



I believe I can fly

Achievements of the Nottingham Sickle Cell and Thalassaemia Service

1988 - 2010

Dedicated to all the individuals and groups who we serve and have served and to the individuals at OSCAR whose passion created the vision for our service.

I Believe I Can Fly. Achievements of the Nottingham Sickle Cell and Thalassaemia Service 1988 - 2010

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It has been a privilege for Bright Ideas to be involved in this history project to summarise the quite breathtaking and life-changing achievements of the Sickle Cell and Thalassaemia Service since its inception in 1988. Bright Ideas would like to thank all those who took part in the interviews and who provided information for this history project.

Local People

A range of children, young people and adults who use the Sickle Cell and Thalassaemia Service

Nottingham Sickle Cell and Thalassaemia Service – present staff

Joanne Bloomfield	Manager and Lead Specialist Nurse
Beryl Douglas-Green	Specialist Nurse (Adults)
Christobel Pinto	Specialist Nurse (Children)
Adewumi Ajayi	Specialist Nurse (Children)
Manju Manson	Clerical Assistant

Nottingham Sickle Cell and Thalassaemia Service – former staff

Joy Cummings-Jones	Manager
Gemma Bailey	Manager

Other Interviewees

Mrs Delores Barnes	OSCAR (Organisation for Sickle Cell Anaemia Research)
Dr Marie Donohue	Consultant Clinical Haematologist, Nottingham University Hospitals Trust
Dr David Curnock	Consultant Paediatrician, Nottingham City Hospital (Retired)
Richard Newland	Business Owner, Jamaican Ways
Orlando Thomas	Pro-Active Arts

Thanks to Bright Ideas team members

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Peter Darling	Proof Reader (pdproof)

‘When my son was diagnosed with sickle cell at the age of 18 months I thought I’m faced with an illness that I know nothing about.’

Mother of child looked after by Nottingham Sickle Cell and Thalassaemia Service
January 2010

‘When I was pregnant, because I had undiagnosed sickle cell, I was really ill. I weighed just over five stone and struggled throughout the pregnancy. This happened 40 years ago but I still find it really upsetting now to remember and talk about.’

Woman who uses Nottingham Sickle Cell and Thalassaemia Service
December 2009

‘Before I was contacted by the Nottingham Sickle Cell and Thalassaemia Service I was in a dream world, not knowing what to do. After my first appointment with the Service, my hopes were raised.’

Mother who uses Nottingham Sickle Cell and Thalassaemia Service
November 2009

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Section 1: Introduction

During 2009–2010 research was undertaken to trace the history of the Nottingham Sickle Cell and Thalassaemia Service. Key personnel who had worked for the Service or had been associated with it since its formation in 1988 were interviewed to gain an understanding of how the Service had developed. In addition archive material including service reports and newsletters were examined to try and establish what had been the instrumental factors in forming the Service in Nottingham and what changes had been made over the years to benefit those using it. Finally people who had accessed Nottingham Sickle Cell and Thalassaemia Service during the last twenty-one years were also interviewed to find out how they had engaged with the Service over that time. This also gave them the opportunity to discuss their experience of living with undiagnosed sickle cell at a time when few health professionals recognised the symptoms, or to relate how they felt when their child was diagnosed with it.

Prior to 1988 there was no specialist provision for people who were affected by sickle cell anaemia in the Nottingham area. Now the Nottingham Sickle Cell and Thalassaemia Service provides a service for people registered with a GP in Nottingham City, Gedling, Rushcliffe, Broxtowe and Hucknall. In January 2010 there were 133 people with sickle cell and thalassaemia disorders in Nottingham registered with the Service. With a growing ethnically diverse community in Nottingham, including an increase of new residents from African countries (table one) and an expanding number of UK and overseas students (table two), the number of people who will be potentially affected by sickle cell and thalassaemia is increasing.

In 2007 the estimated population figures for the city of Nottingham demonstrated a potential 44 per cent increase in this group within a six-year period as opposed to an estimated increase in the general population of just over 7 per cent, demonstrating that the work done by the Nottingham Sickle Cell and Thalassaemia Service will continue to be vital in the future. Put another way, the 1991 Census figures for the city of Nottingham suggested that 10.8 per cent of the population were at risk of being affected by sickle cell and thalassaemia, whilst in 2007 it was suggested that just over 21.3 per cent could be in this category, and this is thought to be a conservative estimate.

Table 1: Population Figures for Nottingham City¹

	2001	2007 estimate	2009 estimate
Total population for Nottingham City	268,900	288,700	292,400
Increase in population most likely to be affected by haemoglobinopathies			
Black or Black British (all persons)	11,700	13,700	Not available
Asian or Asian British (all persons)	17,600	23,700	
Chinese or other Ethnic group (all persons)	3,000	8,000	
Mixed (all persons)	8,400	9,400	
Total	38,000	54,800	

Table 2: Ethnicity Breakdown of Students at the University of Nottingham 2002 – 2009²

	Black	Asian	Mixed	Total
2002-2003	1%	6%	1%	8%
2003-2004	1%	6%	2%	9%
2004-2005	n/a	n/a	n/a	n/a
2005-2006	1%	8%	2%	11%
2006-2007	2%	9%	3%	14%
2007-2008	2%	10%	3%	15%
2008-2009	2%	11%	3%	16%

Section 2: Past Achievements

Introduction of the Universal Newborn Screening Programme



In 2005 universal newborn screening for sickle cell commenced in England. During the period April 2005 – March 2007, 1.2 million babies were screened and 17,000 were confirmed to be carriers of haemoglobinopathies, with a screen positive result of a national birth prevalence of just above 1 in 2000.³

Unless parents refuse screening or babies are born abroad prior to living in the UK, the national screening programme will mean a future where diagnosis of blood disorders is in place from birth and care can therefore be managed far more effectively. The national screening programme has had an impact on the workload of the Nottingham Sickle Cell and Thalassaemia Service, with increasing numbers of healthy carriers who require follow-up.

An evaluation of people using the Nottingham Sickle Cell and Thalassaemia Service carried out in 2009 by Bright Ideas Nottingham revealed that many people

had the experience of not having their condition diagnosed until adulthood.⁴

This meant that their symptoms were often misdiagnosed. One woman reported that before her sickle cell was diagnosed she narrowly avoided having a major operation, as medical staff initially put her intense stomach pain down to a burst appendix.⁵

Others reported how living with undiagnosed sickle cell affected their enjoyment of daily life:

*'One of my happiest memories when I was training as a nurse in the 1960s was participating in a trip to Derbyshire with my fellow students. I was really happy as it reminded me of being back home in Jamaica, in the countryside I had grown up in and left behind. We waded through an icy cold river in our bare feet. As I had undiagnosed sickle cell anaemia, contact with the freezing water meant I suffered greatly afterwards and was very ill.'*⁶

Key work in the early years of the Nottingham Sickle Cell and Thalassaemia Service focused on raising awareness about the need to be screened and giving people the opportunity to come forward, generally through self-referral, and be screened in an environment where they felt comfortable. Most importantly, following a positive screening result, access to counselling and ongoing advice and support assisted them to manage their condition effectively, reducing hospitalisation and serious illness.

One woman recalls how she had to take matters into her own hands to insist that doctors found out what was wrong with her son. Her constant trips to her GP

with her baby, who had terrible swollen joints, were in vain. Finally she decided enough was enough and insisted that full tests were carried out on him to find out what was wrong, and at the age of 18 months he was diagnosed with sickle cell. When she found out the diagnosis in 1981, she was faced with an illness that she knew nothing about. There was no one to turn to for help and advice and she embarked on a steep learning curve, finding out all she could about the illness, and swiftly became an authority on the condition. She found that, with nowhere else to turn for support, people often came to her for advice.

