



Organisation for Sickle Cell Anaemia Research & Thalassaemia Support  
(OSCAR SANDWELL CO LTD)

## ANNUAL REPORT

1 April 2009 – 31 March 2010



**This year marks the 100th anniversary since Dr. James Herrick published his first observations on 'peculiar elongated cells' – what is now known as Sickle Cell Disorder**

**THE ORGANISATION IS SUPPORTED**

**BY**



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**Officers:**

Chairperson	Donald Campbell
Vice Chairperson	Roy Hewitt
Treasurer	Clive Fitchett

Clarence Cameron	Director
Ronald Beckford	Director
Sharon Wilson	Director
Ventreasa McQuinn	Director

**Staffing:**

Rachel McFee	Centre Manager
Lorna Patterson	Administrator
Stan Simms	Caretaker
Sophia Perkins	GG Children's Centre – Support Worker
Rebecca Solomon	Sessional workers
Khudeya Khanom	Sessional worker
Mary Millard	Cleaner
Temi Folayan	Health Liaison Officer (left April 09)
Jamila Begum	Support Worker (finished June 2009)
Zarah Mughal	Community Champion
Abdul Alim	Community Champion

**Volunteers:**

Mrs Smikle	Karl Henry	Kevin Dunkley
Wendy Mclean	Venteresa McQuinn	Gurmel Bhatti
Joyce Nelson	Elaine Dixon	Thandeka Brown
Tyabb Rashid		
Balbinder Kaur		

**Work Experience Placement:**

Lorye McFee	A Hussein
Abilio Jaribo	Lee Mountford
Rheo Daley	
K. Allen	
C. Kaila	

Registered Charity Office:

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B70 8PL

Registered Charity Number:

1080588

Company Registration Number

373668

Solicitors:

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Reporting Accountant

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Bankers

Unity Bank PLC  
Nine Brindleyplace  
Birmingham  
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## INTRODUCTION

### MISSION STATEMENT

*Working together with service users, voluntary, statutory services and stakeholders to improve the quality of life for people affected by Sickle Cell and Thalassaemia in the Sandwell area.*

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.

In July 1998 the Centre at Lodge Road was formally opened by Derick Heaven, His Excellency, The Jamaican High Commission.

The organisation for 22 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 ( $b^{\wedge}b^{\wedge}$ ), 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 2009-2010

OSCAR has withstood the test of time over the past year by going through a very trying period for our management, staff and members and volunteers. With some new staff, contractor workers and volunteers we have managed to keep the ongoing core services requirements on track with dedicated efforts and endeavour by all.

As always, funding continues to be a key issue in our sustainability and the outcome of our progress, with this year proving no different. To that end a major overhaul and streamlining of the Organisation's operation and expenditure has been carried out with excellent results so far. The issue of fundraising is still very high on our agenda so we are therefore aiming to address this issue which will hopefully be fruitful in the near future. In doing so we have identified two areas for development, the first being marketing our core service within our community and beyond, and the second is establishing a Social Business Enterprise.

With a robust recruiting panel we managed to recruit two new staff, one fulltime and the other parttime, giving us an establishment of two fulltime and 3 parttime employees. With our current workload it is evident that the Organisation requires a minimum 5 fulltime staff. This has been reflected in our Business Plan in order to generate funding as is relevant for future progress and growth.

It is our aim to build an effective team which will take us forward in developing our Organisation to its full potential. A united team effort will spell success, the success we crave and desire for the future support of our clients.

My thanks to you all.

**Donald Campbell - Chairman**

## **SUB COMMITTEE REPORTS**

### **PERSONNEL COMMITTEE** **2009-2010**

Amongst its routine servicing of the Organisation the Personnel Committee was forced into fulfilling a recruitment criteria. There were vacancies to be filled but our recruiting policy and procedure needed updating. This we did over many hours of debating in order to create a robust document for the future.

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 are proving to aid staff management greatly. The ongoing revision of our filing system, policies and procedures for all areas are providing the Organisation with more effective and transparent working patterns.

