



Sickle Cell
& Thalassaemia
Support Project



Foreword

After reaching last years milestone of 21 years of operation the organisation has continued to deliver services to our service users as well as increasing awareness amongst professionals and the public. We are now well established in three areas within the West Midlands – Wolverhampton, Walsall and Dudley ensuring that through the delivery of the screening programme that good outcomes exist for parents, babies and those living with the conditions.

As NHS restructuring continues, along with the welfare reforms we recognise the important role we play in supporting our service users through these changes. The introduction of our outreach services we hope will be a timely intervention so as to meet these challenges.

I would like to take this opportunity to say a massive thank you for all the dedicated

individuals who have volunteered their time and energy to the cause. This, coupled with equally committed staff, for me remains the secret of our success over the years.

The organisation is overseen by a board of volunteers who act in the best interest of the organisation and service users and I wish to acknowledge their considerable contribution and insight to the work of the organisation.

I'm proud of our efforts over the years and my wish for the coming year is that stronger links are formed between our commissioners as well as volunteers involved in the outreach project allowing us to meet the needs of our service users.

Thanks again to everyone for all you have done during the past year.



Clarence Crosdale
Chairman

Co-ordinators Report

Like many other organisations we have also been affected by the general economic climate, however much still needs to be achieved in order to deliver the best outcomes for our users. The national changes in health and social care have been a minefield and it has been a challenge in its self to understand how services will be commissioned and from whom in the near and future years.

We remain confident and privileged to be continuing to serve this community, growth, development and bespoke services are to remain central in our desire to ensure we fully meet both the social and health needs of the client group.

However, despite the last year being a challenge, we face the future confident that the Sickle Cell and Thalassaemia Support Project will continue to add great value to the voluntary sector and the communities we serve.



Sutinder Herian
Project Co-ordinator

About Sickle Cell & Thalassaemia

Sickle Cell Disease and Thalassaemia Major are in a group of blood disorders called haemoglobinopathies and are amongst the most common inherited disorders in humans.

Sickle Cell Disease

Sickle Cell Disease is a potentially serious blood condition that affects the way oxygen is carried around the body. In England, Sickle Cell is as common as cystic fibrosis – affecting an estimated 12,000 people in the UK. Worldwide approximately 14 –16 million people are said to be suffering from the Sickle Cell Disease.

Sickle Cell is the most common serious genetic disorder in England and as such it must be viewed as a mainstream issue for the National Health Service (NHS). It is estimated that about 360

babies are born each year in England with Sickle Cell Disease and a further 9,600 babies are found to be carriers of the disease. The growing number of children – many of whom come from disadvantaged communities in urban centres, require services at a specialist level which match those available for other conditions (such as cancer and cystic fibrosis) to foster health equalities and to provide a better quality of life for both the child and their family.

Sickle Cell Disease (SCD) shortens the normal life span of red blood cells. While the normal red blood cell is shaped like a smooth and flexible disc, the Sickle red blood cell may become distorted into a sickle shape after oxygen is released from its haemoglobin, so have a shorter working life.

The sickle shaped red blood cell is hard and sticky and can form blockages in small blood vessels. These blockages lead to repeated acute and chronic tissue damage and can cause episodes of severe pain. The shorter lifespan of Sickle Cell also leads to chronic anaemia.

Episodic pain events known as crises, infection and lung complications are the more common problems caused by Sickle Cell Disease. Other complications may include stroke, kidney and heart damage, damage to joints, and other debilitating conditions.

Thalassaemia Major

Thalassaemia Major (Beta Thalassaemia) is the most severe form of thalassaemia. It results in the inability of the body to produce haemoglobin, thereby causing life threatening anaemia. Beta Thalassaemia is thought to affect more than 700 people, with approximately 214,000 carriers in the UK.

Thalassaemia is based on problems in the production of either the alpha or beta chains that make up haemoglobin. This causes inefficient production of normal haemoglobin and the increased breakdown of red blood cells causing anaemia.

There are many forms of Thalassaemia, among which Beta-Thalassaemia Major is the most common.

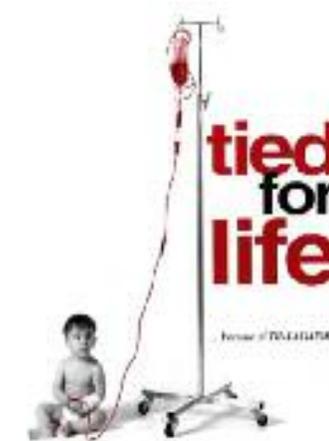
Children who are born with Beta Thalassaemia Major cannot make enough haemoglobin in their blood.

As a result they become severely anaemic and need blood transfusions every 4/6 weeks, this causes iron overload in the body. To deal with this, some need regular injections for life, but new treatment is now available which is taken by mouth, but the transfusion need is unchanged.

Both conditions can restrict a child's or adult's ability to conduct normal daily activities, and can also have profound psychological effects on the individuals and their families.

Who can it affect?

Sickle Cell and Thalassaemia are more prevalent in people who have originated from Africa, the Caribbean, the Middle East, Asia and the Mediterranean. However, because of the increasingly diverse society in England, people who carry the gene for Sickle Cell, Thalassaemia and other haemoglobin variants can be found in any ethnic group.



Carrier

What is the difference between a carrier (trait) and the disease?

- Carriers are usually healthy.
- Being a carrier is not an illness and will not develop into the disease.
- Carriers usually do not know they are carriers until they have a specific blood test.
- Carriers can pass the condition onto their children, who can be affected by the disease
- At the time of planning a family, carriers are advised to have their partners tested to identify if there is a possible risk to their child.

Disease

How do you get the Disease?

