



**Organisation for Sickle Cell Anaemia Research & Thalassaemia Support**

**(OSCAR SANDWELL CO LTD)**

## **ANNUAL REPORT**

**April 2008 – March 2009**



**Sickled Cells**

THE ORGANISATION IS SUPPORTED

BY



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OSCAR SANDWELL CO LTD MANAGEMENT COMMITTEE 2008/2009

**Officers:**

Chairperson  
Vice Chairperson  
Treasurer

Donald Campbell  
Roy Hewitt  
Clive Fitchett

Flo Reynolds  
Clarence Cameron  
Ronald Beckford  
Sharon Johnson  
Rachel McFee

Director (now resigned)  
Director  
Director  
Director  
Director (now resigned)

**Staffing:**

Lorna Patterson  
Stan Simms  
Sophia Perkins  
Rebecca Solomon  
Khudeya Khanom  
Mary Millard  
Sharon Wilson  
Sonia Lindsay  
Temi Folayan  
Jamila Begum

Administrator  
Caretaker  
GG Children's Centre – Support Worker  
Sessional workers  
Sessional worker  
Cleaner  
Senior Development Officer (left Sept 09)  
Chief Executive Officer (left Jan 09)  
Health Liaison Officer  
Support Worker

**Volunteers:**

Mrs Smikle  
Wendy Mclean  
Joyce Nelson

Karl Henry  
Venteresa McQuinn  
Elaine Dixon

**Work Experience Placement:**

Joanne Glasgow  
Simone Shaw  
Hazel Gittens  
Kizhar Choudhry

Registered Charity Office:

120 Lodge Road  
West Bromwich  
West Midlands  
B70 8PL

Registered Charity Number:

1080588

Company Registration Number

373668

Solicitors:

Shakespeare Solicitors  
10 Bennett's Hill  
Birmingham B2

Reporting Accountant

Gary Peter Brookes  
24 Abbotsford Drive  
Dudley DY1 2HD

Bankers

Unity Bank PLC  
Nine Brindleyplace  
Birmingham  
B1 2HB

## INTRODUCTION

### MISSION STATEMENT

**Working together, with voluntary and statutory services to improve the quality of life for people affected by Sickle Cell and Thalassaemia.**

OSCAR (Organisation for Sickle Cell Anaemia Research) is located in West Bromwich in the Borough of Sandwell. OSCAR Sandwell is a voluntary organisation with charity and company limited status and managed by a Board of Directors. The ethos of the organisation is to provide direct services that address the well – being and collective needs of people with Sickle Cell and Thalassaemia.

OSCAR as it stands was founded in 1975 by a ‘Sickler’ who through personal experiences, realised there was inadequate information available to people affected directly or indirectly by the blood disorders, the public and medical professionals. OSCAR is the pioneering Sickle Cell organisation in the United Kingdom.

OSCAR operates as both providers of services and as an advocate for sufferers and their families, articulating community needs and campaigning for the development of appropriate services. The activities of the organisation have progressively increased as the understanding of the particular needs of people affected and their families have intensified.

OSCAR Sandwell was established in March 1988 in response to a growing concern expressed by members of the community about the lack of information and support for people with Sickle Cell and Thalassaemia in the Borough of Sandwell.

The organisation for 21 years has developed and established a comprehensive service to meet the needs of Sickle Cell and Thalassaemia sufferers and their carers. In addition the organisation strives to work proactively with both statutory and voluntary agencies to educate schools, community groups, health professionals, churches and the general public in raising the awareness about the above blood disorders.

### **What is Sickle Cell and Thalassaemia?**

**Sickle Cell** disorder is a condition that affects red blood cells in the body which contains the protein called haemoglobin (Hb). People with Sickle Cell Anaemia have Sickle haemoglobin (HbS) which is different from the normal haemoglobin (HbA). Normally, red blood cells last for about 120 days though for sicklers, the red blood cells die after between 30 to 60 days. As a result of the shorter life span of the red blood cells, with low production rates, anaemia occurs i.e. low iron content of the blood.