It is our continued 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 media which are constantly in need of updating and maintenance. A completed database of clients and members is underway with the hope of being able to get required answers at the touch of a button.

We hope to conclude each future year with a Members Event, which is an Open Day to all, where an update of the past year`s work and events will be highlighted.

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 our Organisation as a whole.

My thanks to members of this committee for your valuable time, hard work and contribution over the past year.

**Donald Campbell- Chair of Personnel Committee**

**CENTRE MANAGER'S REPORT**  
**2009-2010**

In 2009-2010 the organisation looked at its operational structure. This review was the start of our ongoing commitment to ensuring we can provide the best services possible and best use of resources we have available.

During April 2009- March 2010 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 steadily grow locally, regionally and nationally. Our key activities are the provision of guidance, advice and information, screening, education and training, health promotion, self help groups, social activities, volunteers, student placement and work experience.

Core funding for OSCAR Sandwell is provided by Sandwell Metropolitan Borough Council (SMBC) and Sandwell Primary Care Trust (PCT) 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 17 volunteers helped to accumulate over 408+ volunteer hours. Volunteering continues to be a two-way process. It also offers an excellent opportunity for personal and professional development, skills sharing, developing new areas of knowledge, building on your professional network and creating lasting personal relationships.

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-** 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** – Nine places were allocated to school work experience young people. We are happy that we have been able to contribute to the education and training young people. Although we were unable to offer placements from any Universities this year we envisage to start this up again in the new year.

**Partnership working** - partnership continues 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. A project proposal was completed in partnership with OSCAR Birmingham and De Montfort University and submitted to the Big Lottery Fund research programme. Unfortunately this was unsuccessful. We continued liaise and work in partnership which allowed organisations to support our events and activities, these were British Heart Foundation, Trident Care and Support, Wolverhampton Sickle Cell Care, Sickle Cell Society, and Patient Support and Network Group to name a few.

**Black Country and Surrounding Area Strategy** – We have seen the need to liaise and communicate with other Sickle Cell and Thalassaemia providers, OSCAR Sandwell attended two Sickle Cell and Thalassaemia forum meetings, these were attended by both statutory, voluntary and community organisations with a remit to look at service provision on a Nationwide scale. The first held Nottingham, hosted by OSCAR Nottingham and the other held in Leicester hosted by De Montfort University, it was envisaged that other groups would host these meetings but limited capacity meant that this did not happen. It is hoped that this forum will pick back up in the following year.

**Governance** – The organisation has continued to worked toward improving and strengthening our governance. to enable us to demonstrate our accountability, transparency, effectiveness and efficient, equitable whilst working within the rule of the law. This is an ongoing priority for the organisation. We have looked for external support from individuals in the voluntary role of Advisor to the Board and recruited one member last year.

### **FUTURE PLANS 2010/11**

- To bring together and inform all stakeholders
- To carryout 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 peer organisations
- Continue to offer core services to our membership and wider community.
- Continue to develop children and young people activities
- Work towards Investors in People accreditation
- 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  
2009-2010**

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 requests made have been from schools, community organisations, groups, local people and users of the service. This year **1405** accessed the project for advice and information on Sickle Cell and Thalassaemia.

Target 2009	Actual	Target 2010	Actual
200	1238	330	1405

**Support and advocacy** – OSCAR continues to offer support and advocacy services to its client group by providing such service as hospital and home visits to enable us to support and advocate on behalf our client group, but with an emphasis to empowering our clients to also help themselves. 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 organisations this year, the number of people receiving a service was **163** individuals

Target 2009	Actual	Target 2010	Actual
75	163	75	165

**Screening** – OSCAR renewed its Service Level Agreement with the Birmingham Sickle Cell & Thalassaemia Service, (provided by Heart of Birmingham Teaching PCT Provider Services) based in Ladywood. The programme started much later in the year and thus meant less individuals took up the service. In total we screened 15 individuals. This service was reviewed with feedback from individuals and its delivery may change to holding sessions at local community venues..

