completed in 1988, was also the title of a CEDDO /Channel Four film on sickle cell anaemia, also called *Flame of the Soul*. The following year Rodney held a solo exhibition entitled *Crisis* (very apt for someone who experienced sickle cell crises) which brought together a variety of his x-ray based works. In May of this year, Marie Oshodi's play about sickle cell anaemia *Blood, Sweat and Fears* was put on at Battersea Arts Centre in London.



Leicester OSCAR held the *First Community Conference on Sickle-Cell Anaemia and Thalassaemia*, at St. Matthews Neighbourhood Centre, Leicester, in June 1988. Dr. Rosemary Shannon, Consultant Paediatrician, of the Leicester Royal Infirmary and Dr Keith Wood, Consultant Haematologist spoke to explain the basic medical facts of beta-thalassaemia and sickle cell on that day. The day was attended by a number of key community workers, including Christina Mendez and Paul Matthews who were asked to recruit and encourage attendance at the larger public conference planned for later that year.

There followed the *Second Community Conference on Sickle-Cell Anaemia and Thalassaemia*, held at Moat Community College, Maidstone Road, Leicester, on the 24th September 1988. Here the two doctors were joined by the late Gordhan Parmar a former Lord Mayor of Leicester who opened the conference, and Councillor Joe Allen, who ruffled a few feathers with a highly political speech about the lack of services for sickle cell as an example of racism dating back to the days of slavery. We were also joined by representatives of national voluntary groups: Neville Clare came up from National OSCAR and was joined by Mahesh Kotecha, the Asian president of the UK Thalassaemia Society. The two presidents presented one another with their society's tie as a mark of mutual collaboration. The conference was also notable for talks by people living with sickle cell or thalassaemia: Richard Fenton again shared his personal experiences of sickle cell, as did mother and son Nila and Viresh Kataria who spoke about living with beta-thalassaemia major, another serious inherited blood condition. Carol King spoke about the need for greater community support, a talk she would be giving for many years to come, as she struggled to get people to take the issue of sickle cell seriously. Elvy Morton provided the excellent catering for the day, and Erskine Cave gave the vote of thanks to round off the conference.

On the same evening a number of linked cultural and fund-raising events were held. These included Asian dancing from Pragatti Kendra (a group funded through the Leicester Workers Education Association), a comedy play *A Baira Maira Bap Re Bap* in Gujarati, and the Sunshine Caribbean Disco. Generous benefactors who supported this conference included the Leicester Jamaica Service Group, the Leicester Barbados Service Group, the Burlington Club, and the Leicester United Caribbean Association, especially Nassah Bellamy and Mr Carol Holmes.

1989



Channel 4 broadcast *Desmond's*. This comedy about a black British family appealed to a mainstream audience and was also popular in the Caribbean and US where it was broadcast on Black Entertainment Television. Political activist, playwright, novelist, historian and renowned cricket writer C.L.R. James (1901-1989) died this year. His Channel 4 lectures in 1983 on Pan-Africanism, Shakespeare, Solidarnosc, American politics, the West Indies and cricket, are an indication of the wide range of subjects about which he was knowledgeable and held insightful views.



Early clinical trials of a drug called hydroxyurea, usually used to treat leukaemia, suggest that it may have a role in helping at least some of those with sickle cell anaemia. Scientists at Johns Hopkins University School of Medicine find that in some patients with sickle cell the drug increases their production of foetal haemoglobin (a form of haemoglobin found usually only in the foetus and during the first few months of life). The effects of sickle cell are sometimes less severe if the person produces foetal hemoglobin at levels representing more than 20 percent of their total hemoglobin.

In the House of Commons, the Secretary of State for Education and Science is asked if he will make a statement on the statutory provision made for children of normal ability whose academic progress is impeded by irregular school attendance caused by the crises of chronic medical conditions such as a sickle cell anaemia. The reply was “It is the responsibility of local education authorities to make suitable education available for all children in their area. Such provision can be made either in schools or ‘otherwise than in schools’- for example, home tuition or hospital education. It is for each authority to determine what provision is appropriate for each child, after having taken account of individual circumstances, such as any particular medical condition”.



After years of campaigning from the group, the Health Authority begins screening for sickle cell at ante-natal clinics. However, at a meeting of the Leicester Community Health Forum, representatives of Leicester OSCAR were told by Alan Buchan, the Director of Public Health, that there were insufficient numbers of people with sickle cell disorders in Leicester to justify the expense of a sickle cell centre. Since the number claimed by the health authority as living with sickle cell disorder in Leicestershire (25) fell well short of the total number known to the group, this represents a good example of how, historically, services avoided their responsibilities for providing appropriate services relevant to black and minority ethnic groups.

1990



Nelson Mandela was released from prison in South Africa following the relaxation of apartheid laws. He had served 27 years after being imprisoned in 1964. This marked the beginning of the end of the formal organization of the much hated apartheid system in South Africa.



Sean Oliver was a talented young musician from Bristol, and a member (with the young Neneh Cherry) of the band Rip, Rig and Panic. Sean was co-writer of the song *Wishing Well*, a song made famous by Terence Trent Darby. He died in March this year, aged 28. Sean had sickle cell anaemia.



Leicester OSCAR, together with Leicester Thalassaemia Group, put up over £1,000 to fund a conference at the Leicester Royal Infirmary for GPs and health workers and to draw Leicestershire Health Authority's attention to lack of counsellors for sickle cell anaemia. A total of 155 people attended the conference, including 41 Leicestershire GPs who could count attendance towards their continuing professional education, as the conference secured post-graduate GP training accreditation. At the conference, Leicester OSCAR member Joyce Benjamin spoke about her experiences of not being believed about the pain she was in when she was admitted through the Accident and Emergency Department, and about the long delays in obtaining pain relief for her crisis. Since that time the local hospital has introduced a policy to enable sufferers to refer themselves directly onto the ward that is responsible for their treatment.

The list of professionals who spoke now reads like a *Who's Who* of famous names in the field of sickle cell. Dr. Sally Davies (who was later to become Head of NHS Research and Development) spoke on the clinical features of sickle cell disease. Other speakers included Dr Philip Darbyshire of Birmingham Children's Hospital, currently chair of the UK Forum on Haemoglobin Disorders, and Dr Mary Petrou, an expert in prenatal diagnosis from University College, London. Elizabeth Anionwu (later Professor Elizabeth Anionwu CBE) spoke about the need for Leicester to have a specialist sickle cell counselling centre. She explained the benefits of having such a centre to co-ordinate services and to provide a more holistic approach to families caring for someone with sickle cell. She pointed out that by 1990 over 20 other districts with a comparable sickle cell population had implemented such a service, including ten districts in London, as well as Liverpool, Manchester, Birmingham, Glamorgan, Nottingham, Coventry, Bristol, West Berkshire, Leeds, Croydon and Wolverhampton. The then chair of the Leicestershire Health Authority, Neil Townsend, who was attending the conference, was sufficiently stirred by this criticism to jump to his feet and promise to look into the lack of provision in Leicester.

Later that year the Leicester OSCAR group, together with their new allies, the Leicester Thalassaemia Group, funded a professional lunch-time seminar at the Leicester Royal Infirmary. At the seminar, Dr. Claire Chapman, now a consultant haematologist, presented the findings of the first year of ante-natal screening of groups thought to be at risk of carrying genes associated with sickle cell and thalassaemia. The seminar was attended by several leading local doctors and nurses, including Dr. Jim Jones of the Public Health Department of Leicestershire District Health Authority. This represented an important breakthrough in pushing the health authority to improve screening and counselling services for sickle cell, and eventually led to the creation of specialist sickle cell and thalassaemia counsellor posts in the area. Again, OSCAR played a considerable role in prompting statutory services to respond to the need for sickle cell services. Carol King and Erskine Cave also joined a national lobby of the House of Commons with Dr. Winterton, a US physician, to press for better services for sickle cell.

1991



Bill Morris was elected the first black leader of a British trade union. Morris took up the post of General Secretary of the Transport & General Workers' Union. Nigerian-born Ben Okri was awarded the Booker Prize for Fiction for his novel *The Famished Road* (1991). Patricia Scotland made legal history becoming the first black female QC (Queens Counsel) at the age of 35. She was born in Dominica in 1956, and arrived in Britain at the age of 2 along with 10 other siblings. After graduating with LLB Hons (London), Patricia Scotland was called to the Bar, Middle Temple, in 1977. She was later to be made a peer in 1997, and was appointed as a judge in 1999.