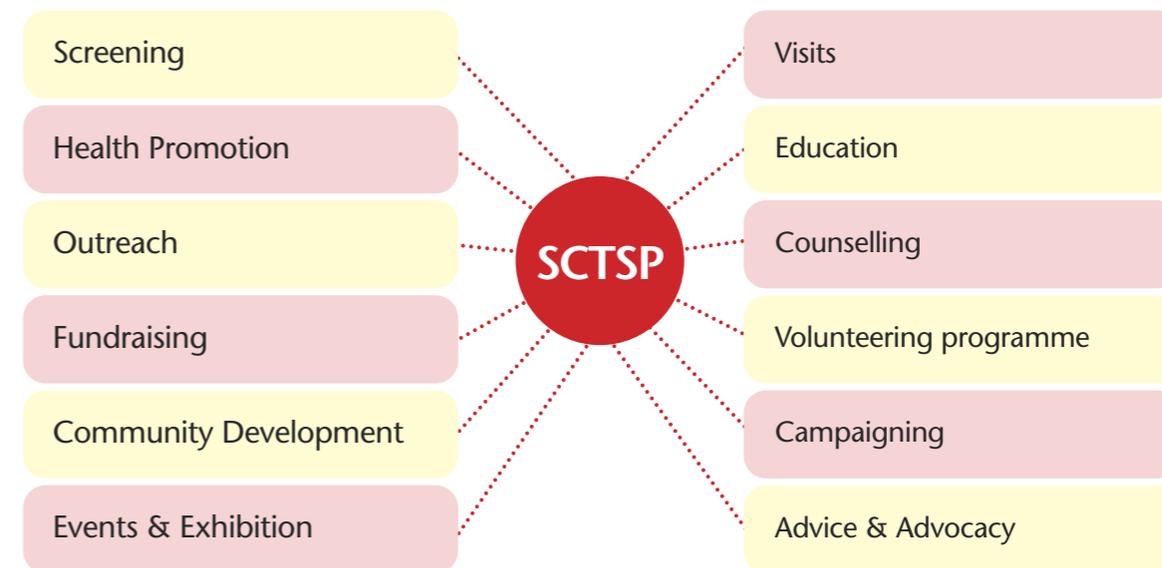
If both parents have Sickle Cell or Thalassaemia trait, there is a one in four chance (25%) for each pregnancy that the child will have Sickle Cell Disease or Thalassaemia Major.

- The haemoglobin within the red blood cells is affected.
- Individuals inherit the condition from their parents, it is present from birth
- The conditions are life-long. Bone marrow transplant is the only known cure and this is rare.
- The condition is an illness and usually requires medical attention.

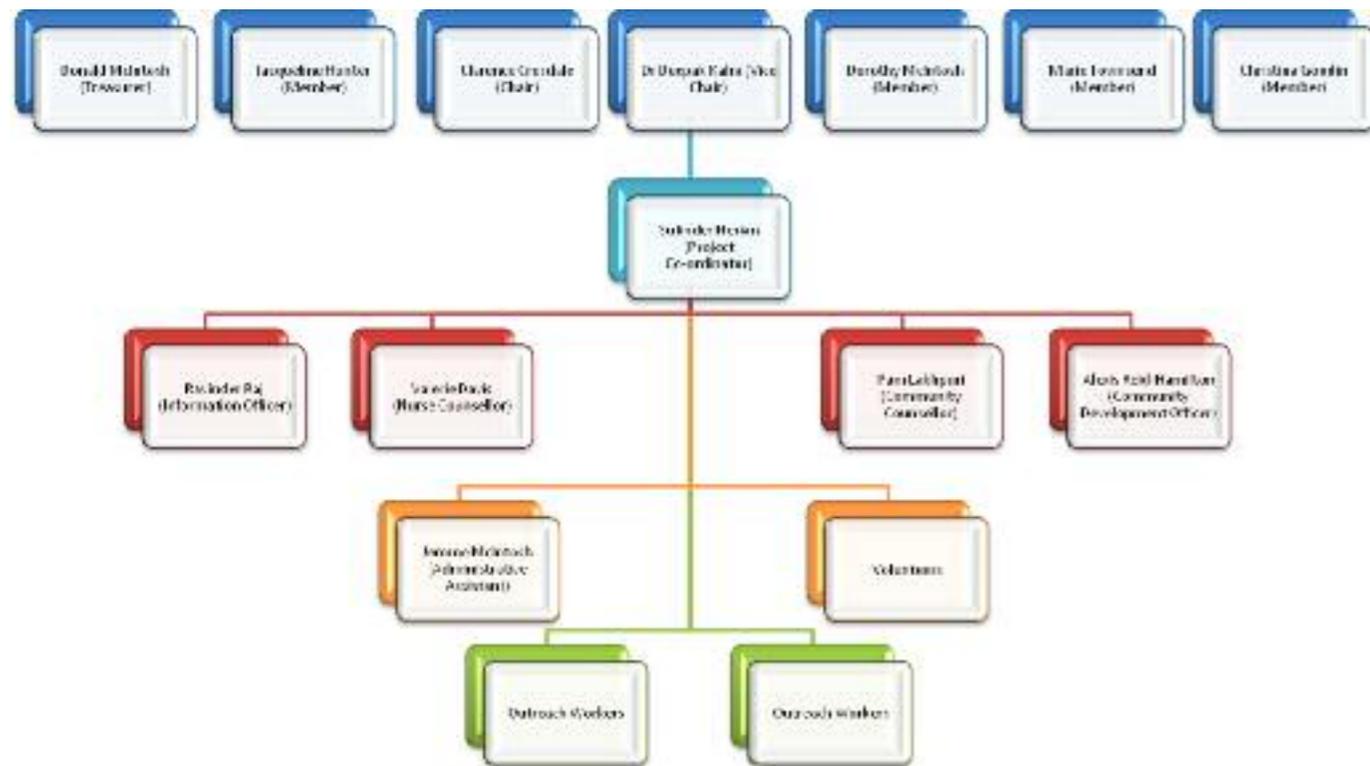
Service Provisions

Services

The organisation expanded its services to cover the three Black Country areas, Wolverhampton, Walsall and Dudley - each area has commissioned specific services under their respective contract. The table below gives an overview of the range of services available to service users.



Organisational Structure



Screening

The NHS Plan (Department of Health 2000) prompted new initiatives to be put into place to modernise antenatal and newborn screening services. This was to ensure that expectant parents can make informed choices about which tests to have.

Screening in early pregnancy is an essential component of good quality maternity care and a fundamental entitlement for the mother and her unborn baby. This commitment covers three different screening programs:

- Antenatal screening for Thalassaemia
- Antenatal screening for Sickle Cell
- Neonatal screening for Sickle Cell

During the period of April 2012 to March 2013, we received and processed 401 unusual blood results (these are individuals that have been tested and identified as having an unusual result).