Target 2010	Actual		
35	15		

**Children summer project** – This year summer project which was conducted in the 2<sup>nd</sup> quarter and continues to be a huge success. This is partly funded by 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 be healthy through activity. Focusing on physical activity which included kick boxing, using gym equipment and working at a local allotment, 28 children and young people took part in the project. 49 children, members of their family, staff and volunteers enjoyed a day out to Skegness.

**Greets Green Expert patient project** – OSCAR was granted an extension until May 09, to utilise an underspend from year one, but funding originally ended in 2008. 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)

**Expert Patient Programme** - As a follow on from the Greets Green EPP, the Expert Patient Programme is an NHS initiative and OSCAR successfully carried out two 6 week programmes the first ended in April with 18 participants and second ended in Dec with 14 participants. Participants gained skills and knowledge about managing their health condition or those caring for someone with a long term health condition. Certificates were given to all attendees.

**Senior Development Worker – Rebecca Solomon**  
**Support Worker – Khudeja Khanom**  
**Report by – Rachel McFee – Centre Manager**

## THALLASAEMIA WORK

### Work Undertaken By Two Community Champions

In April 2009 OSCAR Sandwell took on board two new Community Champions, Abdul Alim and Zarah Mughal, for the Thalassaemia Project which was established from 2006 to 2009, funded by the Big Lottery.

In December 2008 OSCAR Sandwell received a grant of £2,700 from Roald Dahl Foundation to carry out activities with Thalassaemia patients in order to reduce isolation.

In April 2009 both Community Champions led on a trip to Snow Dome in Tamworth for the Thalassaemia patients. This was a chance for the patients to have fun and interact with each other and reduce isolation. OSCAR Sandwell core staff and a staff member from Sickle Cell and Thalassaemia Centre, City Hospital and Haemoglobinopathy Unit at the Birmingham Children's Hospital. There were 10 Thalassaemia patients that came to the Snow Dome.

OSCAR Sandwell held an information session for parents to come learn and share experiences with each other how its like bring up a child with Thalassaemia. Natalie Lawson from Haemoglobinopathy, Children's Hospital and Samantha Beck from Sickle Cell and Thalassaemia Centre, City Hospital came to give a talk about what services they offer and how they would treat Thalassaemia patients at their centre. This was seen as a good partnership building opportunity for all organisations.

Reports were sent to the Roald Dahl Foundation detailing on all activities that were undertaken and they were pleased with the work that James Fitzpatrick, Director of Roald Dahl Foundation came to visit us at OSCAR Sandwell.

Abdul Alim, Community Champion gave a presentation on what the project involved and pictures showing all activities that was undertaken with the grant money from Roald Dahl Foundation.

The Community Champions and one Thalassaemia client went on behalf of OSCAR Sandwell to attend United Kingdom Thalassaemia Society's annual conference on 20<sup>th</sup> June 2009 at The Hallmark Hotel in Manchester. The event was attended Thalassaemia patients, Thalassaemia patient's family and carers, general public and other organisations. They had approximately 150 people that attended. The programme included presentations by professionals, 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.

Abdul represented OSCAR Sandwell at a trip to Go Ape, Worcester. Haemoglobinopathy Unit invited us to speak to the young Thalassaemia and Sickle Cell patients about what services we offer and how we get involved with the patients. This gave us an opportunity to meet the young patients at a different environment rather than meeting them while they have their treatment at the hospital and at an exciting atmosphere as they were all

ready to climb up on ropes and try out different activities. During lunch break the youngsters were able to ask questions about OSCAR Sandwell's services and how it can benefit them.

Both Champions supported the Children's Summer Project, Zarah left in August 2009 to continue her studies.

OSCAR Sandwell wanted to ensure that engagement with Thalassaemia patients continued and developed.

In September, three Thalassaemia patients developed an idea of setting up a support group for Thalassaemia patients and their family/carers. They have experience living with this condition and believe that there is not a lot of support for patients and carers whom need help and assistance with the condition.