When sickle haemoglobin (HbS) gives up its oxygen to the tissues, it sticks together to form long rods inside the red blood cells making these cells rigid and sickle-shaped. Normal red blood cells bend easily but these rigid *sickled* red blood cells are unable to move easily through blood vessels, blocking them, which in turn restricts oxygen from getting through to where it is needed. This restriction of oxygen flow through the blood can cause severe pain and can possibly lead to the damaging of vital organs.

Sickle Cell disorder is a condition that normally affects people of African, Caribbean, Middle Eastern, Asian and Mediterranean origin, but not exclusively.

**Thalassaemia**, like Sickle Cell, is an inherited disorder of the haemoglobin. There are two main Thalassaemia types, Thalassaemia Major and Thalassaemia Minor (trait).

A normal haemoglobin molecule contains four protein (globin) chains (two alpha globin chains and two beta globin chains). Different genes are responsible for producing each chain. In Thalassaemia, there is an inherited defect in one of these genes. If the alpha chain is affected, this causes Alpha Thalassaemia. If the beta chain is affected then this causes Beta Thalassaemia. There are a number of different types of Thalassaemia within these groups, alpha thalassaemia being less diverse than beta thalassaemia.

Where a person has inherited haemoglobin A from both parents, they will have **two** usual beta genes ( $b^b$ ), one from each parent, and four alpha genes ( $aa/aa$ ), one pair from each parent.

They would, therefore, produce normal amounts of BETA and ALPHA to make healthy red blood cells. Some people inherit one usual and one unusual Beta gene, in which case they have a condition known as Beta Thalassaemia Major (Hb AbThal), sometimes referred to as a trait. Some people do not inherit the usual number of Alpha genes in which case they would have a condition known as Alpha Thalassaemia Minor (trait).

## CHAIRMAN Foreword 2008-2009

This has been, without any doubt, a very trying year for our organisation including its management, staff and members. We have seen almost a complete turnover of staff, from management to volunteers, reducing our internal working experience to the very minimum. However, the ongoing projects and daily routine were rescued and placed back on track with the help of temporary staff and new employees.

As always funding continues to be a key issue in our sustainability and the outcome of our progress, with this year proving worse than ever due to the world wide economic decline. The issue of fundraising is still very high on our agenda and I believe it is fair to say that the state of our financial wellbeing is very much under threat without a sustainable business arm to provide a reliable income. We therefore need to make suitable provision to bridge this gap to ensure OSCAR Sandwell, not only has a future, but a bright one.

That said, we have managed to add to our Greets Green Service Level Agreement by proving our worth in the community through the Sickle Cell Project which ended last year. This did not only strengthen our cause but brought about a slight increase in our annual funding for this service. The 3 year Thalassaemia Project ended in July 09 with a clear view of outcomes and achievements and through the various recommendations we are also hoping to realise some sustainability to increase the support to present and future clients.

Our monthly screen has proven to be successful is now fully recognised in our Service Level Agreement. We therefore aim to promote this to its maximum exposure as a service and strength of our organisation in the community.

Although still below the level establishment of staff we are hoping and to fill the gaps sooner rather than later, and continual efforts being made to create a fundraising team, with the efforts of staff, advisors and volunteers, we are hoping for success in the near future.

I call on all Directors, Members, Staff and Advisors for a united effort by individual effect engagement in carrying out one function or another for us to realise our goals. A united team effort will spell success, the success we crave and deserve for the future support of our clients.

My thanks to you all.

**Donald Campbell - Chairman**

## SUB COMMITTEE REPORTS

### SOCIAL ACTIVITY COMMITTEE 2008-2009

Dear Colleagues

The past year has been very lean, financially, due to various factors, the main one being the current economic climate. With the demise of staff reduction and fewer volunteers to boost the Social Committee it has certainly had an adverse effect on organising many of our usual activities. Our last Dinner Dance had a positive and a negative result. Although we made an overall financial loss on the night the awareness of OSCAR's mission was very positive.