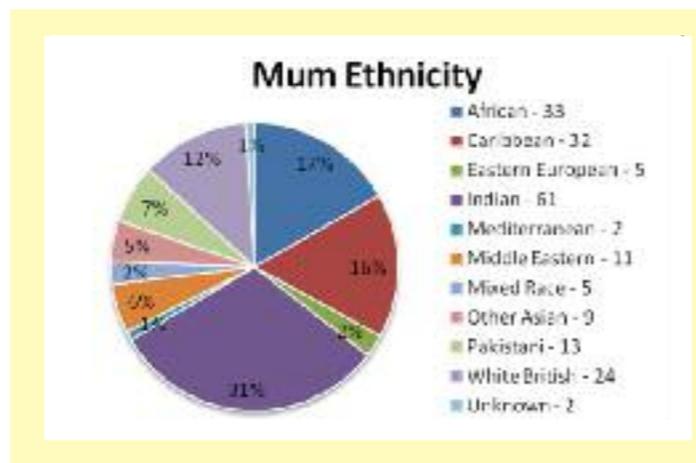
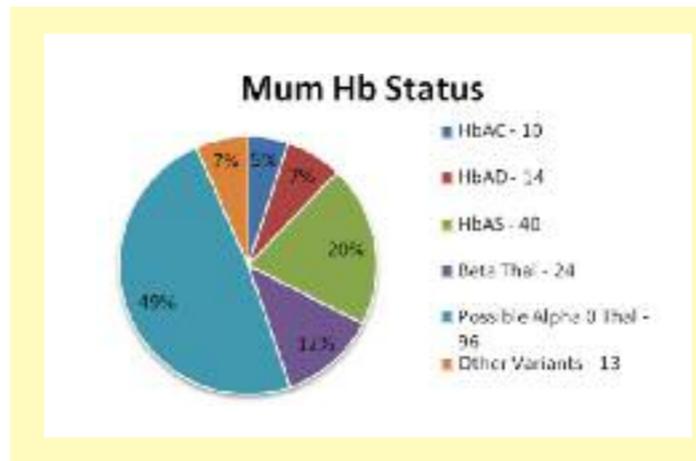
Antenatal Screening

The Project runs joint clinics with the Antenatal Team at both New Cross and Manor Hospital. All parents found to have an unusual haemoglobin variant are invited to the clinic in order to ascertain any risk to their unborn baby. Partners are encouraged to be screened. The couple are offered the option of an appointment allowing us to give further information on the condition and its implication, to include prenatal diagnosis and parental choice.

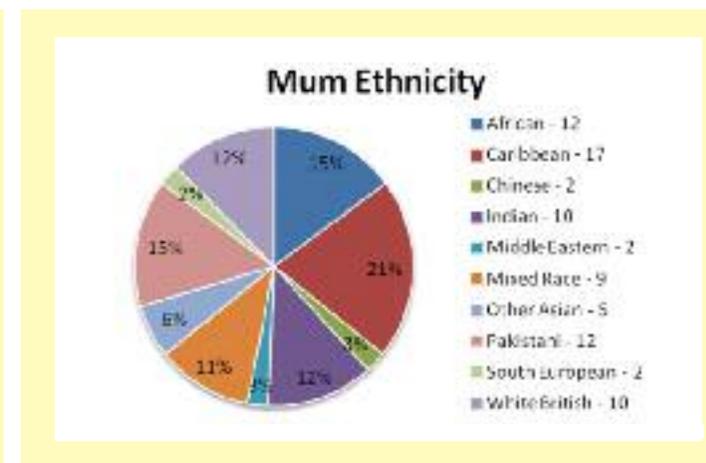
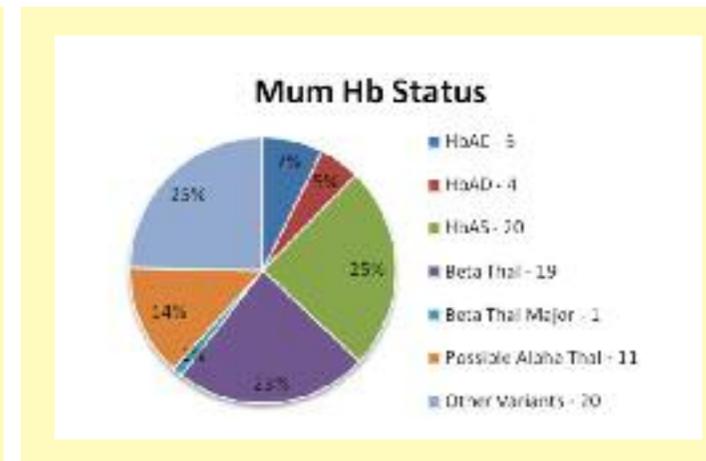
In this period, we identified 278 women to have an usual haemoglobinopathy status, of those 78 partners were also screened. However, 174 individuals did not require counselling as either an appointment was not necessary or they had previously received counselling.

	Area	
	Wolverhampton	Walsall
Number of women found to have an unusual Haemoglobinopathy	197	81
Number of Partners screened	43	35
Number of partners previously screened	51	20
Number of individuals attended counselling	99	94
Previously counselled/no appointment necessary	142	32
Number of at risk couples identified	12	12