The support group aims to provide a service that will benefit the patients and also the community as they will be giving talks on what Thalassaemia is and how an individual and their family are affected by this condition.

In January 2010 a meeting was held at OSCAR Birmingham where Elaine Miller who is a representative of United Kingdom Thalassaemia Society came to meet the support group and discuss ways of working together. OSCAR Birmingham and OSCAR Sandwell supported the patients that were leading on the support group and now the support group are known as THALASSAEMIA AWARENESS AND SUPPORT GROUP (TASG).

Abdul and Rachel McFee, Manager were invited to attend a health event at Wolverhampton University. At this event Abdul who is also a Thalassaemia patient was interviewed by Laboratory workers from City Hospital and medical students from Wolverhampton University. They were interested to find out how it is like to manage a health condition like Thalassaemia and take part in other activities such as education, work and socialising.

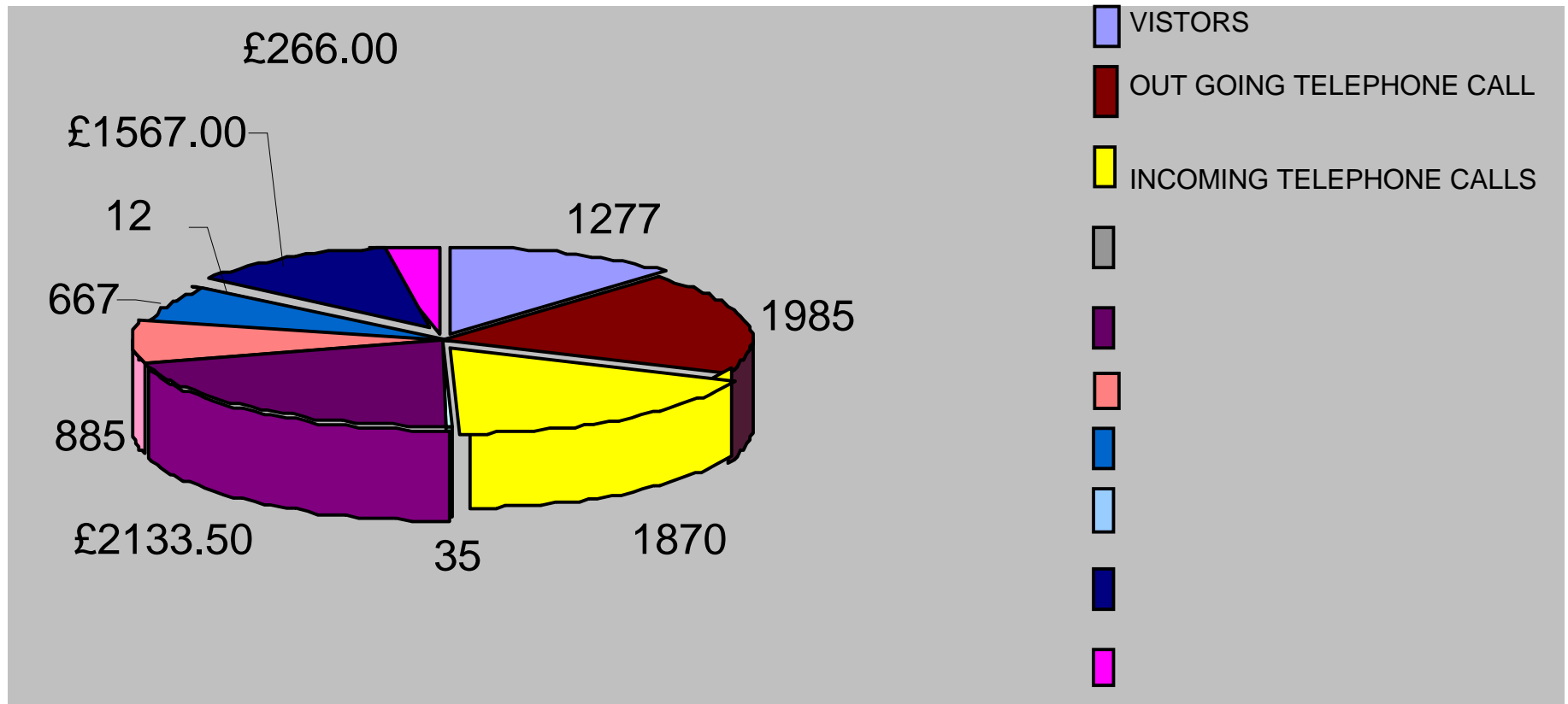
Abdul and Balbinder Kaur, TASG member attended an award ceremony which was organised by National Blood Service to award and recognise people that have donated blood in their life. Awards were given to people that had donated 50 bags of blood, 75 bags and 100 bags in their life. The event was held at the Botanical Gardens, Edgbaston. Abdul and Balbinder gave a speech about how they have lived their life with Thalassaemia and what they have been able to achieve.