*'One day a white woman came to me to ask for help as her husband had just been diagnosed with sickle cell and was very ill. She had never heard of it before and was very worried. Her children were at my son's school and a teacher had told her to come to me for help. I told her all about it and said she must make sure he kept warm.'*⁷

A few days later,

*'Late one night there was a bang on the door. It was the woman. Her husband had been taken into hospital, having a crisis. She came to tell me he had died. She was distraught. I will never forget it.'*⁸

The 1995 Nottingham Sickle Cell and Thalassaemia Service Annual Report stated 'It is the experience of this service that clients with major sickling conditions for whom early diagnoses were made and who received adequate information, counselling and support have a greatly improved standard of life as opposed to clients for whom late diagnoses were made, and who were unaware of the significance

of their condition and were unable to receive the support and counselling provided by the service.'⁹

The importance of early diagnosis is therefore essential and might have saved the life of the man who found out, too late, he had sickle cell. Furthermore, diagnosis backed up with information on the condition is essential.

Someone who later accessed the Nottingham Sickle Cell and Thalassaemia Service reported how in 1995 they were diagnosed with no support or counselling:

*'I was told over the phone that I had sickle cell. No explanation was given and there was no face to face contact. I remember being shocked because I knew nothing about sickle cell disease... I felt let down that I had not been diagnosed as a child and felt extremely fearful as the only previous experience I had was my uncle dying of sickle cell anaemia.'*¹⁰

Similarly, the experience of a man diagnosed outside the framework of the Nottingham Sickle Cell and Thalassaemia Service demonstrates again how, without the provision of counselling and support, people can feel great anxiety. When he was diagnosed by his doctor in Jamaica he was told that he would be 'lucky to see 16'! When he passed this milestone, he was told 'he may live to the age of 21'. The anxiety and stress that this could cause people is immeasurable.¹¹

In contrast, a mother whose child received a diagnosis of sickle cell anaemia through the newborn screening programme and who had follow up contact and

support from trained staff at the Service had the following experience:

*'At times it was overwhelming... The more she thought about it, the more upset she became. Eventually, because of the support she received from the Nottingham Sickle Cell and Thalassaemia Service, she was able to access the information she needed and move on.'*¹²

Similarly another parent remembers,

*'If it wasn't for the enormous help, support and information supplied to us by the Nottingham Sickle Cell & Thalassaemia Service I don't know what would have become of my son and our family. I'm immeasurably grateful for all the help given to us by the counsellors, enabling me to cope in these stressful times.'*¹³

With antenatal screening and newborn screening a new era is now starting in the UK for those affected by sickle cell. No one born in the UK, unless parents have refused screening, should remain undiagnosed. From the outset of their child's life, parents will be given the appropriate advice and counselling by the Nottingham Sickle Cell and Thalassaemia Service to ensure that their child lives as pain-free as possible and achieves their potential. However, with the arrival of people from overseas who may not have been screened or diagnosed in their country of birth, we in Nottingham may still see the occasional case of individuals learning for the first time that they have sickle cell anaemia.

Where carriers for sickle cell have been found in the newborns, the offer of screening to families has later led to the retesting of older siblings who were not

previously thought of as being affected by blood disorders. Parents who had previously been told they were not carriers in Africa have given birth to babies with sickle cell, which has caused disbelief. The frequency with which this occurs demonstrates that the validity of testing methods in Africa may not be robust, or the information has not been explained or understood by the person affected. The Nottingham Sickle Cell and Thalassaemia Service therefore plays an important role in helping families to understand their results and the potential risks in future pregnancies.

*'The official diagnosis in 2006 was extremely shocking for the family given that both parents had tested negative for sickle cell anaemia in Nigeria. They wondered how that could be possible and at first they struggled emotionally. The news had more of an impact on their immediate family as they didn't share it with others until much later and close family members were not in this country. This is when the Nottingham Sickle Cell and Thalassaemia team are really needed. Their input has provided a point of support for the family.'*¹⁴

The Foundation of a Sickle Cell Service in Nottingham

New sickle cell service in city

NOTTINGHAM Health Authority has obtained funding from the Inner Area Programme to start a sickle cell service, and Joy Cummings-Jones has taken up a new post as co-ordinator/counsellor with an office at the Victoria Health Centre.

Joy, a general nurse and midwife, has worked for the past five years as a health visitor in the Sneinton area. For four of those years she has been involved with a local sickle cell group (OSCAR).

Screening

The team consists of Dr Nigel Russell, consultant haematologist at the City Hospital, and Pam Harrop, part-time secretary.

Joy says: "From the first week in May we will be offering screening, counselling, follow-up care and support to all black and mixed race people.

"We will be a resource and information centre and are



● Joy Cummings-Jones

offering in-service training for all staff.

"We envisage working very closely with OSCAR to increase the awareness of this disorder within the black community and society as a whole."

Cutting of the launch of the Service featuring Joy Cummings-Jones - Nottingham Evening Post

Source: Nottingham Sickle Cell and Thalassaemia Service Archives

The move to create a service that would screen and then offer advice and counselling to those affected by sickle cell began to gather pace in the early 1980s. The drive to set up a sickle cell service in Nottingham was led by individuals in the community associated with the charity OSCAR (Organisation for Sickle Cell Research). OSCAR was first set up in the UK in 1974, the first branches appearing in London and Birmingham. The purpose of OSCAR was to raise awareness about sickle cell, push for better medical services and offer social support to those affected by it. The Nottingham branch started in 1983 and over the next few years members of the organisation lobbied for a service offering specialist health care and information so those affected by sickle cell would not have to rely on self-help or the voluntary sector. In 1979 the foundation of a very successful sickle cell service at Willesden Hospital in Brent, where the first specialist sickle cell counsellor was based, led to the call for similar units to be set up across the UK.

During the 1980s many groups were set up in Nottingham with the intention of improving social conditions for those in the black community. These included initiatives like the opening of the Marcus Garvey Centre and the foundation of ACNA and UKAIDI. OSCAR was a vital part of this network of voluntary organisations, whose aim was to improve the health, well-being and socio-economic conditions of those in the black community. Individuals participating in OSCAR at this time were actively seeking a dedicated service to improve access to health provision for those affected by sickle cell disorders. Nottingham was fortunate to have individuals who were prepared to fight for these

services to be set up. These included active members of OSCAR like Chevrolet Davies, Ivy Read and Delores Barnes (to name but a few). Their campaigning helped the community acquire the services that they needed and their contribution must not be forgotten.

At this time, Joy Cummings-Jones was a nurse working on the haematology ward at the hospital in Nottingham. Joy was one of the few nurses who understood sickle cell and showed empathy for those who were affected by it. In 2009, holding the position of Assistant Director for Patient and Public Involvement, and having been awarded the MBE for services to medicine in 2008, Joy looked back to her time working on the wards in the 1980s. She recalled how OSCAR approached her for help in achieving their aims of establishing a service in Nottingham similar to the model of the service that had been set up at Willesden. She remembers how people who had sickle cell felt isolated and how there was a lack of knowledge about the condition among many health professionals, which often meant a delay in appropriate treatment when someone with sickle cell was first admitted to hospital during a crisis.

Joy remembers how Chevrolet Davis in particular was 'a woman with a mission' and rallied other members of OSCAR around her to fight for funding for the services that they needed. So the drive for the establishment of the Nottingham Sickle Cell and Thalassaemia Service was not led by the Health Authority but came rather from the community. Joy was able to put a case forward for initial funding of the service. She was assisted in this by Dr David Curnock, Consultant Paediatrician at Nottingham City Hospital. Having spent some time in Africa as part of his medical training, Dr Curnock was fully

aware of sickle cell disorders and took a special interest in them. His commitment to and interest in sickle cell are fondly remembered by his former patients.

'Dr Curnock has helped me for 18 years of my life and has never let me down. His friendly smile and his many answers to my various questions which were never patronising have been gratefully received. His medical knowledge never ceased to amaze me and through the rough years of my life his determination and his patience were excellent.