Wolverhampton



Walsall



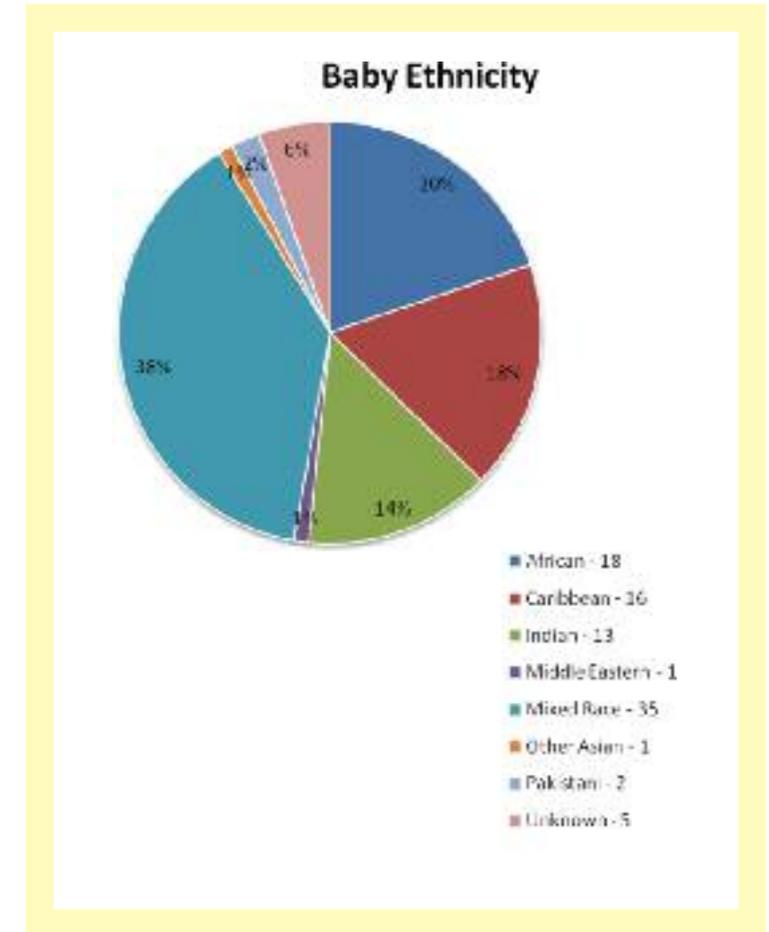
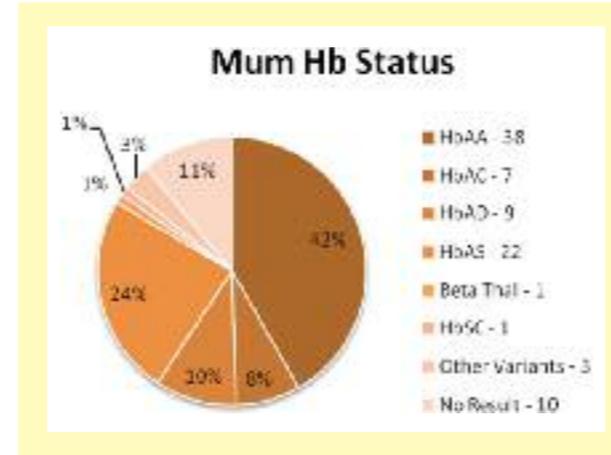
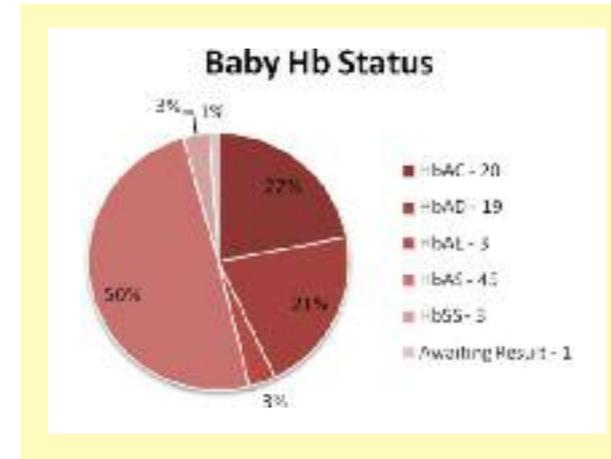
Newborn Screening

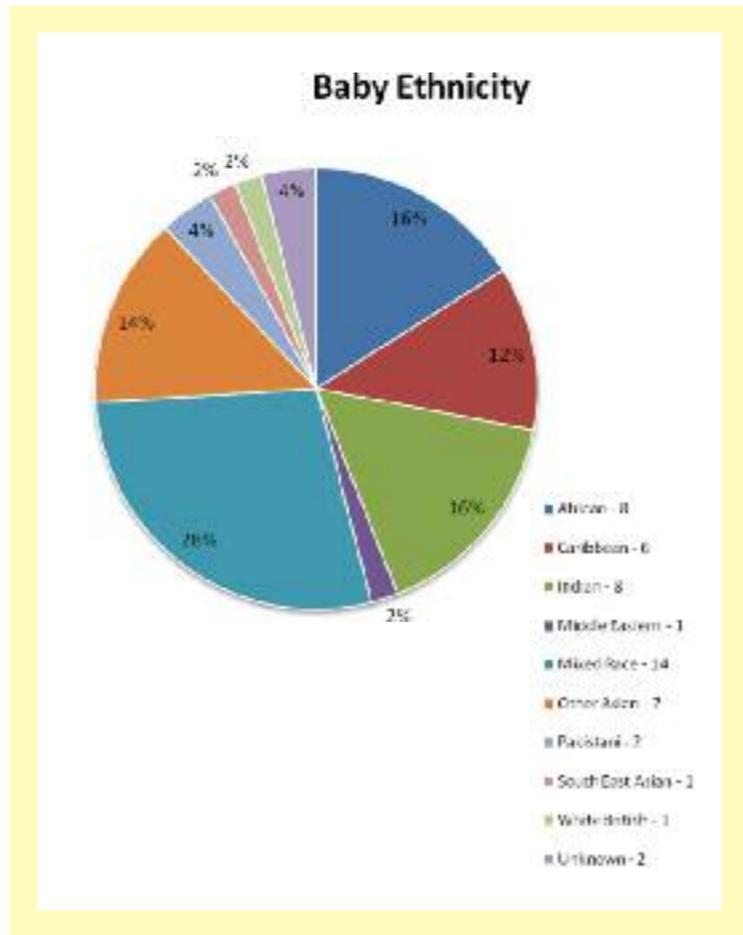
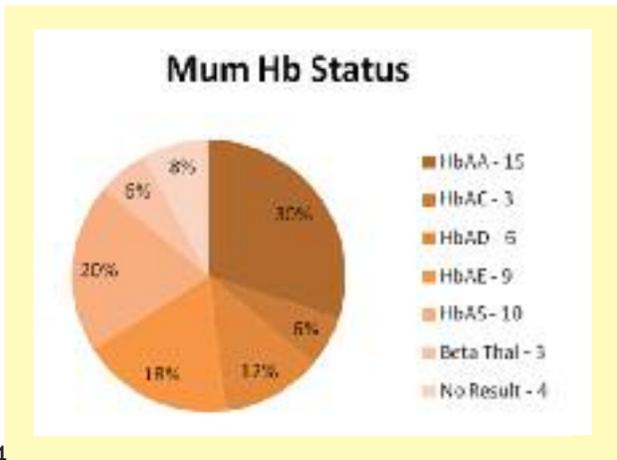
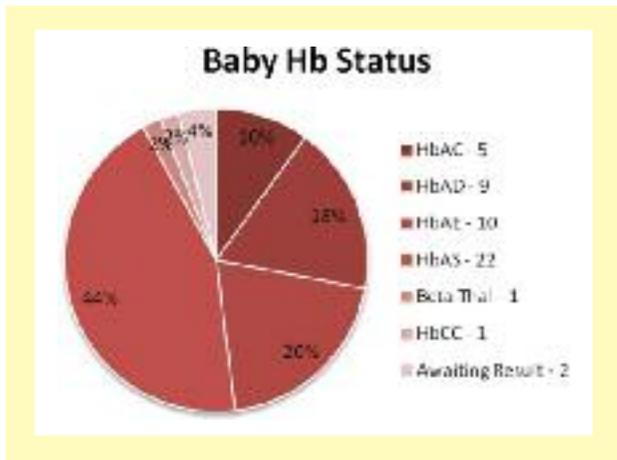
Through the neonatal screening programme, all parents are offered the chance to have their newborn babies screened for Sickle Cell as part of the routine 'heel prick' or 'blood spot' test. This test is designed to pick up several health problems including Sickle Cell as early as possible. Those babies thought to have Sickle Cell Disease are referred directly to the hospital clinicians with the option of being referred to the Project for ongoing support. Those thought to be carriers are contacted by the Project with the option of an appointment allowing us to give further information on the condition and its implication.