The legendary jazz trumpet musician Miles Davis (*Round Midnight*) died this year. He had struggled all his life with a sickle cell disorder. In *Miles: The Autobiography* published in 1990, he writes of a time in 1961: “And by now I was in a lot of pain all the time from what I found out was sickle-cell anaemia, which was causing arthritis in my joints, especially in my left hip joint. That was irritating me, and working out in the gym didn’t seem to help (Davis, 1990: 252) and “In 1961 I won another *Down Beat* poll for Best Trumpet and also for having the Best Combo. [...] So everything was looking good, except for my having sickle-cell anaemia. It couldn't kill me, but it was serious enough to be a downer. Still, everything else was looking up” (Davis, 1990: 255).

Dr Felix Konotey-Ahulu, a physician of Ghanaian descent, published his masterpiece *The Sickle Cell Disease Patient* (published by Macmillan Education Ltd, London 1991, with a foreword by Professor Roland B Scott, MD of Howard University). The book is an epic account of sickle cell from all angles, covering 36 chapters with 4,500 references, and over 643 pages. Felix Konotey-Ahulu came from a family with the sickle cell gene, and his ancestors had witnessed siblings in sickle cell crisis before the western medical scientists had identified sickle cell as a molecular disease. In the book he traces his own family lineage with regard to sickle cell; gives extensive accounts from his medical practice at Korle Bu Teaching Hospital in Ghana; and provides the most comprehensive African perspective on sickle cell to date (especially the role of polygamy in maintaining a high rate of the sickle cell gene in some African populations). He has been honoured with awards from the Martin Luther King Foundation, the Ghanaian Academy of Arts and Science; the Guinness Award for Scientific Achievement in the Commonwealth; and the Third World Academy of Sciences.



A regular Christmas party for children with sickle cell and their families was held this year, as in many other years, at the Leicester United Caribbean Association at Rutland Street in the city centre. Where possible, Leicester OSCAR also provided a gift voucher at this time of year to families they were in contact with. Amongst the help given by OSCAR this year was to help with the telephone bills of a family with two young children with a sickle cell disorder. The group also applied, unsuccessfully, to the Inner Area Programme at Leicester City Council for a grant to establish a drop-in centre for people with sickle cell and thalassaemia in the Highfields area of Leicester. Sadly this year Erskine Cave, one of the founder members of Leicester OSCAR, experienced a severe stroke. Such was the level of enthusiasm and hard work that Erskine had brought to the sickle cell cause that this had a great impact on the organization’s capacity to undertake its community work.



Spike Lee's film *Malcolm X* premiered in New York. Denzel Washington earned an Oscar nomination for his portrayal of the black civil rights leader assassinated in 1965. At the UK General Election, John Taylor was the black Conservative candidate for the safe Tory seat of Cheltenham. In a result widely regarded as evidencing the persistence of racism in parts of the British electorate, he failed to hold the seat.



So That his Death Will Not Have Not Been in Vain. Sickle Cell Trait. A Serious Issue to be Considered by the Military by Peggy D Friend is published. Peggy's son Buddy had died a few years earlier. The book is critical of the lack of research into the sickle cell trait, suggesting that the fear of discrimination against those with the trait previously experienced by those trying to enter the military, or obtain insurance, had led researchers in the USA to miss the potential significance of sickle cell trait.



Leicester OSCAR was saddened by the untimely death of one of its founder members and most active supporters, Richard Fenton. At the time of his death, Richard was not in Leicester, but in the South of England, and, for the group, this highlighted the importance of specialist treatment being available to an equal standard across the whole country.

Richard was only 33 years old when he died. Richard was a founder member of the Leicester Organization for Sickle-Cell Anaemia Research in 1985, and contributed enormously to the educational and fund-raising activities of the group. Richard was always a willing speaker at conferences for the public and for professional health workers, and also spoke frequently about the problems facing people with sickle-cell anaemia at seminars for health workers, teachers and youth workers. He was the first person with sickle-cell anaemia in Leicester to come forward so publicly to tell people about sickle-cell, for he felt passionately that this was the way forward in reducing ignorance about the disorder and reducing the stigma sometimes felt by sufferers. The appointment of the first sickle-cell counsellor for Leicester 1993 reminded OSCAR of how this important source of support was never available to Richard himself. Had he lived Richard would have continued to be an enthusiastic member of OSCAR, for it represents something of the hope that he had that sickle-cell would become more widely known and talked about. For, to use his own words, education about sickle-cell anaemia is not just for the sake of the current generation but "it's for our children, and our children's children that we need better community support". At his funeral service at Christ the King Church in Beaumont Leys, Erskine Cave read out what Richard had said when he addressed the conference at Moat Community College a few years before, and OSCAR members joined in a last hymn at his graveside.

God be with you till we meet again; by His counsels guide, uphold you,
With His sheep securely fold you; God be with you till we meet again.

God be with you till we meet again; neath His wings protecting hide you;
Daily bread still provide you; God be with you till we meet again.

God be with you till we meet again; when life's perils thick confound you;
Put His arms unfailing round you; God be with you till we meet again.

God be with you till we meet again; keep love's banner floating o'er you,
Strike death's threatening wave before you; God be with you till we meet again.
Till we meet, till we meet, till we meet at Jesus' feet;
Till we meet, till we meet, God be with you till we meet again.

1993



This was the year of the murder of the London teenager Stephen Lawrence. A-level student Stephen Lawrence was murdered by a group of white men while waiting for a bus in Eltham, South-East London. The failure to capture his killers provoked his parents to begin a campaign to shame the authorities into finding the culprits. To date no-one has been convicted, but through his death the racism of Britain's organisations began to be re-evaluated. In the world of sport, Paul Ince became the first black captain of the England football team. In the USA, videotape of motorist Rodney King being beaten by white officers sparked riots in Los Angeles.



The Standing Medical Advisory Committee on Sickle Cell, Thalassaemia and Other Haemoglobinopathies Report (commonly referred to as the SMAC Report), a working group of the Department of Health was published. It made a wide range of recommendations for the medical treatment of sufferers; for screening and counselling of carriers, and for the development of more co-ordinated services for sickle cell across the country. Unfortunately the recommendations were not made compulsory on health authorities. Neither did the government make any money available to support these developments. As a result most of these recommendations remained unimplemented. With respect to voluntary groups such as Leicester OSCAR, the report stated:

“There are numerous national and local self-help groups which represent the interests of patients with haemoglobinopathies and their families. Associations such as the Sickle Cell Society, the Organization for Sickle Cell Research (OSCAR) and the UK Thalassaemia Society have an important part to play in increasing community awareness and promoting carrier screening. They also provide invaluable help to counsellors in the form of posters, and information leaflets and booklets that can be given to members of communities at risk before screening, and where a carrier has been identified. They often provide a contact point for enquiries, and allow carriers and families of patients to meet each other”

[Department of Health, 1993: 14]



Nimmi Steward, the first counsellor for thalassaemia and sickle cell in Leicester, was finally appointed by the health authority. Leicester OSCAR was pleased to be invited to be on the interview panel that appointed Nimmi to her post. The sickle cell and thalassaemia counselling service had its first location in the old St Peter's Health Centre on Sparkenhoe Street in Highfields. It later moved to the Charnwood Health Centre, off Uppingham Road. Since that time a number of other counsellors have held posts as sickle cell and thalassaemia counsellors, including Monique Pinks, Vanita Jivanji (current head of service); Tina Hill, Melita Dixon, Lucille Fifield, Damaris Mashayo and Merle Oni. As a school nurse, Merle had been supporting the group way back in the late 1980s. Indeed, many of these counsellors have supported OSCAR in giving talks on sickle cell at conferences and seminars, and have attended OSCAR's fund-raising events to offer us their support.

1994



Nelson Mandela was elected as South Africa's first black president, with the African National Congress winning the popular vote.

Lord David Pitt of Hampstead was the longest serving Black Parliamentarian, having been granted a life peerage in 1975. Born in Grenada, he came to Britain in 1933 to study medicine at Edinburgh University. His achievements in his two respective fields of medicine and politics were immense. In 1943 he was practicing medicine in Trinidad and Tobago. In that same year, he was founder member and leader of the West Indian National Party. In 1947 he returned to live in Britain, where he served as a Member of the London County Council; as Chairperson of the Greater London Council and, from 1985-88, as President of the British Medical Association. He was Deputy Chairman of the Community Relations Commission from 1968-1977, and Chairman in 1977. Pitt was a member of black peoples' and anti-discriminations organisations such as the League of Coloured Peoples and the Campaign Against Racial Discrimination which he chaired in 1965. As a prominent member of the House of Lords, inner city issues were among his major concerns. He was Chairperson of the Shelter National Campaign for the Homeless; Chair of the Race Equality Unit of the Institute of Social Work; President of the African-Caribbean Medical Society and Co-Chairperson of the Urban Trust, which provided pump-priming finance for projects in inner city areas. Following his death in London on December 18, 1994, he was buried with full honours in Grenada.