*I feel very privileged to have such a great doctor who was able to deal effectively with my sickle cell and refer me to other great doctors to deal with the numerous problems which surfaced during my early teenage years. His familiar face and friendly smile which always greeted me during clinic and ward rounds will never be forgotten.'*¹⁵

David Curnock recalls how Joy persisted in making sure funding was achieved, and eventually, in 1988, a specialist sickle cell service was set up in Nottingham. At first it was a community-based project, with half the funding coming from the Inner Area Programme and the rest from the Health Authority. The Service was the first to be set up in the East Midlands, ahead of Leicester and Derby. Joy was appointed the co-ordinator of the Service and she saw it as her mission to ensure the Service survived and flourished in its early years. By 1991, in recognition of the fact that Nottingham had been identified as having a BME population in excess of 10%, full Health Authority funding was secured for the Service, as, according to the World Health Organisation guidelines, an appropriate service was needed for a community of that size.¹⁶



Staff working with Nottingham Sickle Cell and Thalassaemia Service 1993-1994. Back row from left: Stephanie Johnstone, David Walker, David Curnock, Tony Walker, Shila Bhambra. Front row from left: Gemma Bailey, Jennifer Clarke, Becky Stone, Marie Donohue

Source: Nottinghamshire Sickle Cell and Thalassaemia Service

Initial Aims of the Service

Joy set up the Service from scratch, with the office being based at the Victoria Health Centre on Glasshouse Street, a good central location in Nottingham near the Victoria Shopping Centre. The initial aims of the Service were:

1. to provide a screening and counselling service for those in the community affected by sickle cell, including carriers
2. to give advice, support and education to those who are affected by sickle cell anaemia
3. to provide information on sickle cell and other related blood conditions to the community and health professionals
4. to form a link with other centres and voluntary organisations nationwide involved in working with sickle cell anaemia.

In the early months of setting up the Service the priority was to publicise it to people in the at-risk groups and to health professionals. The Service wrote to various community groups in Nottingham, other health organisations and key health workers in order to raise awareness of its existence and the services it provided. Joy also contacted other sickle cell centres that were already operating in the UK at the time, visiting Brent and Birmingham to learn about best practice.

She contacted local radio stations and newspapers to raise public awareness, and began to develop information and publicity leaflets and posters for the Service. She designed an information display that

was set up in the hospital outpatients department and in libraries across the Nottingham area. The increasing number of enquiries from the public in the first year of the Service meant that the initial information leaflets and counselling packs were reviewed and improved as a better understanding was reached of what service users might require.

In addition to her work on raising awareness, the main bulk of her work was spent running a drop-in screening clinic and offering follow-up counselling where appropriate through an appointment system. Support work involving home and hospital visits to those who had been diagnosed with sickle cell was necessary, as well as spending time liaising with OSCAR. Joy also worked to establish a network of consultants at the Nottingham hospitals who had an

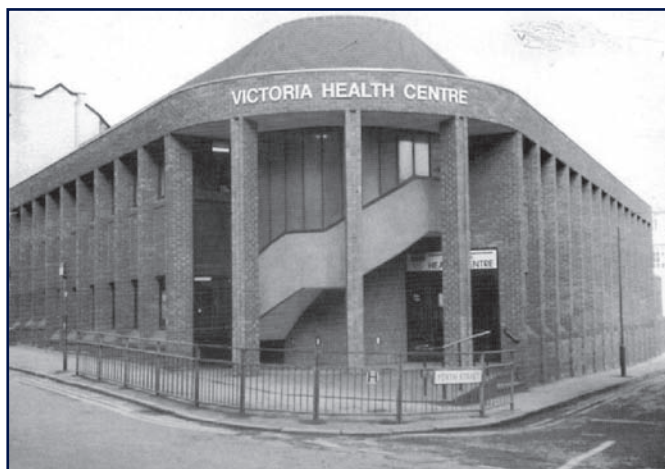
interest in sickle cell so that clients could be directed towards them. It was a busy time for her, as she worked hard to raise the profile of the Service and establish operating procedures for the new service, with just the assistance of one part-time administrator and no other nursing staff.

Within six months of setting up the Service, Joy's energy and her determination to make the Service a success were paying off. From setting up the first screening clinic at the Victoria Health Centre in August 1988, in eight months over 300 people were screened for sickle cell. Out of these initial screening sessions, a relatively high number of people were discovered to have sickle cell anaemia or to be carrying the gene, demonstrating how many people had been living in ignorance of their condition (Table Three).

Table Three: Results from initial Sickle Cell Screening Clinic held in Nottingham August 1988 – March 1989.¹⁷

Common HB	156	50% of those screened were normal
HB AS	86	
HB AC	15	
Beta Thal	22	
Other traits	11	43% of those screened were carriers
Affected	17	5% were affected
Awaiting results	5	2% awaited results
Total screened:	312	

The clinics initially demonstrated that among those coming forward to be tested there was a high percentage of carriers, and the percentage testing positive for sickle cell itself well exceeded the population norm. This was probably because at this time there were still many individuals who had lived undiagnosed with sickle cell well into adulthood.



Victoria Health Centre Clinic 1993

Source: Nottingham Sickle Cell and Thalassaemia Service

One woman, now in her sixties, came to the Victoria Health Centre clinic in the late 1980s and tested positive for sickle cell anaemia. For many years, following earlier testing, she had been told she was a carrier, yet, as a trained nurse, she knew she periodically displayed many of the symptoms. It was her concern about this that took her to Joy's clinic at the Victoria Health Centre, where she was finally tested, her results showing that she did indeed have sickle cell anaemia. Years of misdiagnosis were at an end. Over twenty years later she still recalls how important it was to be able to access the Service and

to find a sympathetic and approachable member of staff:

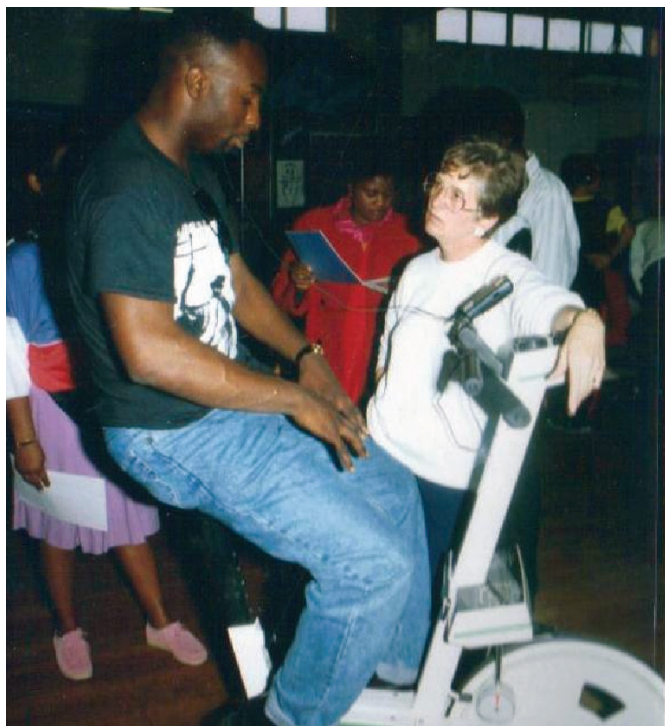
*'I was able to talk to Joy. I felt comfortable with her and was able to ask questions about my condition.'*¹⁸

Her experience demonstrates how important the provision of the Service was in diagnosing the condition and then supporting the client through specialised counselling.

The Service also recognised that clients could benefit from interacting with each other through the process of mutual support. Therefore a support group for parents of children with sickle cell was set up in the summer of 1990. This gave parents the opportunity to voice their opinions and feelings to the professionals within a safe, supportive environment.