The table outlines all babies identified as having an unusual haemoglobinopathy.

Area	Number of newborn babies identified as carrying an unusual haemoglobinopathy	Number of newborn babies identified with a disorder	Number of Parents counselled	Number of additional family members counselled	Number of Partners screened as a result of counselling
Wolverhampton	91	2	102	32	58
Walsall	45	1	73	23	32

Wolverhampton





Genetic Counselling

All unusual results via the Antenatal, Newborn or self processes are referred to the Project for the offer of a counselling appointment and the main focus of counselling is to ensure:

- Individuals at risk of Haemoglobinopathies have full access to information
- Access to one – to – one counselling sessions.
- Appropriate and understandable language is used.
- Liaison with other professionals on counselling issues are undertaken.

- Counselling is provided respective of cultural backgrounds and the ethnic customs of families.

Counselling can be offered on three aspects;

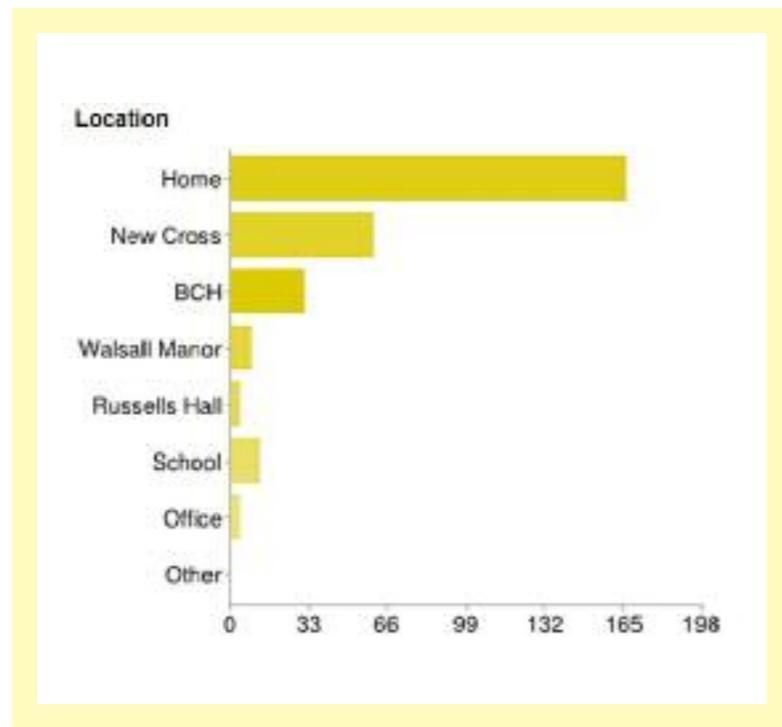
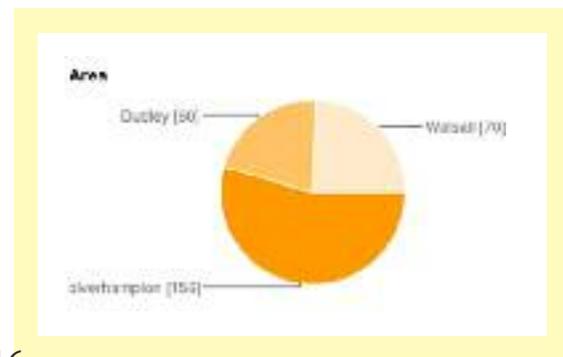
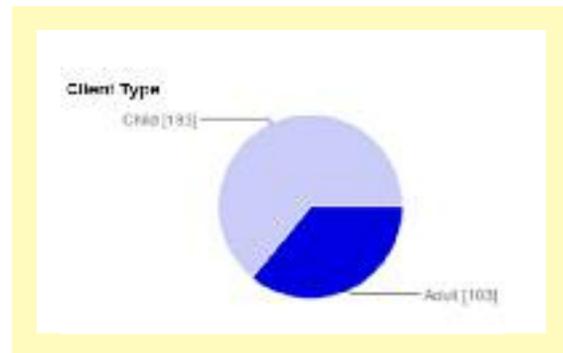
- Genetics (diagnosis and risk factors)
- Health and Social (effective care and management)
- Psychological (coping strategies)

Across Wolverhampton and Walsall a total of 263 individuals received counselling via the Antenatal and Neonatal screening programmes. Counselling is delivered at a number of venues which include individual's homes, Antenatal Clinic at New Cross and Manor Hospital and at the Projects offices at St Johns Square.



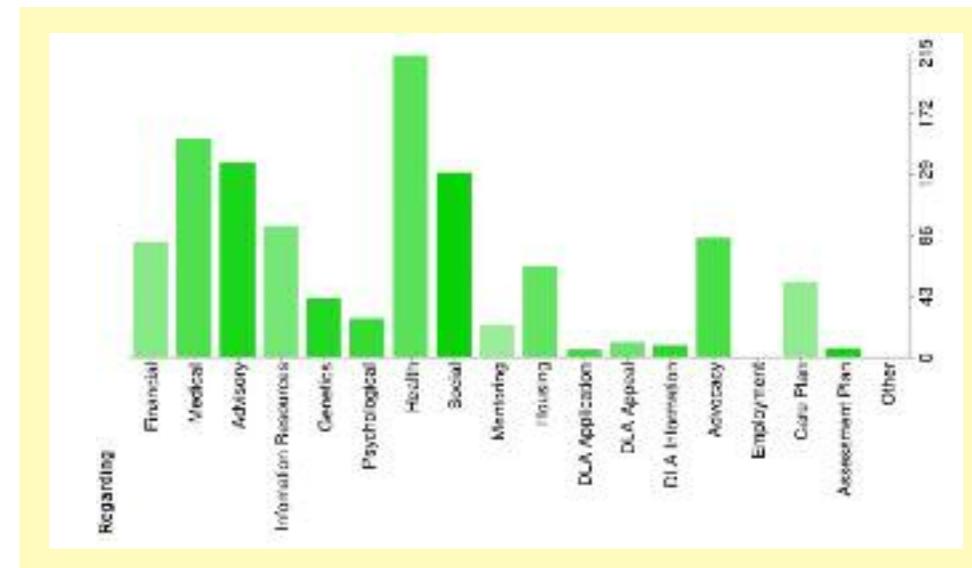
Visits

The Project also carries out visits to clients as part of our commitment to support service users in the management of their condition. Home visits are provided for affected children and their families. During this period the Project carried out 166 home visits and a further 104 hospital visits to provide assistance as and when required. A further 12 visits were carried out to schools and 4 visits were arranged at St Johns.