This year saw the death of Linus Pauling, the only person to win two (unshared) Nobel prizes, one for Chemistry, in 1954, and the Nobel Peace Prize in 1962. Linus Pauling, together with Harry Itano, had been credited with being the first to identify that sickle cell anaemia was a molecular disease, the first such known example, in 1949. More controversially, in one of his later letters he wrote:

“I have suggested that the time might come in the future when information about heterozygosity in such serious genes as the sickle cell anaemia gene would be tattooed on the forehead of the carriers, so that young men and women would at once be warned not to fall in love with each other.”

Linus Pauling, Letter to S. Leonard Wadler, August 15, 1966.

It seems that even the greatest scientists could, on occasions, make some spectacularly inappropriate and discriminatory remarks about sickle cell.



Leicester OSCAR was involved in conducting interviews for research leading to the publication of a report into the level of community awareness of sickle cell in Leicester. Carol King, Erskine Cave, Winston Nurse, Theo Badu and Monique Pinks were amongst those who collected data for the project. The report was given to the Public Health Department of the Leicestershire Health Authority, and confirmed the need for specialist nurse counsellors to undertake the work of counselling carriers of sickle cell. Leicester OSCAR also collaborated with brother and sister Kenric and Shirley Burgess to raise awareness about sickle cell through Radio Carnival FM.

1995



In the USA, the Million Man March was organized by Louis Farrakhan – an historic gathering of hundreds of thousands of black men in Washington D.C. Also in the USA, former American football legend OJ Simpson was found not guilty of murder. 1995 also marked the 100th anniversary of the death of Frederick Douglass. Douglass was a former slave, and later an eloquent public speaker and an accomplished author campaigning for the abolition of slavery in the USA.



This was the year in which two African-Caribbean males, Alton Manning and Dennis Stephens died in suspicious circumstances whilst in custody, and in both cases it was later wrongly suggested by the authorities that the fact they had sickle cell trait may have had implications for their untimely deaths. It was also the year Tionne ‘T-Boz’ Watkin of the band TLC (‘No Scrubs’, ‘Unpretty’, ‘Waterfalls’) was voted as one of the 50 most beautiful people in the world by People Magazine. Tionne has a form of sickle cell called haemoglobin SC disorder and is now a spokesperson for the Sickle Cell Disease Association of America.

The UK Forum on Haemoglobin Disorders, a professional education forum for health workers (and, at least initially, for community members as well), met for the first time at the Imani Ujima Centre in Highfields. The *Leicester Mercury* newspaper covered the inaugural meeting with a photograph showing Nimmi Steward (the Leicester sickle cell and thalassaemia counsellor) hosting some of the leading figures in sickle cell/thalassaemia research including Dr Sally Davies; Dr Adrian Stephens; Dr Bernadette Modell, and Dr John Old.



18th February, 1995 saw OSCAR organize a conference on sickle cell awareness entitled *Sickle Cell '95*. - a national awareness seminar held at the Imani Ujima Centre. Our friends from Nottingham OSCAR came and videoed part of the proceedings of the conference. Speakers included: Dr Claire Chapman of Leicester Royal Infirmary; Dr. Norman Parker of Whittington Hospital, London. Leicester OSCAR contributed a donation of £1,000 towards the costs of research into the management of pain and nutrition of people with sickle cell anaemia led by Dr. Norman Parker of the Whittington Hospital in East London. The monies given and presented to Dr. Parker contributed towards research published as follows:

D'Sa S, Parker N, Coppack SW, Ling KLE (1998) Sequential assessment of oxidant stress and clinical severity during a sickle cell crisis *British Journal of Haematology*, 101 (suppl 1), 51.

Dr Parker himself recalls:

“The society were kind enough to donate, I think, £1,000. This funded a small study which produced an abstract presented at the British Society for Haematology. With more funding the data was pointing to a Lancet quality publication. Our patients have also been heavily influenced by the interest in nutrition and are doing much better than before”

In this way the work of Leicester OSCAR has helped people with sickle cell in other parts of the UK, as well as in Leicester itself.

On August 5th Carol King was quoted in the *Leicester Mercury*, saying that it is “important that potential carriers know about risks and go for blood tests before planning to have children”

1996



Britain's record on race relations was harshly criticised by the United Nations. They condemned the number of non-whites who suffered police brutality, high black unemployment, under-representation of ethnic minorities in politics, the army, the police, and the large number of black children expelled from schools. The government later signed up to a common EU plan to combat racism after negotiating an opt-out that freed it from an obligation to criminalise certain forms of racist behaviour. John Taylor, who had previously failed to win the safe Conservative seat of Cheltenham, became the first black Tory life peer. He took up his seat in the House of Lords as Lord Taylor of Warwick.



Hertz Nazaire, a talented US painter of Haitian extraction, used his experiences of living with the pain of sickle cell anaemia as an inspiration for his striking artwork. He recalled: “I got home one day in 1996 after a long stay in the hospital after a very painful sickle cell crisis. I was home but still feeling a lot of pain, I knew I may need to return to the hospital again and I was dreading it. After taking some medication to help with pain, I still could not rest, I stayed up all night drawing with oil pastels on two black illustration boards that I had in my room. I finished the paintings, *Hope* and *Ten Redefined* by the morning. I placed all of my frustrations and pain into creating two pieces of art that I felt best represented what living with the chronic pain of sickle cell feels like to me. I painted the third and last painting *Need not Suffer Alone* a year later while living with a friend”.

Hertz remembered: “My wish has always been to get the images into the pain community to aid with Sickle Cell Pain awareness and education. The works have been featured on PBS and CBS News, and published in many books and health magazines worldwide. Every Sickle Cell Conference I have attended I have found one or two medical professionals using my images for a presentation on Pain or some new drug for Sickle Cell. So as a person living with this pain the images work very well for raising awareness of this disease, but as a struggling artist life has been very challenging”. Hertz’s work can be seen (and, equally important, can be purchased) at <http://www.cafepress.com/haiti1804/392238>



OSCAR continued to raise the profile of sickle cell by securing coverage in Leicester Mercury and on Radio Leicester. The local radio show *Talking Blues* with Herdle White has been a regular friend of sickle cell and has made space for the OSCAR group to raise the issue of sickle cell on air each year.

In 1996 a teenager living in a convent home in Jamaica had come over to Leicester on an educational visit organized by Earl Robinson at Leicester City Council. He became ill and was taken to the Leicester Royal Infirmary in extreme pain. It was there that he was diagnosed for the very first time in his life as having sickle cell anaemia. Having no relatives or friends in the UK, he was visited in hospital by Carol King and her daughter Donna. Carol recalls they were able to cheer him up with a gift of a Michael Jackson tape. He was subsequently able to return home safely to Jamaica.

1997



This was the year in which Labour won the General Election and the Prime Minister Tony Blair appointed Paul Boateng, a regular supporter of sickle cell causes, to a junior ministerial position. Also this year the volcano at Soufriere Hills on the Caribbean island of Montserrat erupted, and parts of the island were evacuated. Eventually over 200 people from that island settled in Leicester, joining the long-standing Montserratian community established in the 1950s and 1960s. Carol King was later to be honoured by the Governor of Montserrat for her social work with the evacuees who came to Leicester.

President Clinton formally apologised for Tuskegee: a 1930s government experiment in which a number of African Americans from Tuskegee, Alabama who had syphilis were prevented from receiving treatment. The experiment lasted for 40 years, long after antibiotics were discovered. Some of the men died, went blind or mad and many of their relatives were infected.

Oona King was first elected as a Member of Parliament for Bethnal Green & Bow in May 1997, the second black woman MP to be elected. She was to lose the seat, controversially, in May 2005.