Satisfaction with the Service among clients was a key factor in bringing more and more people through the doors of the Victoria Health Centre clinic to be screened. In these early days, during the first year of operation 1988-1989, over 50 per cent of clients came to the Service after being told about it through word of mouth. Between January and August 1989 uptake of the service rose by 300 per cent and this was helped by holding community events like the 'Sickle MOT' to raise awareness of the Service. Held in various venues in Nottingham it used the car as an analogy in an endeavour to raise interest in good human body maintenance and positive health attitudes. It aimed to make the public who attended the event 'Sickle Wise' – and as well as offering checks on health issues like blood pressure, lung function and eyes it offered screening for sickle cell. At one event held in Hyson Green, Nottingham,

nineteen new clients were identified following screening, demonstrating that in the late 1980s people living with undiagnosed sickle cell were not unusual and that the Nottingham Sickle Cell and Thalassaemia Service was invaluable to them.¹⁹



Nottingham Sickle Cell MOT 1989

Source: Nottingham Sickle Cell and Thalassaemia Service

In the second year of the Service, a staggering figure of approximately 50 per cent of all screenings carried out were on people who were over the age of 15. Screenings in the over-25 age group far exceeded the 0-5 age group, perhaps demonstrating how many young people and adults were previously

unaware of the importance of screening. It was noticeable that the majority of people coming to the Service for screening were women, with a low uptake in males in the 16-25 age group. Approximately one third of males were screened compared to two thirds of females in the same age group. In the following year focused efforts were made to increase this. Frank Bruno, the boxer, was invited to try and raise awareness of the importance of screening. Events were held in sports centres around Nottingham but despite these measures there was no improvement in uptake of screening in this category, and over the next few years getting information through to this age group of men continued to be a priority for the Service.



Frank's a hit at clinic

HEAVYWEIGHT personality Frank Bruno dropped in on Nottingham's Victoria Health Centre to help celebrate a special day.

He visited the sickle cell and Thalassaemia clinic which screened its 1,000th customer — 18-year-old Andrew Pearson from Sherwood.

Andrew received a special certi-

ficate signed by Frank, who has been starring in *Aladdin* at Nottingham's Theatre Royal. Frank said he hoped other young people would come forward to be screened.

Frank and Andrew are seen here with a birthday cake to mark the occasion.

Sickle cell disease mainly affects people of Afro-Caribbean, Asian and

Latin American origin. It is a hereditary condition which attacks the red blood cells making them weaker and prone to infection.

The special clinic aims to identify both carriers and sufferers through its voluntary screening programme. Of the 1,000 people who have so far been screened, 250 have been identified as carriers or sufferers.

Celebrity boxer Frank Bruno helps raise awareness of the importance of sickle cell screening in young men - Nottingham Evening Post

Source: Nottingham Sickle Cell and Thalassaemia Service

The Service expands to cover Thalassaemia

By the end of 1990, two years after being set up, the Service was firmly established and a full-time clinic at the Victoria Health Centre was available for screening and counselling, operating one day a week as a drop-in clinic. Two years after opening, 889 people had been tested by the Service. Analysis of the figures demonstrated that 66% were from the African-Caribbean community. The high percentage of people from the African-Caribbean community reflected the fact that the Service's remit was to undertake education and awareness-raising activities in relation to sickle cell, and did not yet include thalassaemia. In the second year of operation the Sickle Cell Service therefore expanded into screening and counselling for thalassaemia and so became named the Nottingham Sickle Cell and Thalassaemia Service.

There was a low uptake in the population which may be affected by thalassaemia, and this was addressed in 1990 by securing funding to employ a part-time Asian counsellor, who had previously worked as a health visitor. Her main, but not exclusive, role was to work with the population at risk of being affected by thalassaemia, and their carers. The Service then did ground-breaking work raising awareness among the communities that were at risk, visiting Asian, Italian and Cypriot community centres, mosques and temples, as well as targeting professionals such as health workers, social workers and link workers.

Due to the stigma which surrounded those affected by thalassaemia, a 'cautiously sensitive approach' was taken by the Service in their awareness-raising

campaign.²⁰ In recognition of this, Joy worked in liaison with the local Asian Women's Project to establish how best to educate people about the importance of undertaking thalassaemia screening. It was also important to raise awareness about thalassaemia, both because many people, although at risk, were unaware of it, and because of the stigma associated with the condition. In support of this work, counselling packs on thalassaemia were introduced and translated into different Asian languages.



Improving communication with the hospital

In 1991 Joy Cummings left the Service, having successfully established it and having secured on-going funding. The new co-ordinator, Gemma Bailey, had previously worked as a health visitor and had developed an interest in sickle cell whilst working as a midwife at Greenwich District Hospital in 1985-1986 where she had undertaken research into the need for a sickle cell service in the area.

Gemma was an inspired service manager; she intensified the campaign for raising awareness about sickle cell and thalassaemia particularly within the hospitals among health professionals. Courses were designed for multi-disciplinary medical/nursing hospital and community staff. These were later developed in 1995 in partnership with the QMC, the City Hospital and OSCAR into the first ENB (English Nursing Board) course in Care & Management of Adults and Children with Sickle Cell/Thalassaemia and related disorders. It was the first course of its kind to run outside London, and involved a current member of the Nottingham Sickle Cell and Thalassaemia Service staff, Christobel Pinto. Later Gemma won a Guinness Travel Fellowship Award to visit the world-renowned Medical Research Council Laboratories on sickle cell in Jamaica, allowing her to study best practice and take back ideas to Nottingham to implement at the Nottingham Sickle Cell and Thalassaemia Service.



Gemma Bailey

Source: Nottingham Sickle Cell and Thalassaemia Service

By 1992 both the City Hospital and the QMC (Queen's Medical Centre) were running successful monthly clinics specifically for patients with sickle cell or thalassaemia with a counsellor from the Service in attendance. This meant a more 'holistic' framework of care was offered to service users, and communication between the Hospital and the Service improved. Under Gemma's management the Service worked to establish named key workers on the wards who had an understanding of haemoglobinopathy disorders and who took responsibility for ensuring that other members of staff were well informed.

Lack of knowledge about sickle cell among medical staff which led to delayed or inappropriate treatment was recognised as a key issue which needed to be solved. One of the nurses, Denise Crouch, who was appointed to be one of the first named key workers in 1992, recalls:

'Working on an acute medical ward specialising in haematology, I realised I knew very little about

sickle cell and thalassaemia. After talking to several of my fellow colleagues I realised their knowledge was also very limited. I decided to educate myself to increase my knowledge of haemoglobinopathy disorders and gain a greater understanding of the problems experienced by clients with these conditions. I undertook a health studies assignment on sickle cell disease and became a link nurse.²¹

The QMC developed an open door policy for all adult clients, allowing them direct access to the ward and immediate commencement of care and management. Standards were also written to determine the care of those affected by sickle cell and thalassaemia disorders. Then, in 1995, in conjunction with the Leicester Sickle Cell and Thalassaemia Service, the Service developed client-held records for which they subsequently won a Queen's Nursing Initiative Innovation Award. It was hoped that giving clients their records would mean that if they were admitted to hospital they would be able to produce their own notes. This would enable health workers and professionals to provide prompt, individualised, essential emergency treatment and produce continuity of care.

Part of the purpose of client-held records was to ensure that clients were admitted straight to the hospital ward, hence avoiding lengthy waits in the Accident and Emergency department. However, an involvement day in 2009 for people who use the Nottingham Sickle Cell and Thalassaemia Service highlighted that there was still a problem with immediate access to medical treatment, with people often being taken to Accident and Emergency initially instead of being taken straight to wards to commence treatment.²² In 2010 the Nottingham

Sickle Cell and Thalassaemia Service started work on developing a more effective version of these client-held notes as a universal measure across the region. This will help people to manage their health and will act as a record of their health care which can be shared with any health professional they meet.