Support

- Guidance and referrals can be made to relevant agencies regarding Welfare benefits, such as housing, disability living allowance, social services etc.
- Hospital visits: support is provided when children attend the hospital for care and treatment.



"I found you and your service and support really helpful. You helped me while I was in hospital and your organisation has been supportive to my family. You have helped me more to understand my rights and how to be treated as a patient and what to expect from staff at the hospital."

Care Plans & Assessments

All affected children have assessments carried out; these are done with their parents/carers. All children attending nurseries and schools have a care plan, which is done with their parents/carer, school staff and other relevant health professionals; these can include their consultant, haemoglobinopathy nurse or counsellor.

During this period 53 care plans have been implemented at over 20 schools in Wolverhampton and Walsall.

Awareness sessions have also been delivered to some of the teachers involved with the care of affected children.

Below is a list of schools which have had care plans have been implemented:

Walsall Schools:

- Blue coat- infants school
- Whitehall nursery & infants School
- Alumwell Junior
- Yew Tree Primary – Junior
- Kingshill Infants
- Bentley West Infants
- Hydesville Secondary
- Aldridge Secondary
- Barr Beacon School
- Blue coat- secondary
- Sure Start- Chuckery
- Aldridge secondary school

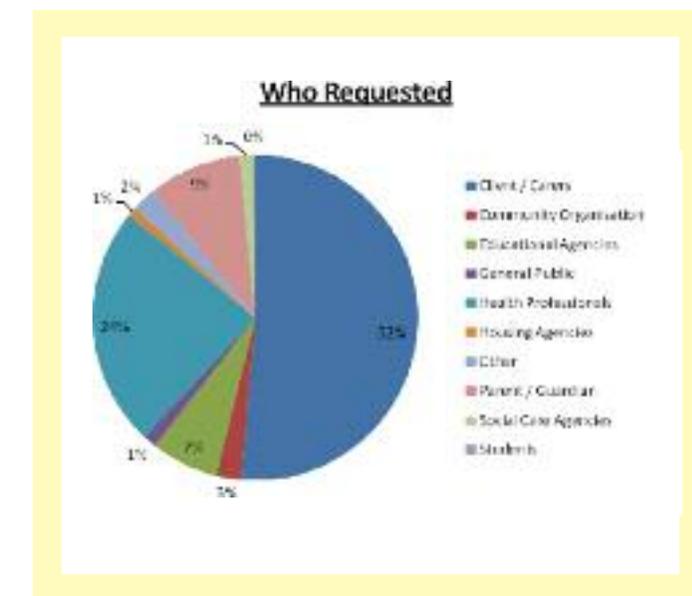
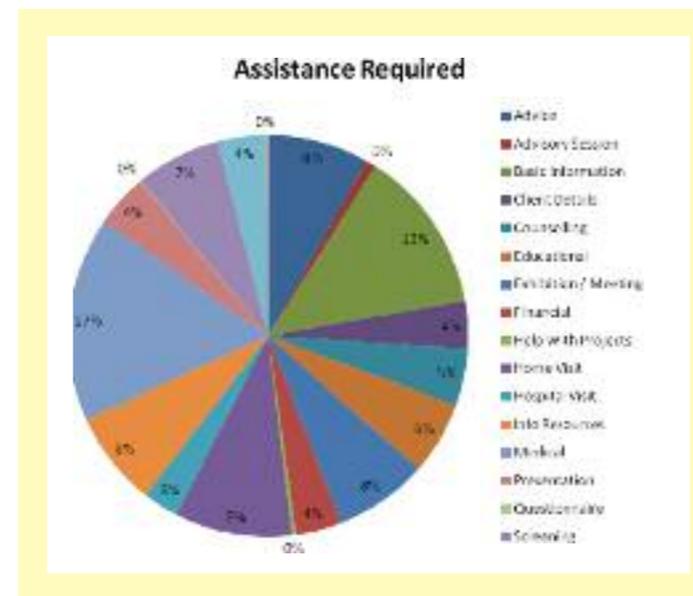
Wolverhampton Schools:

- Eastfield Primary infants
- Dovecotes Infants
- West Park nursery & Infants
- Oxley Primary
- St Stephens Church of England
- Trinity Church of England
- Woden Primary
- Bantock Primary
- St Edmunds Secondary
- St Peters
- St Lukes Primary
- St Marys & St Johns Primary school
- Graisleys Primary school