A study by researchers at the Massachusetts General Hospital and other Boston hospitals first suggested that inhaled nitric oxide (NO) gas might successfully treat sickle cell disease and its characteristic episodes of pain, called sickle cell crises. Nitric oxide is referred to as the WD-40 of blood vessels as it dilates blood vessels to help maintain good blood flow, prevents abnormal clotting, and controls inflammation. The researchers described how nitric oxide causes sickle haemoglobin molecules to combine more effectively with oxygen, and how this should reduce formation of the sickle cells. The result was seen both in laboratory studies and in several volunteer patients with sickle cell disease who breathed low concentrations of nitric oxide. The common gas nitric oxide -- not to be confused with the anaesthetic nitrous oxide -- plays many roles in the body, including relaxation of blood vessels. The body makes NO and uses it to dilate blood vessels, so blood can flow through them easily. NO prevents the inflammatory white cells of that repair process from sticking to the cells that line the arteries. NO also reduces clotting by keeping the platelets in the blood from sticking together. Finally, the researchers reported that NO protects vessels by knocking out a substance called superoxide that generates highly destructive particles, "free radicals," that can damage vessels.



Leicester OSCAR was acknowledged in a study published in an international professional journal. The journal was *Health and Social Care in the Community*. The study was undertaken before the appointment of a specialist sickle cell counsellor. The study showed that the sickle cell cards (called haemoglobinopathy cards) that were issued when someone was identified as being a carrier for sickle cell did not seem to get beyond the patient's notes at their GP surgery, and that, as a consequence, people who had been screened and found to be carriers of sickle cell were no more knowledgeable about the basic facts of sickle cell than those who were not carriers. This demonstrated the importance of the cards being sent to the specialist sickle cell counsellor rather than the GP. In this way the counsellor could offer an individual counselling session to the person with sickle cell, explain about sickle cell and how it is inherited, and give them their card in person.

Leicester OSCAR was pleased to be able to attend the grand opening of a purpose-built centre for the OSCAR group in Bristol in Stapleton Road on 26th September 1997.

1998



A task force published the first report on racism in UK football. The inquiry found that racism was deeply entrenched in the game. At a time when black footballers were succeeding at the highest level, the number of black spectators was decreasing. In 1998, the poet Benjamin Zephaniah was appointed to the National Advisory Committee on Creative and Cultural Education to advise on the place of music and art in the National Curriculum.



Donald Rodney, a conceptual and visual artist with sickle cell disorder, died on 4th March of this year. One of his sketchbooks from 1984, part of his archive now held by the art gallery Tate Britain, mentions the Birmingham branch of OSCAR and sketches genetic diagrams used in explaining graphically the inheritance of sickle cell.

This was the year that the Director of the Prison Service was questioned by Jeremy Paxman on the BBC current affairs programme *Newsnight* and referred to sickle cell as an issue when questioned about the deaths of black prisoners in UK prisons. He was questioned about the death of Alton Manning in custody following an inquest verdict that Manning had been unlawfully killed by being placed in a neck hold. Manning had been the third black man to die in UK prisons between October and December 1995. The Director of the Prison Service raised the possibility that sickle cell may have been implicated in the relatively higher number of deaths in custody of people of African-Caribbean descent. The “research” to which the Director of the Prison Service referred apparently reported that people of African-Caribbean descent were more likely to suffer positional asphyxia (where someone’s position prevents them from breathing, often associated with physical restraint techniques) than whites. Thus it was to be inferred that sickle cell trait might be an explanation for the disproportionate deaths in custody from positional asphyxia whilst being restrained by prison officers. By the Friday, the Director of the Prison Service had apparently apologised “if my remarks caused any offence”, and explained that his remarks were based on expert advice given to the prison service in 1996. He claimed that other experts disagreed with that advice, and that “what we need to do is to commission some further research” (*The Guardian*, 1998). No such research was ever commissioned.

William Beckley-Lines died whilst in the Royal Green Jackets of the UK army. At the end of a two-mile run William collapsed and died at Catterick Army Barracks. The cause of death was attributed to “exhaustion, and sickle cell anaemia” The family paid for a second post mortem which disclosed bruises to his genital area that had not been revealed in the first examination.



Leicester OSCAR hosted the *Midlands Forum for Sickle Cell/Thalassaemia*, at the African Caribbean Centre, Leicester 14th November 1998, a gathering of OSCAR groups from Leicester, Nottingham, Sandwell, Birmingham and Dudley.

Winston Nurse, a founder member of Leicester OSCAR, was elected as a City Councillor for the ward of Rushey Mead. Carol King was given the Pioneer and Achievers Award by the African Caribbean community.

1999



This was the year Sir William Macpherson's report into the police handling of the murder of Stephen Lawrence contained a withering attack on racist attitudes within the Metropolitan Police force. The report sparked the most profound reappraisal of race relations and the justice system and brought the phrase 'institutional racism' into wider usage. The report influenced the passing of the Race Relations (Amendment) Act, 2000. The act placed a duty on public bodies to (1) assess whether their functions and policies are relevant to race equality; (2) monitor their policies to see how they affect race equality; (3) assess and consult on policies they are proposing to introduce; (4) publish the results of their consultations, monitoring and assessments; and (5) ensure the public have access to the information and services they provide.



In this year the book *In the Blood: Sickle Cell Anaemia and the Politics of Race* by Melbourne Tapper was published in the USA. The book took a highly critical look at the development of science around sickle cell. The views of scientists in the 1920s were that a black body was naturally a diseased or flawed body. These racist views led scientists to disbelieve the existence of sickle cell in white patients. In the 1930s fear of sexual relations between black and white people led some scientists to wrongly believe that sickle cell would have worse effects in a person of mixed heritage because the disease "naturally" belonged with black Africans. Tapper's book documents that it was not until the 1960s, and the work of the Black Panthers in the USA, that sickle cell gained any prominence as an issue that required support, medical services and community education.

The well-known children's author Malorie Blackman, famous for her books such as *Noughts and Crosses* published *Forbidden Game* a book for 8-12 year olds in which the hero Sean, who has sickle cell anaemia, saves his school party when they become lost.

Lord Ahmed asked a question in the House of Lords about the numbers of people with sickle cell disorders in the UK. The figure given by the Parliamentary Under-Secretary of State, Department of Health, Baroness Hayman was, at only 6,000, almost certainly an underestimate. The previous year the *British Medical Journal* had cited figures of 9,000 people living with sickle cell disorders for London alone. This highlighted the continuing problem of official bodies underestimating the level of need.



Leicester OSCAR continued with its Christmas parties for children with sickle cell, and continued to use the good services of the *Talking Blues* radio show to get across the sickle cell message. Leicester OSCAR was also pleased to mark the 50th birthday of Don Smith, the founder of the sickle cell support group in Birmingham. Don's 50th birthday address included the words: "Why am I celebrating getting older? [...] It was widely thought that people suffering from sickle cell disease would not live beyond their 30th birthday. Well, I'm very sorry to have to disappoint them. I have had SCD all of my life and have suffered greatly as a result, but it never reduced my sense of willingness, ambitions, determination and ability to achieve or strive to succeed in all of my attempts".



The Race Relations (Amendment) Act was passed. David Lammy was elected Member of Parliament for Tottenham at a by-election on 22nd June 2000 following the death of Bernie Grant. In sport, Denise Lewis won a gold medal in the Heptathlon for Great Britain in the Olympic Games in Sydney.



The government White Paper *The NHS Plan* contained the first reference in a major policy document to improving services for sickle cell by promising to put in place “a new national linked antenatal and neonatal screening programme for haemoglobinopathy and sickle cell disease by 2004.” In the USA, the rap artist Prodigy, originally of Hip-Hop band Mobb Deep, released his solo album entitled HNIC. It contained the track *Feel My Pain*, a reference to the painful episodes that Prodigy experiences on account of his sickle cell anaemia.



Leicester OSCAR hosted the meeting of the Midlands Forum on Sickle Cell & Thalassaemia, which included the OSCAR branches from Nottingham, Bristol, Birmingham, Sandwell and Dudley. The contrast with the degree of funding from local councils, and other statutory bodies compared to Leicester is remarkable. On Tuesday 18th July 2000, Dr. Karl Atkin, spoke at Charnwood Health Centre in Leicester on the research conducted in the North of England and the Midlands. Leicester OSCAR produced a summary which was distributed in the form of a newsletter at that year's Caribbean Carnival on Victoria Park in August. A summary of some of the main findings were:

Not all problems experienced should be put down to sickle cell: for example many young people argue with their parents as part of the process of growing up. Many young people disliked talking too much about their sickle cell. Inside the family they did not want to worry their parents. Outside the family they met prejudice and ignorance about sickle cell. Most young people with sickle cell cope successfully most of the time. They do this by taking each day as it comes; by emphasizing their similarities to other young people; and by learning not to become angry and resentful about their sickle cell.