By 1994, Peter Roberts, Director of Primary Care Services for Nottingham NHS Trust, stated that 'within the East Midlands, the Nottingham Sickle Cell and Thalassaemia Service is now known as the most well established unit, providing efficient care for those at risk or affected by haemoglobinopathy disorders'. The Service then reached out to those affected by these disorders beyond the Nottingham City boundary as it cared for clients from across Nottinghamshire, Leicestershire and Lincolnshire. It assisted in setting up a similar service in Derby and advised the Health Authority in Sheffield.

The Nottingham Sickle Cell and Thalassaemia Service therefore played an important role in educating and raising awareness about sickle cell and thalassaemia in the East Midlands, and Gemma's drive and determination to develop the Service was a key factor in its development. The Service has developed Counselling Packs that colleagues across the UK have purchased as a recognised teaching tool. In partnership with OSCAR, the Service has also produced an information film about sickle cell anaemia.

The Annual Report in 1995 suggested that media interest coupled with the Service's own on-going educational programme was so effective at raising awareness of the importance of screening that the service became a victim of its own success, screening or counselling 639 clients in the period which ran



from April 1994 to March 1995, compared to 319 seen in the same period three years earlier.

An example of this was the 'Teenage Workshop' held in September 1995 which was aimed at young adults with sickle cell and thalassaemia. A total of 90 people from Nottingham and Leicester attended. Outreach work like this meant that the Service had an ever increasing workload with limited staff and resources, and this was addressed in 1995 when the Service obtained further administrative support and the part-time counsellor was employed on a full-time basis.²⁴

Over the next couple of years the Service focused on raising awareness of thalassaemia. This followed moves by the UK Thalassaemia Society, which launched a national awareness campaign after a survey discovered that only 5 per cent of the at-risk population had heard of thalassaemia. The continued awareness-raising campaigns for sickle cell and thalassaemia resulted in a total of 792 clients being seen by the Service in 1997-1998.²⁵

Important medical advances in the mid nineties would revolutionise the treatment of people with sickle cell and thalassaemia. The introduction of hydroxycarbamide for sickle cell anaemia was a major step forward in treating clients and helping them to prevent painful crises occurring. Similarly the development of the Baxter Infusor for Dexferrioxamine injections and Clinipur needles became available for use, to aid the thalassaemic patient in the administration of Desferal, a life-saving drug to prevent iron overload.

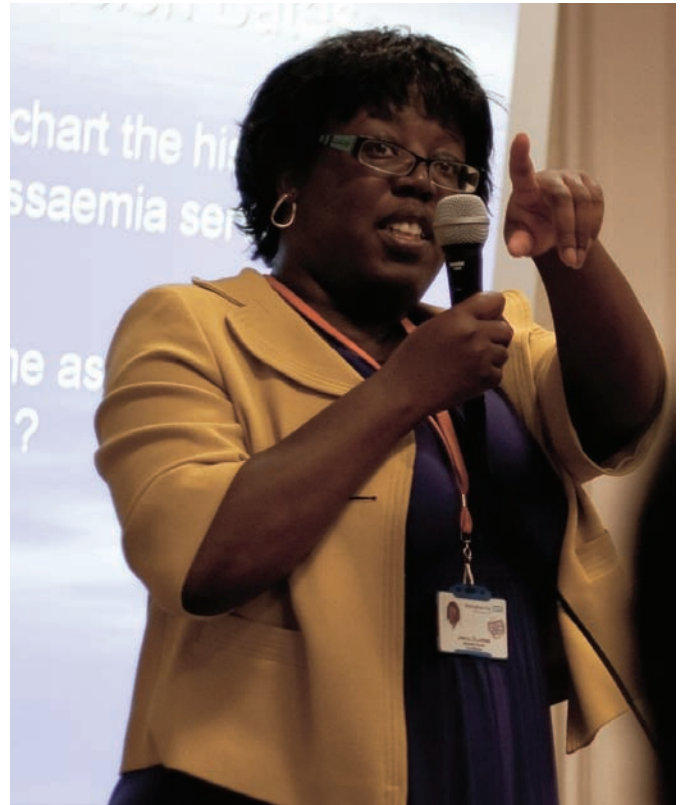
In 2000 Gemma Bailey left the Service. Over the next couple of years it proved difficult to find a suitable replacement, and consequently the Service experienced a setback during this time as it operated at a much reduced level and the development of awareness-raising measures was frozen.

Section 3: Past Achievements

In 2002 Joanne Bloomfield was recruited as the new Manager for the Service. Joanne had previously worked as a health visitor in Derby. Her interest in sickle cell arose from when she was training to become a children's nurse in Sheffield and working as a student health visitor in Leeds. She also remembers hearing about someone in her home town of Chesterfield with sickle cell. Her first contact with a patient with sickle cell was at the Queen's Medical Centre where the patient was in overwhelming pain. It was frightening to see what he and his wife were going through.

Her arrival at the Service provided an opportunity to revitalise it and give it a new direction. It was a new opportunity and a very steep learning curve as initially she knew very little about sickle cell. Joanne rose to the challenge, and now, as well as the overall management, her role also includes being the Lead Specialist Nurse. As the most senior nurse in this specialism in Nottingham and in the East Midlands region she has expert knowledge and experience in all aspects of sickle cell and thalassaemia.

When Joanne first started work with the Service it had approximately 80 clients. In 1996 a study was carried out which estimated there were about 85 people living with sickle cell and thalassaemia in the Nottingham Health District.²⁶ In 2010 there were 133 people registered with the Service.



Joanne Bloomfield, current Service Manager

Source: Bright Ideas Nottingham

In 2002 she was supported by Nottingham City PCT to study for a Masters degree in Multicultural Issues in Health and Social Care. Her dissertation was on the experiences of mothers whose children were found to be carriers for sickle cell by the Newborn Screening Programme. She was aware that prior to the introduction of the universal newborn screening programme there was a lack of attendance at follow-up appointments by carriers identified in the previous screening programme, where babies were screened

according to the ethnicity of their parents. She felt that it was important that health professionals were proactive in ensuring parents got the information and knew what the implications were for the future. As a result of this research she designed patient information on sickle cell and a pathway to ensure the prompt communication of information to all parents.

In 2004 she was awarded a travel scholarship to visit the Children's Hospital of Philadelphia. This hospital sees about 600 children with sickle cell anaemia within the specialist centre which is headed by Dr Kwaku Ohene-Frempong. During her time in the USA, Joanne also attended a three-day sickle cell conference in Baltimore. Her experience in the States highlighted the advantages that people with sickle cell have here in the UK. They are as follows:

- Health care is free at the point of need.
- Patients can be tracked when they move to a different area.
- Partnership working with acute and primary care

Her achievements to date include:

- partnership working with Kemet radio to raise awareness of sickle cell
- raising the profile of sickle cell and the Nottingham Sickle Cell and Thalassaemia Service, which has encouraged members of the community to raise money for the sickle cell charitable fund
- leading on the development of Transcranial Doppler Screening information for parents
- leading on new service developments to transform the way in which the Service engages and involves the people who use it

- successfully securing funding for additional staffing, which has significantly enlarged the team.
- presenting a paper written by herself and Lisa Robinson (Director of Bright Ideas), '*An Evaluation of the Sickle Cell and Thalassaemia Service Using Patient Narratives*' at an international conference.

Working for the Service has given her the opportunity to put her twenty-five years of experience in the NHS into improving the health needs of people from Black and Asian groups and from the wider community. She feels that the Service is a good example of how the staff team reflects the client group and community it serves. The aims of the Service in 2010 have changed little since it started in 1988.

The staff still focus on the core values of offering patient-centred care, concentrating on case management, genetic counselling, health promotion, training and education. It is an integrated service, with service users coming from all age groups, from new-born babies to older adults.

There are several key policy documents which influence the continual improvement of the Service today:

- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK, 2008
- Standards for the Linked Antenatal and Newborn Screening Programme, 2006
- Standards for the Care and Management of Children and Adults with Thalassaemia, 2008.