The aim is to revitalise this committee to a level which will aid OSCAR's financial position whilst providing fun and entertainment for our clients, members, colleagues and supporters alike.

Your assistance as a volunteer in organising social activities would be more than welcome.

Many thanks.

**Mr. Roy Hewitt – Chairman of Social Activity Committee.**

**PERSONNEL COMMITTEE**  
**2008-2009**

Vibrant and committed to the cause is how I would describe this committee. With full capacity of members we were able to cover many areas and grounds over the past year.

One such area was to deal with major staffing issues, some of which are still ongoing due to circumstances beyond our control, where we had to improvise on a regular basis to keep the organisation on its feet. Advertising and recruiting new staff was not an option, but with hard work and temporary staff and measures in place we were able to achieve stability.

The introduction of an appraisal system and the update of our supervision procedures will, I believe, aid staff management greatly. The ongoing revision of our filing system and policies are providing the organisation with more effective and transparent procedures.

It is our aim to make regular contact with all members to offer support and guidance, keeping them in touch with the organisation`s daily life. We are also hoping to reach many people, young and elderly, via our website and Face Book, communication medias which are constantly in need of updating and maintenance. A completed database of members, clients and client members is underway with the hope of being able get answers which are often required at the touch of a button.

Our committee meetings are normally frank and open in discussing matters which affects us all. It is therefore extremely important to maintain this momentum in the future in order to support the other committees and the organisation as a whole.

My thanks to members of this committee for you valuable time and contribution. Long may it last.

**Donald Campbell- Chair of Personnel Committee**

**CENTRE MANAGER'S REPORT**  
**2008-2009**

As the new Centre Manager of OSCAR Sandwell it is important that I note as part of my report that the organisation has undergone changes to staff in this year (2008-2009) with long standing members moving on to other endeavors, but although they are no longer with us, it is important that we recognize and highlight in this report all the good work that they have undertaken.

During April 2008- March 2009 the organization has continued to work towards meeting it's strategic objectives for the past 12 months. We have continued to fulfill our legal duties and obligations to the Charity Commission and Companies House, all returns have been submitted to the relevant bodies as required.

The profile of OSCAR Sandwell Company Limited continues to grow locally, regionally and nationally. Our key activities are the provision of counseling, advice and information, screening, education and training, health promotion, self help groups, social activities, volunteers, student placement and work experience.

Funding for OSCAR Sandwell is provided by Sandwell Metropolitan Borough Council (SMBC) and Sandwell Primary Care Trust (PCT), Greets Green Partnership – New Deal for Communities Programme and the Big Lottery fund. Through Service level agreement or grant which is measured through performances and outputs.

Volunteers have contributed to the delivery of our services ranging from project work, administration and health promotion activities. Last year a total of 25 volunteers helped to accumulate over 600+ volunteer hours. Volunteering continues to be a two-way process.

Our focus was on developing our services for those affected by Sickle Cell or Thalassaemia Blood disorder in Sandwell, the Black Country and surrounding area of the West Midlands. We have worked in partnership and collaboration with many statutory and voluntary organisations to enable improved services to our client group.

**Community involvement** - OSCAR has continued to involve itself within the Greets Green Strategy contributing to its targets. We continue to work in partnership to develop and deliver with Greets Green residents, through our activities such as, NHS Expert Patients Programme. This partnership has helped to raise awareness of OSCAR Services. The centre continues to offer its room hire service for many individuals, groups and organisations both Statutory and Voluntary who have all benefited from the service. This again creates and continues to raise further awareness about OSCAR work, and often generates interest.

**Student placements** –This year we have offered work placement to four unemployed youngsters under the new deal trainees programme. Two places were allocated to social worker trainees from Birmingham City University. Three places allocated to

school work experience young people. We are happy that we have been able to contribute to the education and training of unemployed young people.