There is particular concern about sickle cell crises, even when the person is not in pain. This is because they are worried about the pain: they feel a sense of panic when a crisis approaches and worry about their parent's reactions. One young mother with sickle cell anaemia described the pain of a sickle cell crisis as 3 times worse than childbirth! Of particular concern were the minority of doctors and nurses who knew nothing about sickle cell. In some cases this was made worse if they were so arrogant that they felt they knew better than the person with sickle cell how they should be treated.

Some people with sickle cell anaemia found that they were denied adequate pain relief because of racist myths either that black people were likely to become drug addicts or that they had lower pain thresholds and were more likely to make a fuss about pain. In one case a consultant had had to discipline junior medical and nursing staff because they had not followed protocols that would have provided sufficient pain relief. Even where services were very good young people with sickle cell anaemia were still uncertain what they as clients could and should be asking for from the services. There was particular praise for specialist sickle cell workers, either specialist nurse counsellors or community development workers, particularly for the advocacy and social support they were providing.

There was concern about the lack of support and knowledge in services such as housing; education and social services. Lack of understanding of the condition meant that some people had not been awarded the Disability Living Allowance. People felt that schools lacked knowledge about sickle cell. They felt they were too easily 'written off' by teachers and that it was difficult to get the extra work needed to catch up.

2001



Almost 3,000 people were killed in the September 11th attacks on the World Trade Center in New York. An earthquake struck the Indian state of Gujarat, killing 12,000 people. Described as one of the finest poetical playwrights to have written in English, in this year the Nigerian, Wole Soyinka, became the first black writer to be awarded the Nobel Prize for literature. Certainly he is the grandfather of African literature, pioneering African drama written in English. In the world of sport, this was the year that former Leicester City favourite, Emile Heskey, scored the fifth goal in England's historic 5-1 win over Germany in the football World Cup qualifying matches.



In this year the book *The Politics of Sickle Cell Anaemia* by Elizabeth Anionwu and Karl Atkin was published by Open University Press. The book was one of the first to deal with sickle cell as a social and political issue, as well as a medical one. The book gave recognition to the work of OSCAR and the Sickle Cell Society in being the community activists who had pushed for changes in the face of institutional racism on the part of some health and social services commissioners and providers:

“..organizations such as the Sickle Cell Society, OSCAR and the UK Thalassaemia Society continue to struggle to secure appropriate and accessible haemoglobinopathy provision and also to provide other successful examples of black empowerment. These organizations offer important social and emotional support for individuals and families, provide information and advice, as well as lobby for improved provision. [...] Their contribution is much appreciated by individuals and their families and they play an important role in the politics of sickle cell and thalassaemia” (Anionwu and Atkin, 2001: 109)

Professor Graham Serjeant published the third edition of his classic medical text *Sickle Cell Disease* with Oxford University Press. Professor Serjeant had patients in Jamaica with sickle cell disorders who lived well into old age and at least one, Isadore Simms-Franklyn, who has celebrated her 85th birthday.



Gloria Daley, one of the committee members at Leicester OSCAR, was awarded a Community Achievement Award for her voluntary contributions to the community. Leicester OSCAR chairperson Carol King was given a Special Person Award for continuous efforts in raising awareness about sickle cell. On 1st October this year, Carol also secured a whole page spread in the black newspaper *The Voice* to talk about the sickle cell cause. The paper records: “Carol says she was very moved when she visited a London hospital and saw the physical condition of a pair of twins who had the illness. It was her first experience of sickle cell as she had never come across the illness in the Caribbean”.

2002



Paul Boateng, Member of Parliament for the constituency of Brent in North London, and a long time supporter of sickle cell causes, made history this year when he became Britain's first black Cabinet minister after being appointed chief secretary to the Treasury. The American singer-songwriter and actress Ashanti released her first album, also called *Ashanti*. She later declared that she herself had sickle cell trait and had lost relatives to sickle cell anaemia.



Health minister David Lammy MP was quoted in the black newspaper *The Voice* as saying that sickle cell patients cannot demand the freedom to decide what painkilling drug they should receive. His comments came amid controversy over a government decision to withdraw the use of the drug pethidine in the treatment of the disease. In an interview with *The Voice*, Lammy urged sickle cell patients to accept diamorphine as an alternative painkiller. Lammy was quoted in the major black newspaper *The Voice* as saying: "I am aware of concerns over the withdrawal of the drug pethidine for sickle cell sufferers. But it is important in this department that we are led by decisions of clinicians and it is they who have told us that the alternate drug, diamorphine, is preferable for sickle cell anaemia. It is the drug of choice." He added that the decision was supported by the Sickle Cell Society, the country's largest sickle cell charity. The sickle cell campaigning body Outrage Against Treatment in Hospitals of Sickle Cell Patients (OATHS) claimed that sufferers had been stigmatised and were victims of racism in the NHS

At the Sickle Cell Society Annual General Meeting at the Commonwealth Institute in London, awards are presented by Derrick Evans. Derrick is better known as TV's Mr Motivator and is a former pupil of the old Moat Boy's school in Leicester.



Sickle Cell: Past, Present and Future was a conference jointly organised and run by Leicester OSCAR and De Montfort University, Leicester. Local speakers included Dr. Claire Chapman of University Hospitals of Leicester NHS Trust, and Vanita Jivanji and Lucille Fifield, the specialist nurse counsellors for sickle cell and thalassaemia. Professor Adrian Taylor and Brenda Scotland spoke of overcoming fear of exercise as a means of improving health of those living with sickle cell anaemia and the potential of moderate exercise to improve health. Glenda Augustine spoke about the innovative day hospital for patients living with sickle cell at City Hospital Birmingham. People with sickle cell in crisis can self-refer to the small unit staffed by three specialist nurses. This day care facility helps the person with sickle cell by avoiding any delays in pain relief that might be caused by having to go through the hospital's accident and emergency department or by being treated by staff who do not have specialist knowledge and experience of sickle cell. At the conference Leicester OSCAR were supported by comments from people with first-hand experience of sickle cell, including Hanif Ebrahim, father of two children with sickle beta-thalassaemia, one of the forms of sickle cell disorders. Also speaking from the audience were Tony Slowley from Bristol OSCAR who shared his experiences of being a sufferer, and Charles Washington from Nottingham OSCAR who recalled the first time he witnessed a friend in a sickle cell crisis.



Baroness Amos was made Parliamentary Under-Secretary of State at the Foreign and Commonwealth Office in 2001. She joined the Cabinet as International Development Secretary in May 2003 before becoming Leader of the House of Lords and President of the Council in October 2003. Trevor Philips, a long time supporter of the sickle cell cause, was appointed by the Home Secretary to be the chairman of the Commission for Racial Equality.

Althea Gibson, the first black woman to win Wimbledon, died this year. Her background was in the streets of Harlem, New York, and to even play tennis at that level showed her strength of character in the face of racial prejudice. She was the first black woman to compete at the US Open in 1950 and at Wimbledon in 1951, and went on to win both titles in 1957 and 1958.



Robby Robinson, one of the most successful professional body-builders in history, known as *The Black Prince*, and a former winner of the Mr America, Mr World and Mr Universe titles, reported that Arnold Schwarzenegger had more than once directed a tirade of racist abuse at him and other black body-builders. Robby was also reported in body-building magazines to have sickle cell anaemia.

A study published by the Office of the Deputy Prime Minister in 2003 found that black families were less likely to own their own properties and were more likely to reside in council and housing association properties in deprived areas. Half a million children live in crowded conditions across the country. Mother-of-five Dana Henry lived in a two-bedroom flat in west London and had been waiting over six years to be relocated. Her 10-year-old son suffered from severe sickle cell and had to sleep on a sofa bed in the living room. She told *The Voice*: “Darius has had 60 admissions for sickle cell crises since he was born. He cannot share a room with his sisters because he has to sleep with a needle in his arm. The conditions we live in are horrible and the entire family is affected”.



As is usual, Leicester OSCAR supported other branches of OSCAR in their activities. OSCAR took four Leicester OSCAR members to Nottingham to attend: *Sickle Cell: How Does it Affect your Community*, a Nottingham OSCAR Conference held at the City Hall, Nottingham on February 28th 2003. The speakers included Verna Davis, the Centre Manager for the Manchester Sickle Cell and Thalassaemia Centre; Olufunke Adedeji a public health doctor from Nottingham; Kofi Anie, a psychologist working with people with sickle cell disorders in London, and Ade Olujohungbe, a consultant haematologist from Liverpool.