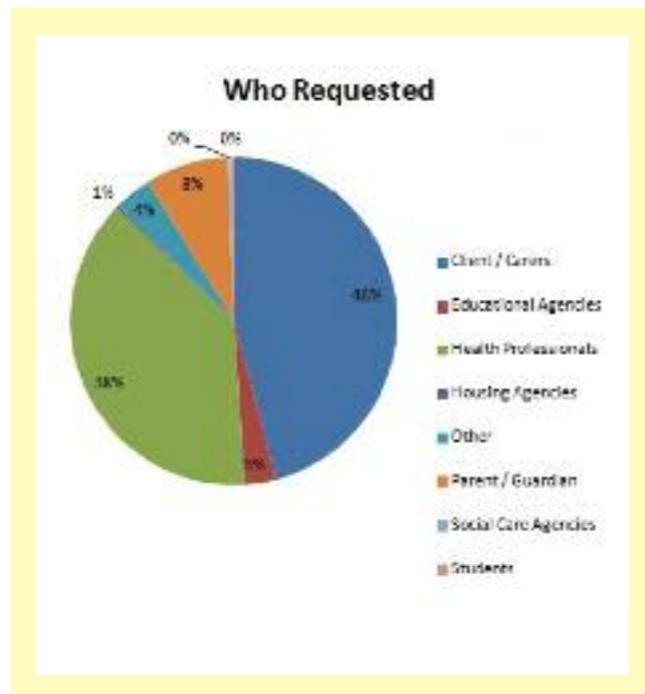
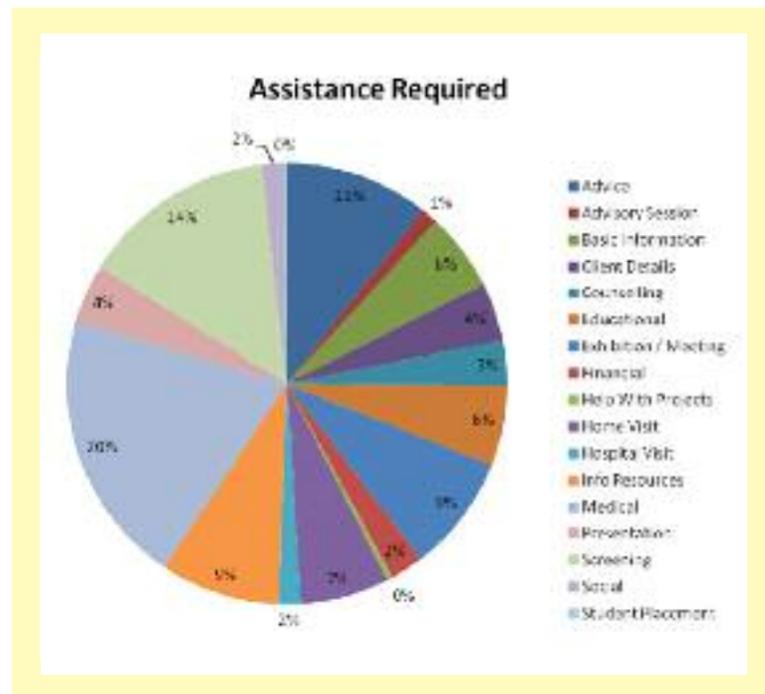
“My son and I were getting frustrated each time he moved up a year explaining to the teachers about sickle cell. I rang the SCTSP they helped to devise a care plan and gave useful information to the school. We now revise the care plan each year and school and new teachers receive information and the beginning of each new year of school”.

Enquiries

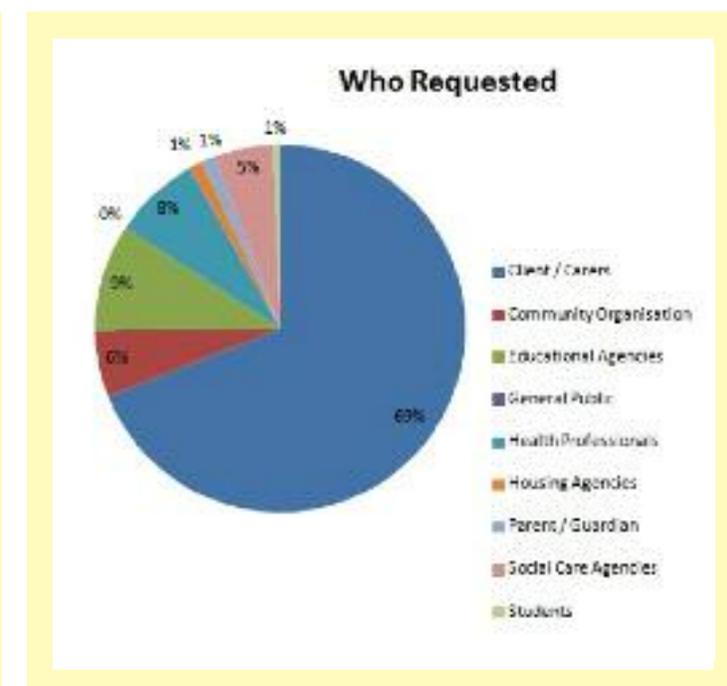
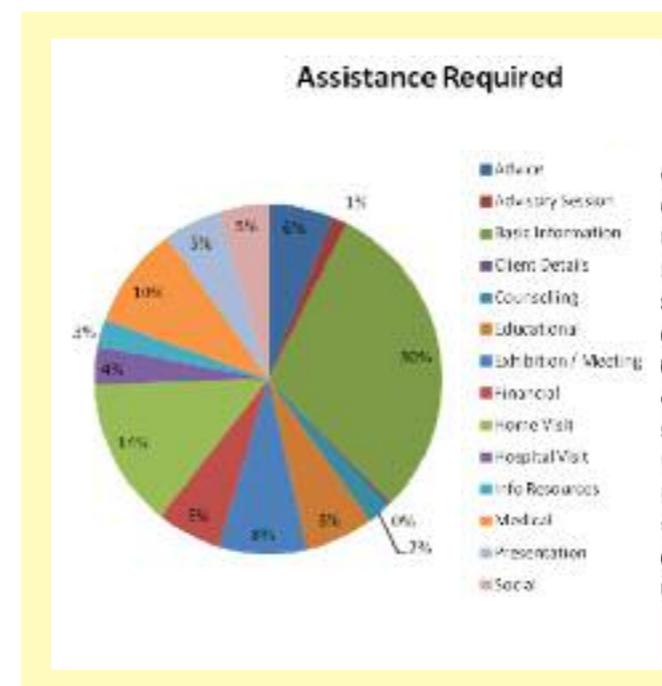
Enquiries are usually made through; telephone calls, visits to the office, letters of correspondence and emails. All enquiries are recorded in order to assess what requests are being made and also to determine any requirements to makes changes to our services and review the deployment of resources. During the year, the Project received 904 enquiries. All enquiries are treated in the strictest of confidence and no personal details are passed to any other organisation without the expressed consent of enquirers. The diagram below demonstrates the type of enquiries received by the Project and who the requests have been made by.



Walsall



Dudley



"The service was really good and very helpful. You helped with paperwork and have always been at the end of the telephone if I ever need anything. Whenever I need any help or support I know it's all confidential and know I will get the support I need."