The staff are one of the key strengths of the Service. Additional funding in 2008 meant that two full-time nurses could be recruited, so there is now a named nurse for both children and adults. The current staff structure is as follows:

- Joanne Bloomfield
Lead Specialist Nurse and Manager
- Beryl Douglas-Green
Specialist Nurse (Adults)
- Christobel Pinto
Specialist Nurse (Children)
- Adewumi Ajayi
Specialist Nurse (Children)
- Manju Manson
Clerical Assistant

All the staff are dedicated to their work and the majority have long-established links with people who use the Service. Both Beryl Douglas-Green and Christobel Pinto have worked in the field of sickle cell and thalassaemia for many years, Beryl having worked as a Specialist Nurse for the Service prior to Joanne's appointment and Christobel having taught on the sickle cell and thalassaemia course that was set up in the mid nineties at the Queen's Medical Centre. Christobel is the longest-serving member of staff, having served continuously since 2001. The newest member of staff, Adewumi Ajayi, has been with the Service since December 2008 and works with children. She brings a special understanding to the post as she has members of her family who are affected by sickle cell.



Members of staff Manju Manson and Christobel Pinto
Source: Nottingham Sickle Cell and Thalassaemia Service

Male counsellor

The Service has an all-female team, and they have recognised that boys and men may be more comfortable if they have access to a male specialist nurse to discuss specific health issues. It was therefore decided to hold a one-off special clinic at the Mary Potter Centre in December 2008, with more planned for the future.

Hospital links

In 2010 the Nottingham Sickle Cell and Thalassaemia Service continues to have excellent links with the hospital. Adult service users see Dr Marie Donohue at the adult clinic in the Centre for Clinical Haematology at the City Hospital. She is also present at the paediatric clinics to provide continuity for young people when they transfer to adult care. Dr Forman sees the children and is based at the Queen's Medical Centre. Both consultants have cared for this client group consistently for several years now, Dr Donohue having started in 1994. Again, this is a strength within Nottingham, enabling acute services to build up strong links with the Service and the people who use it. The hospital consultants were praised in the external Service Evaluation Review recently undertaken by Bright Ideas Nottingham.

Mary Potter Centre

In June 2008 the Service moved into the newly opened Mary Potter Centre in Hyson Green after being located in the Mary Potter Hostel. It is housed in a purpose-built complex with other services from the NHS, Nottingham City Council and Nottingham Housing.

One of the strengths of the Service is its location in the heart of the community; this is also true of the Leicester Sickle Cell and Thalassaemia Service. The Service in Derby, while offering a clinic once a week in the community, is located in the hospital, making it more difficult to find and to access.

Universal Newborn Screening Programme

One of the most important events to affect the Service was the introduction in 2004 of universal newborn screening. Prior to this, newborn screening was only offered on the basis of the ethnic origin of parents; many children missed out on this and consequently they were often not diagnosed until they were older. A midwife recalls what newborn screening was like when she worked at the City Hospital in 1999:

*'It was quite hit and miss. Not all babies were tested that should have been...there wasn't really a routine system in place and they often slipped through the net.'*²⁷

The 2007/2008 national screening results were published in November 2009 and demonstrated that '359 babies were identified with screen positive

results for a clinically significant condition in 2007/08, suggesting that overall, sickle cell disease is more common than cystic fibrosis in England'.²⁸

In Nottingham, it is the Nottingham Sickle Cell and Thalassaemia Service that follows up newborn babies who have been identified as carriers by the Newborn Screening Programme, within twelve weeks of birth. When a child is born in Nottingham and has sickle cell anaemia the parents are contacted within six weeks of birth. All parents are contacted individually and given relevant information and offered on-going support.

The majority of families seek advice and guidance on what having the condition entails and the Service is able to fulfill this need. The Nottingham Sickle Cell and Thalassaemia Service can effectively offer the family expert advice, answer their questions and settle their minds. In many areas in the UK there is no specialist Sickle Cell and Thalassaemia Service, and a health visitor who may have no specialist knowledge of haemoglobinopathies will perform this role.

Support Group

Since the Service began in 1988 several attempts have been made to set up and maintain a support group for those accessing the Service. In the past this type of support has been facilitated by OSCAR; however, the change in the activity of OSCAR in recent years has meant that it may now be more appropriate for this to be organised by the Nottingham Sickle Cell and Thalassaemia Service. The recent evaluation exercise discovered this was something that people would appreciate. The Service is currently

considering how best to facilitate a support group, with the intention that it should be led by someone who uses the Service.

Drop-in clinic

In an effort to improve access to the Service a drop-in clinic was introduced in January 2009. This is a dedicated clinic which is held every Thursday from 2 to 4 pm for the regular clients of the Service, people who carry the sickle cell or thalassaemia gene and people who visit as a result of a GP referral. However, in reality, no one is ever turned away if they call in to the Mary Potter Centre at any other time, provided staff are available.

More than just health advice – social welfare

The Service has always complemented OSCAR in providing social support, dealing with people's enquiries regarding housing, heating allowances and grants, and providing information about Disability Living Allowance. Both services endeavour to point people in the right direction, and where necessary write letters of support to the appropriate authorities to enable clients to gain the benefits and extended social support that they need.

Furthermore, one of the important roles that the specialist nurses carry out is to visit the school of any child with sickle cell and explain to the teaching staff what the condition means and what measures need to be taken by the school in order to ensure the child's health and safety during school time. This is greatly appreciated by parents and schools alike.

National and regional networking

The Service Manager, Joanne Bloomfield, is a member of the East Midlands Sickle Cell and Thalassaemia Network. This is a group of health professionals working within the East Midlands region to improve the quality of care for patients. During its first year it funded a nursing post at City Hospital for adults and Transcranial Doppler screening for all children. This is a simple scan which identifies children who are more at risk of having a stroke.

Service supporters

Since Joanne became Manager the Service has been involved in far more activities aimed at raising awareness. All the staff are involved in attending events and doing outreach work. The staff also involve themselves in the charity fund-raising events by attending and supporting them. The charity events are snowballing. Some people are now doing events on a regular basis. The profile of the Nottingham Sickle Cell and Thalassaemia Service has also been raised through community awareness campaigns.



Charity Event supporting sickle cell

Source: Nottingham Sickle Cell and Thalassaemia Service

During Sickle Cell Awareness Month the Service works with Nottingham radio station 97.5 Kemet FM. They have been successful in encouraging people to talk about living with sickle cell. It was following an interview with one of the people who use the Service that Kemet DJs Bertie B and Smiler organised a 24-hour stay-awake event on the station and raised £600. The knock-on effect has been that community groups are now approaching the Nottingham Sickle Cell and Thalassaemia Service asking them how they can get involved and participate in raising awareness about sickle cell and thalassaemia and raising money for the sickle cell charity. For example, during 2009 a number of organisations and businesses got involved in fund-raising and awareness-raising, including Long Eaton Windrush Association, Pro-active Arts and Jamaican Ways.

Long Eaton Windrush Association

In 2009 Maxine Daniel organised an event for the Long Eaton Windrush Generation Association which was attended by about 140 people. The main purpose of the event was to act as a reunion and bring the community together but it was also used as an opportunity to raise awareness of certain illnesses and conditions which affect the African-Caribbean community, like sickle cell.

They chose to focus on sickle cell as they felt they needed to do more to raise awareness among the younger generation who may not know that they may possibly be carriers. They also thought that the NHS needs to do more to address this area through research, as it has just as high a profile as cancer in the black communities. Joanne Bloomfield attended the event and talked about sickle cell so that all

questions and concerns could be answered. The event raised £300 for the sickle cell charitable fund.

Pro-active Arts

Orlando Thomas runs Pro-active Arts, which specialises in video and music production and performance. He is involved in youth work, particularly working with young offenders in the community. During Black History Month in 2009 Pro-active Arts organised an event at the New Arts Exchange in Hyson Green, Nottingham, called Jammin', which included musical performance and free food. Part of the event involved Joanne Bloomfield holding a question and answer session about sickle cell. Ninety people attended and over £300 was raised for the sickle cell charity.