Leicester OSCAR was a patient group representative on the advisory group for a research project, funded by the NHS Sickle Cell and Thalassaemia Programme, looking at ante-natal screening for sickle cell and thalassaemia. The research showed that it is possible to minimise the number of real sickle cell carriers missed in a selective screening programme (that is when screening is targeted at only certain groups, based on asking about ethnic/family origins to identify those most at risk) to about 5%. However, it also showed that misplaced beliefs that people belong to distinct biological ‘races’ (a belief that sickle cell, which can occur in *any* ethnic group, demonstrates is false) was leading some health professionals to ignore formal protocols in the mistaken belief that they knew who is at risk on the basis of skin colour.

Carol King went to Montserrat to receive the badge and honour of Montserrat in recognition of her work with refugees from that island who settled in Leicester..

2004



This year was UNESCO's International Year to commemorate the struggle against slavery and to mark its abolition. The United Nations produced a report that blamed the government in Sudan for crimes against humanity in Dafur. Condoleezza Rice was appointed US Secretary of State, the first black woman to serve in that office. In sport, Kelly Holmes won two gold medals at 800 and 1500 metres in the Athens Olympic Games. South Africa becomes the first African nation to be awarded the 2010 FIFA World Cup. This year also saw the death of Ray Charles, American pianist and musician. The controversial businessman Damon Buffini, who grew up on a council estate in Leicester, is quoted as having a take home pay of £3.2 million this year as head of the private equity firm Permira.



This was the year when the poet Benjamin Zephaniah refused the award of the MBE, partly because the Prime Minister Tony Blair had declined to come out of Number 10 to receive a petition about the death of Zephaniah's cousin Mikey Powell, killed when hit by a police car. As with the cases of Alton Manning and Denis Stephens before him, the authorities had confused the issue by reference to Powell's sickle cell trait.

On October 11th 2004, 14 year old Danielle 'Dan Dan' Beccan was shot dead in Nottingham and died from the large amount of blood she lost when the bullet severed an artery. While Danielle's family and friends waited at the hospital for news, her father, who suffers from sickle cell anaemia, was in hospital in Derby. By the time he discharged himself and made his way to his daughter's side at the Nottingham City Hospital, she was dead.

The African Caribbean Leukaemia Trust (ACLT) launched a new campaign in a bid to get black people to give blood. ACLT campaigners spearheaded a hugely successful campaign to increase the numbers of African-Caribbeans on the UK bone marrow register. From under 600 people in 1996, the figure had risen by 2004 to stand at 15,000. They were now working with the National Blood Service to encourage the black community to give blood. An ACLT spokesperson was quoted by *The Voice* as saying: "In some parts of Africa and the Caribbean there are people who have a rare blood group. If you are a sickle cell sufferer with that same rare blood group, for instance, you want those people to be on a register of blood donors to increase your chances of survival."

In the USA, the US Postal service continued a tradition, started in the 1950s, of issuing commemorative stamps that highlight social awareness issues. The Sickle Cell Disease Awareness Stamp, launched at the 31st Annual Convention of the Sickle Cell Disease Association of America was designed by James Gurney and carried the tender picture of mother and baby with the message: "Test early for sickle cell."

The 31st December 2004 marked the 100th anniversary of the first medical observation of sickled cells under a microscope by a Western Scientist, Dr James B. Herrick in Chicago, USA. The sickled blood cells were those of a student from a wealthy family in Grenada, Walter Clement Noel, who was studying to be a dentist. Noel returned to Grenada, where he died in his early thirties. His grave is in the Catholic Cemetery of Sauters, in the north of the island.



Leicester OSCAR gave a presentation on sickle cell anaemia to around 200 members of the congregation at Wesley Hall, Methodist Church, Mere Road, Leicester, on 12th June 2004.

2005



This was the year the world witnessed the slow reaction of US authorities to the devastation of New Orleans by Hurricane Katrina. Rosa Parks, famous for her role in the bus boycott in Montgomery, Alabama died this year. On the 200th Anniversary of her birth in 1805 Mary Seacole, a Caribbean-born nurse who treated British soldiers in the Crimean War, was voted the greatest black Briton of all time in a national poll. Jesse Jackson, the veteran US Civil rights campaigner and twice a candidate to be the Democratic contender for the Presidency of the USA, was in Britain to lend his support to the campaign Operation Black Vote. Jesse Jackson is reported to himself have sickle cell trait. Private Johnson Beharry was awarded the Victoria Cross for his actions during the Iraq War. Paul Boateng MP, a long time supporter of sickle cell causes, announced his retirement from parliamentary politics. John Sentamu, the Bishop of Birmingham became the first black archbishop when appointed to the post of Archbishop of York. He was also the lay chair of the NHS Sickle Cell and Thalassaemia Screening Programme.



This was the year by which all local health trusts in England were due to have universal screening of newborn babies for sickle cell disease. New born screening is undertaken on new born babies within a few days of birth by pricking their heels to obtain a few drops of blood. Infants who are identified as having sickle cell disease can then be treated immediately in several ways (1) by starting daily penicillin to ward off infections, (2) ensuring that the baby has a full and up-to-date set of vaccinations, especially against flu, and (3) by teaching the parents to look out for signs and symptoms of a sickle cell crisis. In this way the proportions of infants with sickle cell who die under the age of five is greatly reduced. It is estimated that 1 in every 2,340 babies born in England have sickle cell disease. This compares to a condition called phenylketonuria (PKU) which affects only 1 in 10,000 babies, and which has had a neonatal screening programme since the 1960s.

On the 6th December Royce Scarlett died from renal medullary cancer: a very rare but very aggressive form of kidney cancer that seems to especially affect people with sickle cell trait. His funeral took place at St Peters Church in Highfields, Leicester on the 15th December.

Further disagreements emerged between some clinicians and some clients with sickle cell disorders over treatment for pain. One London hospital argued that: “Recently published recommendations suggest that injectable opioids such as diamorphine should not be used routinely in the management of persistent pain”. A group of people with sickle cell disorders in North London suggested that doctors had changed the protocols for treating patients without consultation, reflecting a one-sided relationship between doctors and patients.

In this year the book *Ethnicity and Screening for Sickle Cell and Thalassaemia* by Simon Dyson was published by Elsevier. The book was based on interviews with 27 Black African and Black Caribbean specialist sickle cell nurse counsellors. The book reflected an important part of Black history as it recounted how the work of these counsellors compelled them to learn about the politics of ‘race’, racism, and ethnicity as they went about providing their important service to black communities between 1979 and 2005.



Leicester OSCAR marked the 20th anniversary of the group’s existence. Leicester OSCAR also worked to develop an application to the Lottery Fund in order to fund a development worker for the group. Unfortunately this application was not successful.



World events this year included the death of Coretta Scott King, the widow of Civil Rights leader Martin Luther King. Alice Walker, author of *The Color Purple*, was inducted into the Californian Hall of Fame. Trevor Philips was appointed as the Head of the Commission for Equalities and Human Rights, a new organization promoting equality issues across gender, ethnicity, disability and sexual orientation. Anti-racist campaigners feared that this would dilute the cause of anti-racism in the UK.



Martin Lee Anderson, a troubled 14-year old, was imprisoned in a boot-camp in Florida for violating probation incurred following joy-riding in his grand-mother's car. Boot-camps such as these were designed to instil conformity to authority into youngsters by administering short sharp shock techniques based around military-style physical training and discipline. The guards regularly slammed the youngsters against the wall, applied pressure point and takedown techniques. Other inmates reported that in the evenings the guards used to watch tapes of their violence towards the young offenders as a form of sadistic entertainment.

On his very first day in the boot camp, Anderson was involved in the regime of multiple sit-ups, multiple push-ups and a sixteen lap run. Towards the end of the run he staggered and stopped. Videotape later released showed seven guards beat up Martin Lee Anderson. He was continually hauled to his feet even though he appeared already to have collapsed. The camp nurse was in attendance but did not intervene. Ammonia capsules were reported to be regularly used by the guards as a form of punishment for those who did not complete exercises. The ammonia capsules appeared to have been used several times on Anderson, including whilst he was being dragged along. The confrontation lasted for over twenty minutes before either the guards or the nurse began to show any concern. No-one told the emergency room physicians or the paramedics treating Anderson that he had been in a protracted struggle with guards, nor about the use of ammonia on him. Martin Lee Anderson was eventually taken away by ambulance. Early next day, his life support machine was switched off and he was pronounced dead.

At the first autopsy, the medical examiner concluded that the death was not caused by the beatings but was a "natural death", attributable to "internal bleeding caused by sickle cell trait". The body of Martin Lee Anderson was exhumed on March 10th 2006, and a second autopsy performed. The second autopsy identified the cause of death as neither the sickle cell trait nor the beating, but of ammonia capsules being forced up his nose while hands were held over his mouth, leading to asphyxiation. The Reverend Jesse Jackson led protest marches against Martin Lee Anderson's death.