Other activities included

- Heart of Birmingham Awards, Aston Villa Holte Suite
- Awareness session in Oldbury with the Asian women's group
- Transitional CSI event at custard factory, Birmingham
- Scat study day at Ladywood community centre

OSCAR Sandwell now has a database of 36 Thalassaemia patients that we have engaged.

**STATISTICS**  
**ADMINISTRATION AUDIT REPORT FOR APRIL 2009 TO MARCH 2010**



You will see from the chart that we have had 1277 people through our doors this year, also our room hire has increased £2133.50 due to SWEDA Sandwell Women's Enterprise Development Agency hiring our main room for ESOL Classes, this has been a tremendous boost for our room hire service, the contract is continuing this year and we hope next year also. However, we have seen a drop in our donations this could be due to the financial climate we are in, but we have received donation of £1567 this year. We also raise small amounts from our collection boxes at local establishments these tend to fluctuate depending on how generous the general public are, but we have raised £266. With the money we have from our collection boxes and donations, we were able to purchase new tables, general maintenance of the building and some of the money was used for our Christmas party.

**Report by Lorna Patterson - Administrator**

## **ADMINISTRATION REPORT**

**2009-2010**

### **ACKNOWLEDGMENTS**

We would like to take the opportunity to express our sincere thanks and appreciation to everyone who has given their support to the organisation.

- STOCKLAND GREEN METHODIST CHURCH
- JOLLY GREETINGS CARDS
- LADYWOOD METHODIST CHURCH
- OCKERHILL CONVENIENCE STORE
- HUGH GRAHAM
- COUNCILLOR GURCHARAN SINGH SIDHU
- AURORA GRAND LODGE
- DOMDIMES
- JARRETT HAIR SALON
- ROOSTER HOUSE
- FITZ JACKSON FOOD STALL- SANDWELL MARKET
- HOLLY LODGE
- SHIRELAND COLLIGATE SCHOOL
- SANDWELL ACADEMY
- SVCO
- PERTEMPS
- GEORGE SALTER COLLIGATE
- OLDBURY COLLEGE OF SPORTS
- MENZIES HIGH SCHOOL
- STUART BATHURST CATHOLIC HIGH SCHOOL

**SUMMER PROJECT – HEALTHY THROUGH ACTIVITY**



**Summer Project – Building Bird Houses at local Allotment**



**Patients attend a CSI Event in Birmingham**



**OSCAR Birmingham and OSCAR Sandwell Staff and clients attend Sickle Cell Society AGM in London**



@BCL@C40D3067.uuc

**AWARENESS SESSION GIVEN TO ASIAN WOMEN'S GROUP,  
TRANSLATED INTO COMMUNITY LANGUAGE**



**CHRISTMAS PARTY – CHILDREN ENJOY PASS THE PARCEL  
PARTY GAME**



**HEART OF BIRMINGHAM AWARDS – ATTENDED BY PATIENTS AND CARERS**



**CHAIRMAN, STAFF AND MANAGER TAKE PART IN CHARITY STROLLATHON HOSTED BY ADVENTIST YOUTH AT PARK IN SMETHWICK AND HAVE INFO STALL**