Orlando wanted to organise an event that not only raised money for sickle cell but acted as a platform for raising awareness about sickle cell, in recognition of how many people in the community are affected, including people who carry the gene.

Jamaican Ways

Richard Newland runs Jamaican Ways, a café in Radford. Richard has known quite a few people who have been affected by sickle cell. He has witnessed just how much pain people can be in during a crisis and how the effects of that alone can be devastating. He acknowledges that there is always the possibility that in the future some of his descendants may be born with the condition, and that makes him all the more determined to get involved in fundraising for the Sickle Cell Charitable Trust.

In 2008 he organised an event in conjunction with Bensons Brasserie, Nottingham, to raise money for the Sickle Cell Charitable Fund, and hopes to plan more events in the future.

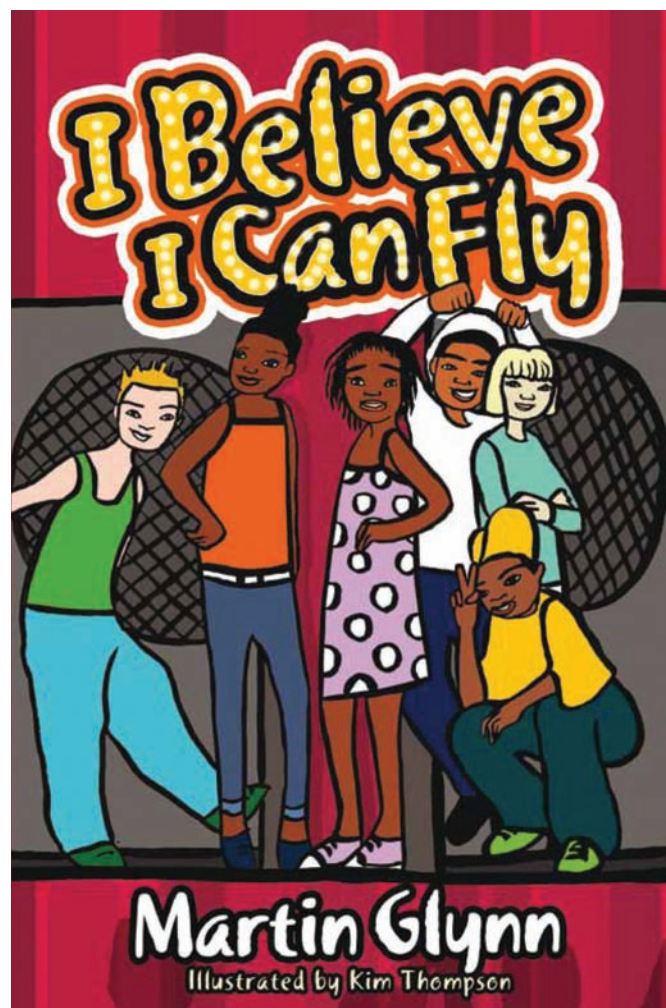
He became involved in fund-raising because he wanted to make a difference. He feels strongly that more research is needed into finding a cure for sickle cell, and believes it is important that more people in the black community become involved in fund-raising. He also believes that more work is needed in helping to raise awareness about sickle cell.

Education

All parents receive a book on the care and management of children with sickle cell. This helps them to understand how to keep their children as well as possible. The Nottingham Sickle Cell and Thalassaemia Service is currently working with Bright Ideas Nottingham and local school children to write and publish a children's book. *I Believe I Can Fly* will be placed in local primary and secondary schools and will aim to raise awareness of the condition and consequently reduce stigma. It will also help children with sickle cell to have a positive outlook on life and realise that they can achieve their goals.

Writing the children's book was one of several public and patient engagement and involvement activities organised by Bright Ideas in partnership with the Service. In July 2009 a special event, again entitled '*I Believe I Can Fly*', was organised to celebrate the achievements of the Service. Over seventy people who access the Service came together to hear inspirational speakers and were given the chance to

voice their opinions on what they wanted to see from their Service in the future and what improvements they thought could be made at the hospitals to improve their care. A report about the event is available.



Section 4: The Future

Since beginning in 1988 the Nottingham Sickle Cell and Thalassaemia Service has developed into an excellent service which is highly regarded and valued by the people who use it. In outstanding modern premises, with dedicated staff and fantastic links with the local hospitals, the Nottingham Sickle Cell and Thalassaemia Service is in a strong position to move forward into 2011 and beyond, continuing its important work in screening, counselling and generally supporting the people who need it.

Appendix 1

About Sickle Cell

Sickle cell anaemia is a genetic condition which affects the red blood cells. Normally, red blood cells carry oxygen from the lungs to the rest of the body. The cells are round and flexible, allowing them to move easily around the body. However, in people with sickle cell anaemia, the shape and texture of the blood cells can change. They become hard and sticky and are shaped like sickles, or crescents. The cells die prematurely, leading to a shortage of red blood cells. This causes the symptoms of anaemia, such as tiredness and breathlessness.

The blood cells can become trapped when moving through small blood vessels, stopping the supply of oxygen to parts of the body. This is known as a 'crisis'. This causes pain and tissue damage, and can lead to other serious complications, such as a stroke, or blindness. There is no cure for sickle cell. The focus is on health promotion, education and self-management.

The disorder was first discovered in Chicago in 1904 when the American doctor James B Herrick began treating Walter Clement Noel, a dental student from Grenada. When Herrick analysed his blood he found that rather than the normal round red blood cells his patient actually had a number of curved and elongated cells that resembled the shape of a sickle. He published his work in 1910 and was the first person to recognise the disease which he termed 'sickle cell anaemia'. 2010 therefore marks the centenary of the year when sickle cell became known to the medical world and beyond.

Sickle cell most likely originated in what is now Saudi Arabia, subsequently spreading into India and Africa. The sickle cell gene offers protection against certain types of malaria and it is thought that the gene arose as a defence mechanism. Later, due to the slave trade, the gene spread to areas not normally affected by malaria, such as South America, the Caribbean, the United States and Europe.

The level of risk of being a 'carrier' of the sickle cell gene	The level of risk of being a 'carrier' of Beta Thalassaemia
West Africa - 1 in 4 people	Pakistan - 1 in 20 people
African-Caribbean - 1 in 10 people	England - 1 in 1000 people
Mixed ancestry – 1 in 10 to 1 in 1000	African/African-Caribbean – 1 in 50

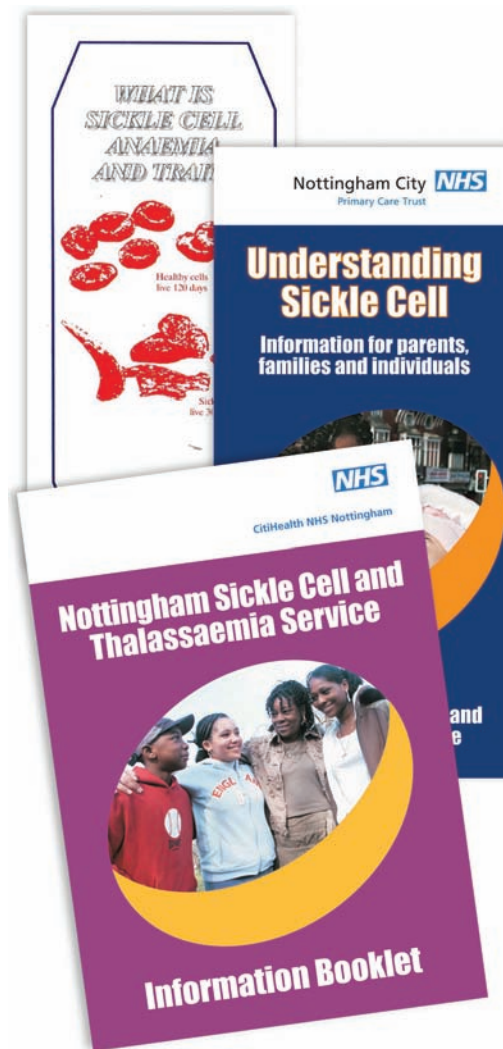
People who are of Black African, Black British or Caribbean ancestry are most likely to be at risk. However, those from India, the Middle East and parts of the Mediterranean can also be affected. Globally, around one in 20 people carry the sickle cell gene.