Leicester OSCAR, along with colleagues from OSCAR Sandwell, OSCAR Nottingham and the Sickle Cell Society took up positions on the advisory group for a national project funded by the Economic and Social Research Council to look at the experiences of young people with sickle cell in education.

By now Radio Leicester had moved from off Charles Street to St Nicholas Place, and *Talking Blues* had become *Caribbean Connection*. But with the help of Herdle White, Shirley Burgess and Everton Osbourne, Leicester OSCAR was helped this year, as in many years, to raise awareness about sickle cell each year on local radio.

2007



James D Watson, the Nobel-winning scientist credited with the discovery of the structure of DNA was widely condemned for remarks attributed to him. Watson was quoted as saying he was “inherently gloomy about the prospect of Africa” as “all our social policies are based on the fact that their intelligence is the same as ours — whereas all the testing (IQ testing) says not really.” He went on to say that he hoped “everyone was equal” but was further quoted as saying that “people who have to deal with black employees find this not true”. The year also marked the 200th anniversary of the passing of the 1807 Abolition of the Slave Trade Act. At the BBC Frank Gillard Awards for Local Radio, Radio Leicester’s Herdle White, whose black music programmes and reporting had been a constant on the station for 39 years, won one of the six Outstanding Contribution to BBC Local Radio awards.



The trial of the guards and the nurse in the death of Martin Lee Anderson took place in Panama City, Florida. An all-white jury of only six people was selected. After nearly two years of waiting, the trial began on October 3rd 2007, and concluded on October 12th 2007. The jury took no more than 90 minutes to select a spokesperson, weigh up highly complex evidence, write out their official four page report, and return eight not guilty verdicts. As well as clearing all defendants of aggravated manslaughter, the jury also cleared all the guards and the nurse of lesser charges, one of culpable negligence and one of child neglect. “You kill a dog, you go to jail. You kill a little black boy and nothing happens” the Anderson’s family lawyer Bernard Crump is reported to have commented.

Professor Elizabeth Anionwu, CBE retired from her position as Professor of Nursing at Thames Valley University. Elizabeth became the first NHS sickle cell counsellor in the UK when she was appointed in Brent, in North West London, in 1979. She is also the leading figure in the campaign to recognize the work of Mary Seacole, the Caribbean nurse who was, until recently, unacknowledged for her contribution to nursing in Crimean War in the nineteenth century. This year also marked the death in Birmingham of Don Smith, one of the original founders of support groups for sickle cell in the UK.



Leicester OSCAR held a seminar at the African-Caribbean Centre in Maidstone Road comparing sickle cell in the UK and sickle cell in Ghana. Guest speaker was Dr Jemima Dennis-Antwi, a member of the Sickle Cell Foundation of Ghana, and former health education officer of the Kumasi new-born sickle cell screening programme. Jemima was visiting the UK to receive her doctorate in sickle cell studies from De Montfort University. She reported on the work of Professor Kwaku Ohene-Frempong, Director of the Children’s Hospital in Philadelphia in implementing this first new-born screening programme in Africa. Through relatively inexpensive measures, including testing new born children at birth for sickle cell disorder, enrolling the infant at a regular sickle cell clinic, preventing infections through the use of simple antibiotics, and by educating the parents on what common signs and symptoms to be aware of in their child, the number of children with sickle cell disorder reaching their teenage years had been greatly increased. Dr Dennis-Antwi also described how in Africa a quarter of a million babies are born with a sickle cell disorder, the majority of whom do not benefit from the type of inexpensive new-born screening programme run in Kumasi and Accra, and the majority of whom die before their fifth birthday.



Barack Obama became the first black person to be the presumptive nominee for the Democrats in the race to become the President of the United States of America. Professor David Gillborn of the Institute of Education in London published his book *Racism and Education*. The book produced evidence from the government's own figures on schools that shows that black pupils start school at a level of achievement equal to or above their peers, but that the longer they are in the education system, the further they fall behind. Jennette Arnold, born in Montserrat, took over as chair of the London Assembly, the elected body responsible for scrutinizing the activities of the Mayor of London. Paul Ince became the first black Englishman to be appointed to manage a Premiership football club, Blackburn Rovers.



The National Confidential Enquiry into Patient Outcome and Death in people with sickle cell or thalassaemia, entitled *A Sickle Cell Crisis?* was published in May of this year. The study was designed to highlight deaths of people with sickle cell disorders, where treatment or care was less than fully adequate, and to improve health care practice on the basis of lessons learned from those deaths. The publication of the report sparked a highly-charged exchange of views in the *British Medical Journal* in which two sickle cell specialists with over eighty years clinical practice between them, Dr Felix Konotey-Ahulu from Ghana and Dr Graham Serjeant, who practised in Jamaica, questioned the extent of the reliance in the UK on opiate painkilling drugs as a central part of the management of people with sickle cell disorders in hospital. They were joined in their comments by a former nurse, Cecilia Shoetan, who lost her daughter to a sickle cell death associated with a lack of monitoring of respiratory rate following opiate use in hospital. Cecilia now organizes the sickle cell support group in Barking, Dagenham and Redbridge.

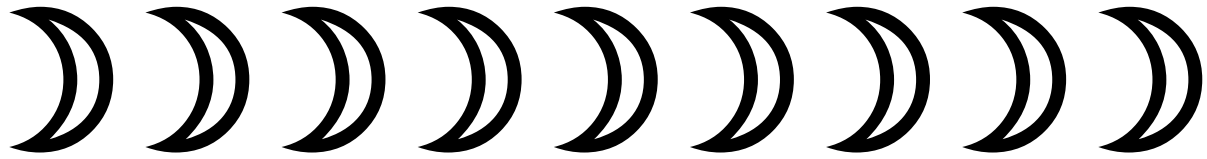


Leicester OSCAR took part as one of several local sickle cell support groups collecting data as part of a national survey, funded by the Economic and Social Research Council, of the experiences of children with sickle cell in schools. The research found that sometimes children are not allowed to go to the toilet by teachers (children with sickle cell cannot concentrate urine as readily, so need to pass dilute urine more often); may not be allowed to drink water in class (being dehydrated can trigger a sickle cell crisis); and may on occasions be mistaken for being lazy when their anaemia had left them tired and finding it difficult to concentrate.

Carol King publicized the work of the OSCAR group at a seminar organized by the Head of the Sickle Cell and Thalassaemia Service, Vanita Jivanji, at Moat Community College on the 24th June. Speakers included Dr Elena Psiachou-Leonard, Consultant Paediatric Haematologist; Dr Jane Wai-Ogosu of the Sickle Cell Society and young adults living with sickle cell disorder. Nearly twenty years had passed since Leicester OSCAR organized the first sickle cell conference at that same community college in 1988.

At the Leicester Caribbean Carnival on August 2nd, Barry Gordon was scheduled to arrive back from his Skegness-Leicester bike ride in aid of sickle cell charities. This was the second annual ride organized, with the previous year seeing Barry complete a route between Leicester and London. Winston Nurse, the long-serving treasurer of Leicester OSCAR was appointed to the position of Alderman of the City of Leicester, the first black man to receive this award.

Sickle Cell Fact File



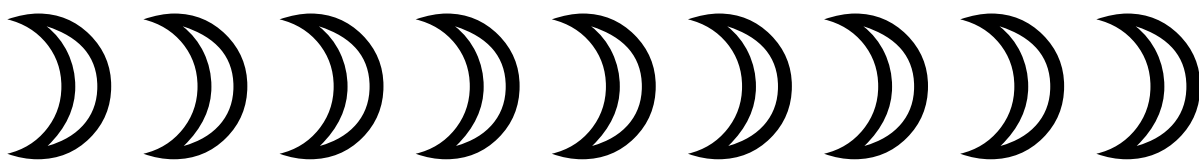
- Sickle cell anaemia is a serious inherited blood disorder.
- In the UK, about 1 in 300-400 people of Black Caribbean descent, and around 1 in 50 of Black African descent have sickle cell anaemia.
- Genes associated with sickle cell are also found especially in people of Indian, Mediterranean and Middle Eastern descent.
- On rare occasions the sickle cell gene can also be found in people of North European descent.
- Sickle cell anaemia is inherited, that is it can be passed on from parents to children (it cannot be caught like you catch a cough or a cold).
- Sickle cell is the most common single-gene condition in England.
- Carriers are not usually ill themselves but can, if the other biological parent is a carrier, pass sickle cell to their children.
- Carriers are sometimes referred to as having sickle cell trait.
- One of the main symptoms of sickle cell anaemia is extreme pain caused by blocked blood vessels.
- All new-born babies in England are now offered a test to see if they have a sickle cell disorder, using blood taken by the heel-prick test
- All mothers-to-be in Leicestershire are now offered a screening test by their midwife to see if they are carrying genes associated with either sickle cell or thalassaemia as part of their ante-natal care.
- The sickle cell gene can be inherited alongside other genes that produce different types of sickle cell disorder. For example, haemoglobin S and haemoglobin C inherited together produce a condition called haemoglobin SC disease.