**Partnership working** - much partnership was developed within this financial year with a range of voluntary and statutory agencies/organisation; this enabled the development and support of initiatives to improve services to our client group. This year saw the continuation of partnership with DeMontfort University researcher who examined the educational needs of children and young people with Sickle Cell Anaemia in the UK. This partnership has gone on to develop a new research topic into employment & training needs of our young people and adults. A project proposal has been submitted to the Big Lottery Fund research programme. It is envisage if successful the new action research project will commence in April 2010 for the duration of four years. This year has seen the strengthening of partnership working across all sickle cell and thalassaemia groups locally, regionally and nationally.

### **FUTURE PLANS 2009/10**

- To bring together and inform all stakeholders  
To carryout an action research into the education & training needs of our service users.
- To implement fundraising strategy for the sustainability of the organisation and various future projects and services.
- Continue to strengthen our governance
- Collaboration and partnership working with sister organisations
- Continue to offer core services to our membership and wider community.
- Continue to develop children and young people strategy
- Work towards PAQSSO quality mark
- To strengthen our volunteer activities  
Continue to develop our services across the Black Country and the surrounding area
- Explore the opportunity of setting up a social enterprise business.

**In conclusion** - our focus has been continuing to develop our services for those affected by Sickle Cell or Thalassaemia Blood disorder in Sandwell, the Black Country and surrounding area of the West Midlands. We have worked in partnership and collaboration with many statutory and voluntary organisations to enable improved services to our client group.

**Rachel McFee – Centre Manager**

**CORE SERVICES**  
**REVIEW OF ACTIVITIES AND FUTURE DEVELOPMENTS**  
**2008-2009**

Our main focus continued to be developing our services for those affected by Sickle Cell or Thalassaemia Blood disorders in Sandwell and surrounding area of the Black Country West Midlands. We have worked in partnership and collaborated with many statutory and voluntary organisations to achieve the aims and objective of the organisation in service provision.

**Advice and Information** –The organisation continues to provide advice and information to members of the organisation, community groups and professionals. The majority of the request made has been from community organisations, groups, local people and users of the service. This year **1238** accessed the project for advice and information on Sickle Cell and Thalassaemia.

Target 2008	Actual	Target 2009	Actual
200	1443	200	1238

**Support and advocacy** – OSCAR continues to offer support and advocacy services to its client group by providing such service as hospital and home visit to enable us to support and advocate on behalf our client group. Much work has gone into supporting clients with issues such as benefits and housing issues making the appropriate referrals where necessary.

**Education and Training** – We have continued to offer education and training to voluntary, community and statutory organisation this year the number of people receiving a service was 163 individuals

Target 2008	Actual	Target 2009	Actual
50	111	75	163

**Screening** –The organisation undertook a pilot community screening programme last year and created a new Service Level Agreement with the Birmingham Sickle Cell & Thalassaemia Service, (provided by Heart of Birmingham Teaching PCT Provider Services) based in Ladywood. We successfully screened 63 individuals. It is envisaged that this will develop into an ongoing programme offered by OSCAR.

Target 2009	Actual		
25	63		

**Children summer project** – This year summer project which was conducted in the 2<sup>nd</sup> quarter and continues to be a huge success. Funding for the project came from Sandwell PCT.

The aims and objectives of the children and young people summer workshop 08 was to engage our Sickle Cell and Thalassaemia children and young people (and their siblings and friends) in workshops that will enable them to interact indoor and outdoors in a safe way. Focusing around hygiene, first aid and health and safety, 38 children and young people took part in the project. 41 children, members of their family, staff and volunteers visited the Drayton Manor Family Theme Park and Zoo. Everyone felt this was a fun and active day out. (Report available on request)