Between 12,000 and 13,000 people in the UK are estimated to have sickle cell anaemia. There is no register of those affected, and this figure is based on the national figure for annual hospitalisations of people with sickle cell. The new national haemoglobinopathy register (NHR) collects data on patients who have sickle cell and thalassaemia. The aim of this register is to improve services and direct resources to where the patients are. This will improve the care that patients receive. It will help with the planning of health care, finding out the number of people who have sickle cell or thalassaemia, and research into improving treatment.

About Thalassaemia

Thalassaemia is the name given to a group of inherited blood disorders that affect the body's ability to create red blood cells and so carry oxygen from the lungs to the rest of the body. It is a relatively rare disorder and those affected require regular blood transfusions. The most serious types of thalassaemia can cause other complications including organ damage, restricted growth, liver disease and heart failure, and death. Beta thalassaemia is the most common and most severe form of the condition in the UK. While alpha thalassaemia can be found in the UK, particularly among people of South Asian and South-East Asian descent, it is typically the mildest form of the condition. It is estimated that between 700 and 800 people have thalassaemia in the UK

but again no exact figure is known because there are no centrally collected figures.



*Sickle Cell information leaflets, then and now, depicting the contrast between healthy cells and sickle cells
Source: Nottingham Sickle Cell and Thalassaemia Service*

Appendix 2

A NOTTINGHAM SICKLE CELL AND THALASSAEMIA SERVICE TIMELINE

- 1910** Dr James B Herrick publishes his paper giving the medical world the first formal description of sickle cell anaemia when he reports that the blood smear of a dental student at the Chicago College of Dental Surgery contains "pear-shaped and elongated forms"
- 1974** OSCAR is set up in London.
- 1979** Brent Sickle Cell Service opens in London.
- 1983** OSCAR Nottingham Branch opens and starts campaign for dedicated clinical service.
- 1988** Nottingham Sickle Cell Service opens. Joy Cummings-Jones is recruited as the Manager.
- 1990** Service expands to become Nottingham Sickle Cell and Thalassaemia Service. Full-time clinic now available at Victoria Health Centre.
- 1991** Joy Cummings-Jones leaves Service. Gemma Bailey replaces her. Client-held notes introduced. Nottingham now has 'at risk' BME population in excess of 10%. Full funding for Service granted by Health Authority.
- 1992** Both QMC and City Hospital are running monthly sickle cell and thalassaemia clinics attended by Nottingham Sickle Cell and Thalassaemia Service staff. Link nurses are appointed on wards to raise awareness of the condition among other nursing staff.
- 1995** English Nursing Board course on sickle cell is developed in conjunction with QMC and Nottingham Sickle Cell and Thalassaemia Service. Nottingham Sickle Cell and Thalassaemia Service and Leicester Sickle Cell and Thalassaemia Service win a Queen's Initiative Innovation Award for client-held records.
- 2000** Gemma Bailey leaves Service.
- 2002** Joanne Bloomfield becomes new Service Manager.
- 2004** Universal Newborn Screening Programme commences in England. Joanne is awarded a travel scholarship to Children's Hospital in Philadelphia.

2008

Key NHS policies introduced:

- Standards for the Clinical Care of Adults with Sickle Cell in the UK
- Standards for the Linked Antenatal and Newborn Screening Programme
- Standards for the Care and Management of Children and Adults with Thalassaemia

Service moves to Mary Potter Centre.

Service recruits two additional full-time staff.

2009

Sickle Cell is recognised as 'clinically significant condition and more common than cystic fibrosis in England'.

External Service evaluation and review and engagement event under the title of 'I Believe I Can Fly' are undertaken by Bright Ideas Nottingham.

Drop-in clinic at Mary Potter Centre.

2010

Children's book I Believe I Can Fly is written, focusing on the experience of a child with sickle cell and based on patients' experiences.

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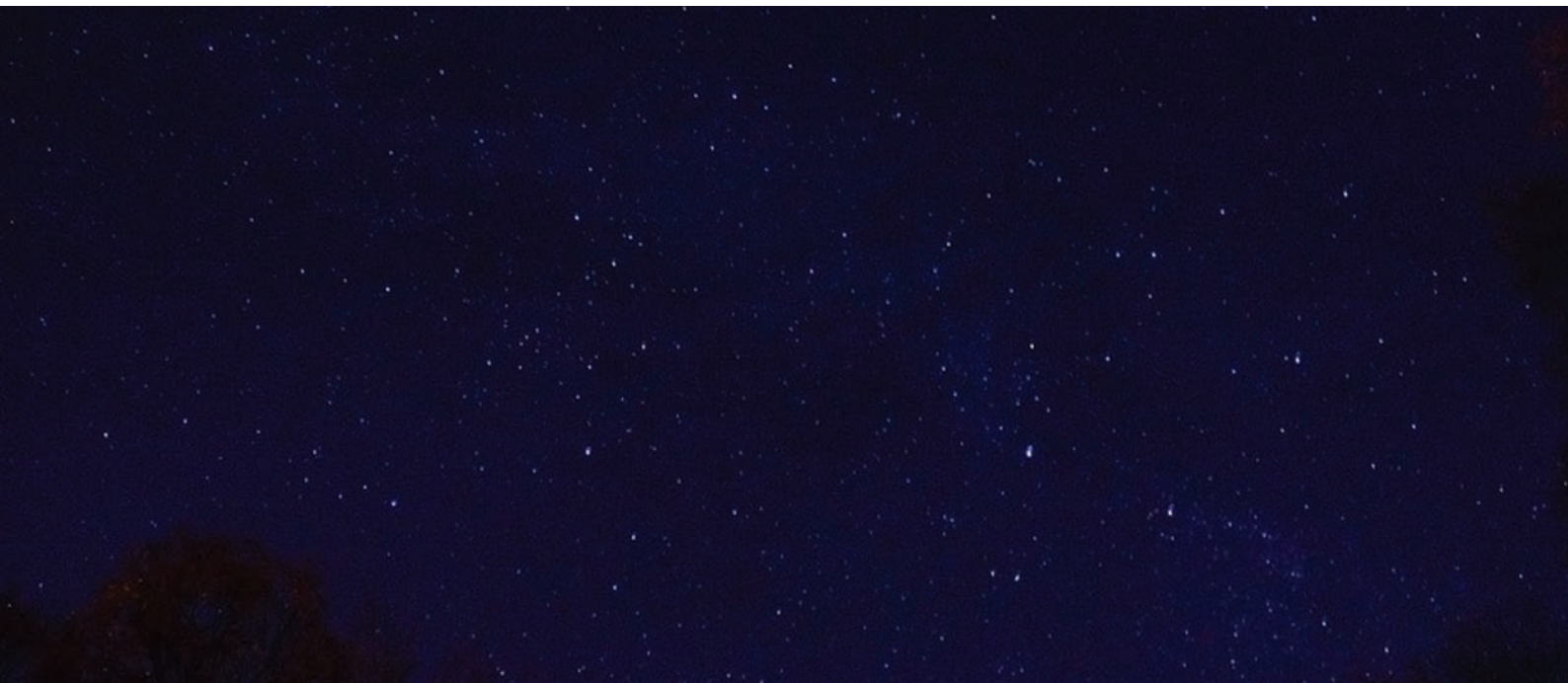
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