Sickle Cell by Numbers



- There is a **1 in 4** chance for each pregnancy that where both parents are carriers of sickle cell that the child will have the serious inherited blood condition sickle cell anaemia.
- There may be over **15 000** people living with sickle cell disorders in the UK.
- About **1 in 300-400** people of African-Caribbean are living with sickle cell anaemia or one of the other sickle cell disorders.
- About **1 in 10** people of African-Caribbean descent in the UK carry the gene associated with sickle cell.
- As many as **1 in 4** people of West/Central African descent may carry the gene associated with sickle cell.
- About **5%** of the world's population carry a gene associated with a haemoglobin disorder like sickle cell or thalassaemia.
- Normal red blood cells usually last about **120** days in the body.
- One in every **2,340** children born in England has a sickle cell disorder.
- It is now over **100** years since sickle cells were first seen under the microscope in 1904.
- It is now nearly **25** years since the branch of OSCAR was founded in Leicester in 1985.
- It is estimated that nearly **250,000** people in the UK are sickle cell carriers (have sickle cell trait).
- Estimates suggest that up to **300,000** children may be born in Africa each year with sickle cell anaemia.



Leicester OSCAR: The Future

To enable our group to continue, we are appealing to the following to increase our membership:

Are you a youth club, community centre or minority ethnic group leader? Are you a school teacher, a social worker, a nurse or a religious leader? Do you or anyone in your family have sickle cell anaemia? Is any member of your family a carrier of the sickle cell gene? Do you have a contact/friend with sickle cell anaemia or sickle cell trait?

If so, please consider joining us and supporting us in fundraising, educational talks, campaigns for services and advocacy for people living with sickle cell and their families. We have films, leaflets, videos and we offer free support and advice to families. We need the next generation of volunteers to step forward and support the sickle cell community.

Get on the right track! Please join us and help support sickle cell. We are now based in the Leicester Depot Building, site of the former Leicester Bus Depot, in the city's new Cultural Quarter, and we are supported in our work there by Maxine Harris.

Leicester OSCAR
Leicester United Caribbean Association
The Leicester Creative Business Depot
31, Rutland Street
LEICESTER
LE1 1RE
Tel.: 0116 261 6850
sicklecellanaemia@hotmail.co.uk

The 2008 Committee:

Chair:	Carol King
Vice-Chair:	Gloria Daley
Secretary:	Muriel James
Treasurer:	Winston Nurse
Social Secretary:	Haskell Lane

Committee Members:	Hazel Andrews
	Rose Beckford
	Erskine Cave
	Naomi Messiah
	Norma White

A special thanks to Miss Maxine Harris at the Leicester United Caribbean Association for her continuous support during the past years to the present.

Carol King
[RMN, City and Guilds Certificated, Management of Continence Certificated, Trainer and Facilitator].

Leicester Sickle Cell and Thalassaemia Centre

At the time of writing in 2008, Leicestershire currently has three specialist sickle cell and thalassaemia workers, namely Vanita Jivanji, Merle Oni and Daxa Parmar. From early 2009 they are due to be based at:

Leicester Sickle Cell and Thalassaemia Service
Charnwood Health and Social Care Centre.
1, Spinney Hill Road,
Leicester LE5 3GH
Tel: (0116) 242 5663.

The service aims to meet the specific health needs of people affected by sickle cell, thalassaemia and other related haemoglobinopathies in Leicester, Leicestershire and Rutland. It provides information, counselling, and social, psychological and emotional support to those affected, their carers, family members and friends. The service also helps informed decisions to be made regarding care and treatment plans and with respect to present and future pregnancies. If you have a blood test at ante-natal clinic and it is found that you are a carrier for sickle cell or thalassaemia, the service can offer counselling and can invite the partner to have their blood tested to see if they are a sickle cell carrier as well. The counsellors can explain the patterns of inheritance for sickle cell and the likelihood of having a child with sickle cell anaemia. Parents are also offered counselling around the results of neonatal screening, that is, the screening of new born babies for sickle cell. The centre also provides co-ordination of care for people with sickle cell disorders and thalassaemia by working with various agencies and by providing teaching, training and professional support.

Websites on the Internet

As many of you will know the internet is an increasing source of information on health issues. There is a great deal of information about sickle cell on the Internet. Some of the sites we have found include:

<http://www.oscartrust.org/>

[Organization for Sickle Cell Anaemia Research]

<http://www.sicklecellsociety.org>

[The Sickle Cell Society]

www.oscarbristol.co.uk/

[Organization for Sickle Cell Anaemia Research, Bristol]

<http://www.webwell.org.uk/African-Caribbean-Organisations/OSCAR-Sandwell.htm>

[Organization for Sickle Cell Anaemia Research, Sandwell]

<http://www.ukts.org/>

[United Kingdom Thalassaemia Society, London, UK]

<http://www.stacuk.org>

[The United Kingdom Sickle Cell and Thalassaemia Counsellors Organization]

<http://www.sicklecelldisease.org/>

[The Sickle Cell Disease Association of America]

<http://sicklecell.starlightprograms.org/>

[Starbright Foundation: Sickle Cell Slime-O-Rama Game for children]

<http://www.cafepress.com/haiti1804/392238>

[Artist living with sickle cell anaemia, Hertz Nazaire, sells his sickle cell art]

<http://www.chime.ucl.ac.uk/APoGI/>

[University College London, Accessible Publishing of Genetic Information This site includes printable advice sheets for giving to counselled carriers of sickle cell and thalassaemia].

<http://www.pegasus.nhs.uk/>

[Professional Education for Genetic Assessment and Screening Network]

<http://www.sickle-thalassaemia.org>

[Brent Sickle Cell/Thalassaemia Centre]

<http://www.haemoglobin.org.uk/>

[UK Forum for Haemoglobin Disorders]

<http://www.sickleandthal.org.uk/>

[NHS Sickle Cell and Thalassaemia Screening Programme]

<http://www.tascunit.com>

[Unit for the Social Study of Thalassaemia and Sickle Cell]

Further Reading

The following is a list of books on sickle cell that are recommended for further reading:

Ahmad, W.I.U. (2000) (Ed) *Ethnicity, Disability and Chronic Illness* Buckingham: Open University Press.

Anie, K (1998) *Coping with Sickle Cell Disease and Pain: A Self-help Manual* London: Brent Sickle Cell and Thalassaemia Centre.

Anionwu, EN. and Atkin, K. (2001) *The Politics of Sickle Cell and Thalassaemia* Buckingham: Open University Press.

Black, J. and Laws, S. (1986) *Living with Sickle Cell Disease* London: Sickle Cell Society.

Blackman, M (1999) *Forbidden Game* London: Puffin [Children's book]

Clare, N (2007) *An OSCAR For My Troubles* London: Neville Clare

Dyson, SM (2005) *Ethnicity and Screening for Sickle Cell/Thalassaemia* Oxford: Elsevier Churchill Livingstone.

Franklin, I. (1990) *Sickle Cell Disease: a guide for patients, carers and health workers* London: Faber and Faber.

Gillie, G (2005) *Need To Know: Sickle Cell Disorder* Heinemann Library

Hill, S.A. (1994) *Managing Sickle Cell Disease in Low Income Families* Philadelphia: Temple University Press.

Midence, K and Elander, J (1994) *Sickle cell disease: a psychological approach* Oxford: Radcliffe Medical Press.

Okpala I (2004) *Practical Management of Haemoglobinopathies*. Blackwell, Oxford.

Serjeant, GR and Sergeant, BE (2001) *Sickle Cell Disease* Third Edition, Oxford: Oxford University Press.

Tapper, M. (1999) *In the Blood: Sickle Cell Anaemia and the Politics of Race*. Philadelphia: University of Pennsylvania Press.

Wailoo, K. (2001) *Dying in the City of the Blues: sickle cell anaemia and the politics of race and health*. Chapel Hill, North Carolina: University of North Carolina Press.

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