**Greets Green Expert patient project** – Although this year is the final year of the project funded by Greets Green Partnership, OSCAR was granted an extension until May 09, to utilise underspend from year one. The objective of the project is to raise awareness on Sickle Cell & Thalassaemia, Advice and information, increase screening (blood test) promote and encourage the take up of blood donations, delivering Expert Patient Training Programme to people with long-term health conditions. The project is managed by a multi-disciplinary steering group who oversees the target of the project. The project achieved all targets set. The project was a major success the strength of the project manifested in an independent evaluation report carried out by Wolverhampton University which highlights the major outcomes that has been achieved.(Available on request)

**Sessional Worker – Rebecca Solomon**

**Sessional Worker – Khudeja Khanom**

**Senior Development Officer – Sharon Wilson**

**Report by – Rachel McFee – Centre Manager**

## BIG LOTTERY FUND – THALASSAEMIA PROJECT

The period April 2008 till March 2009 marked the 3<sup>rd</sup> Year and final year of the Thalassaemia project. Work continued in the form of outreach and raising awareness within local community centre's and a variety of organisations.

In January 2009 the project was extended by three months until June 2009. This allowed us to recruit two new community champions to the project.

The Project attended regular clinics for both children and adults with Beta Thalassaemia Major, encouraging membership to the project and offering Advice, information and support to patients and their families/carer(s).

Clients have been supported with a range of issues some of which include:

- Welfare and benefit rights
- Workshop sessions
- Arranging training programmes to empower clients
- Arranging English language tuition.

The project has continued to receive referrals, this has enabled us to provide, advice & information and needed support to clients; encouraging the use of the free screening service at OSCAR Sandwell.

By networking with other organisations we have made 1-to-1 presentations, group presentations and delivered training sessions to staff; this has improved awareness about Thalassaemia among this agencies.

The project has also being able to provide training sessions about Thalassamia to professionals; these have included Social Wokers, Teachers and Community nurses.

The project maintained contact with clients by:

- Providing activities which encouged interrctation and reduced isolation
- Regular phone calls to check up on thalassaemia patients.
- Hospital visits

### **Work Undertaken By Two Community Champions**

During the project extension from the end of March to the end of June two community champions undertook the following activities:

Funding from the Roald Dahl Foundation (£2,700) meant we were able to organise a trip to the Snow Dome, Tamworth, for the young Thalasaemia patients. 17 people attended, including staff and patients. This was an oppurtunity to have fun and interact with each other and reduce isolation.

We held an information session at OSCAR Sandwell, staff from the Birmingham Children's Hospital and SCaT Centre came to give a presentaion. This was attended by OSCAR staff and community champions. This was seen as a good partnership building

opportunity for all organisation. Reports were produced on all activities and sent to the Roald Dahl Foundation.

The community champions and one thalassaemia client went on behalf of OSCAR Sandwell to attend United Kingdom Thalassaemia Societys annual conference in Manchester. The event was attended by approximately 150 people. The programme included presentations by proffesionals, patient testimonials and workshops. This was a successful conference as it gave the chance for everyone to get together and share their experiences and also to get their views heard.

### **Communication via media**

We have communicated with our young clients using a range of media such as phone, texting, emailing and also Facebook. OSCAR Sandwell has its own facebook page. We use Facebook to inform patients, clients and the general public of the events that are forthcoming.

### **Database**

We have compiled a database with 33 clients, some have Thalassaemia Major and others have the trait. This database will allow us to inform our clients about our services, events and support that we have to offer.

An End of Grant report was completed, highlighting activities undertaken, targets and outcomes achieved and a breakdown of the expenditure. This was sent to the Big Lottery Fund.

### **External Evaluation Report**

An external evaluation of the whole 3+year project was undertaken by a consultant from QSR<sup>2</sup>. He produced a report and made some recommendations. A couple of these are summarised below:

1. ....the organisation should look at ways of widening the community champions programme to incorporate.... particularly refugees and asylum seekers.
2. ....seek to re-energise its relationship with organisations like UK Thalassaemia Society to explore possibilities of joined up working wherein joint funding applications can be developed to secure a future role for OSCAR Sandwell in the delivery of Thalassaemia services.

<i>Identified Beneficiary Groups</i>	<b>Year 3 Actual figures</b>
BME	208
Refugees and Asylum seekers	12

Local GP's and other Professionals

5

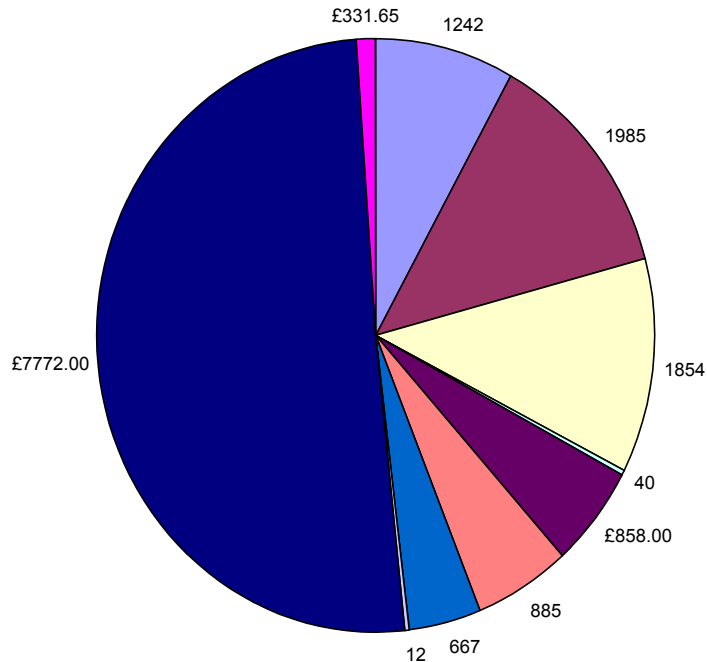
Local Community/voluntary & Statutory organisations

20

**Community Champions: Abdul Alim and Zarah Mughal**  
**Health Liaison Officer: Temi Folayan, Support Worker: Jamila Begum**  
**Report written by: Abdul Alim**

## STATISTICS

ADMINISTRATION REPORT APRIL 2008- MARCH 2009



VISTORS  
OUT GOING TELEPHONES CALLS  
INCOMING CALLS  
VOLUNTEERS  
ROOM HIRE  
OUT GOING POST  
INCOMING POST  
TRAINEES/ NEW DEAL & WORK EXPERIENCE  
DONATIONS  
COLLECTION BOXES

As you can see from the chart we still continue get a lot of people through our doors, our numbers for incoming and outgoing calls are down on last year, but this could be due to a greater use of emails.

Although our room hire is substantially down on last year, we have managed to get bookings to the total of £858.00 for the later part of 2008 and early part of this year.

As you can see our donation is substantially up on last year, we received large donation from Cllr Sidhu, during his time as Mayor of Sandwell, when Oscar Sandwell was chosen as one of his charities. Our collections boxes this year raised £331.65. We had 12 new deal trainees and work experience pupils on placement this year.

Report written by: [Lorna Patterson](#)

## ACKNOWLEDGEMENTS

### **THANK YOU & APPRECIATIONS**

We would like to express our sincere thanks to the Sandwell Metropolitan Borough Council, the Sandwell Primary Care Trust, Greets Green Partnership, the Big Lottery Fund for funding the project for 2008 -2009. We would like to take this opportunity to express our thanks and appreciation to everyone who has given their support to the organisation.

COUNCILLOR SIDHU  
STOCKLAND GREEN METHODIST CHURCH  
HYLTON FAMILY  
ADVENT YOUTH (SEVEN DAY ADVENTIST CHURCH)  
SOROPTIMIST INTERNATIONAL WALSALL  
SHILOH CHURCH  
YVONNE MCKENIZE  
UNIVERSITY OF NOTTINGHAM  
OLIVE DOWNER  
DOMDINES  
OCKER HILL CONVENIENCE STORE  
JARRETT'S HAIR SALON  
FITZ JACKSON FOOD STALL  
LYNDA BRADING STUDIO