Raising Community Awareness

Community Awareness is a vital component for the organisation. Preventative work within the community enhances knowledge and understanding of the conditions and how they can be managed. This year we were part of exhibitions held at various locations across Wolverhampton, Walsall and Dudley including:



Wolverhampton

Carers Week Event
Northcote Farm Town and Country Show
Great Brickkiln Seventh Day Adventist
Asda Wolverhampton
Sickle Cell Charity Fundraiser
ACSHAN Martin Luther King Day
Wolverhampton City Show
Wolverhampton University Health Event
World Sickle Cell Day

Dudley

BME Community Engagement Event
Claughton Centre Open Day
Black History Month
New Testament Welfare Association
Dudley Asian Womens Network
Dudley African-Caribbean Befriending Service
Carers Week at Russells Hall Hospital
Community Cohesion Group
Expert Patient Engagement Event
Big Bash Event

Walsall

Apna Ghar
Asda- Walsall
Asda Living
Asda Darlaston
Asda Bloxwich

Health Promotion

As well as carrying out awareness programmes within community settings the Project has also worked closely with the Regional Screening Programme and the Regional NHS Health Care Bus to promote screening and raise awareness of Sickle Cell and Thalassaemia at health promotion events.

The Regional Screening road show which was done in conjunction with the NHS Blood and Transplant Services took place across a number of areas which included:

- Walsall City Centre
- Merry Hill Centre
- Dudley High Street
- City Show Wolverhampton

The NHS Health Care Bus travelled across the West Midlands and beyond to promote Health initiatives, the Project was invited to be part of the team that took part in delivering information to the public about various Health issues. As well as taking part in areas covered by the Project we were also asked to attend in areas not covered by dedicated Sickle Cell and Thalassaemia specialist services.

The areas covered by the Project were:

- Wolverhampton
- Walsall
- Dudley
- Telford
- Stafford
- Stoke on Trent



Education

The Project works closely with both primary and secondary schools to raise awareness of both Sickle Cell and Thalassaemia with staff and pupils alike. As well as delivering presentations out in the community the Project is also involved in delivering educational sessions to a number of organisations, these have included:

Dudley

- Castle High
- Olive Hill Primary School
- Kates Hill Primary School
- Kates Hill & Sledmere Children's Centre
- Wrens Nest Primary School
- Adcote School for Girls
- Rainbow Day Nursery
- Thorns Community College
- St Johns & St Edmonds Primary School



Wolverhampton

- Young Voices
- Wolverhampton College
- Christ Church Infant School
- Smestow School
- Re-Entry (Park Village)
- Re-Entry (Park Village SEN Group)
- Re-Entry (Bilston)

Training

The Project actively supports health professionals within the primary care setting, as well as allied health professionals working in the wider community with regular training programmes.

During this period training sessions have been delivered in both Wolverhampton and Walsall.

Wolverhampton

School Health Nurses & Nursery Nurse / support workers: 45

Health Visitors, Nursery nurses/support workers: 35

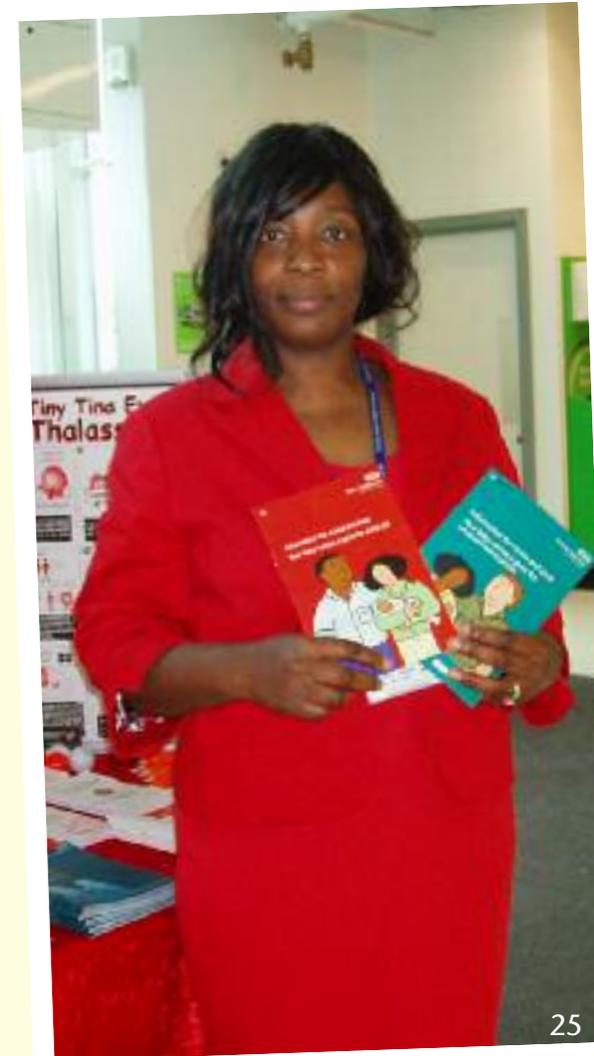
Schools in Wolverhampton

Walsall

During this period the Community Counsellor has delivered training sessions to over 50 Health Visitors and Support Workers. A further 30 school Nurses have also attended training sessions.

Training has also been delivered to GP reception staff and teachers of children affected by Sickle Cell and Thalassaemia.

Following a request made to the Project the Community Counsellor provided training to staff working at the Walsall Women's Refugee Centre, who come into contact with individuals who may be socially excluded from accessing appropriate health care services.



Fundraising

Raising some dough with Krispy Kreme's

For **World Sickle Cell Day** this year we teamed up with Krispy Kreme Donuts to raise awareness of the condition and raise money at the same time by selling Krispy Kreme donuts. Krispy Kreme provided donuts to the Project at a special fund raising price, which we then sold raising a total of £349.85. All of the proceeds from the day went towards the Projects Hardship fund.

The event itself was held at City of Wolverhampton College and was extremely well received by both students and lecturers alike. It was so well received in fact that by 14.00 we had run out of donuts!

We were also lucky enough to be mentioned on the official Krispy Kreme twitter feed for our endeavours. The Project would also like to take this opportunity to thank the staff at Krispy Kreme donuts (Bullring Store-Birmingham) and everyone who bought donuts for helping us raise this money for our Hardship fund.



Outreach Project

sponsored by Lloyds TSB Foundation

When the Sickle Cell and Thalassaemia Project began over two decades ago, it was in response to the obvious inequality in service provision in haemoglobinopathies for affected communities in Wolverhampton, the lack of knowledge of these groups and inadequate health service provision available to them.

However, as recent changes in benefits and welfare support have put additional pressure on those already living with these chronic conditions and therefore, the demand on our service also changes. Due to the increase in requests for outreach services, the organisation successfully secured a two year grant to deliver much needed community

services for the affected client group. To objective of this service is to form a multidisciplinary team to provide a range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital and premature admissions, support discharge from hospital and maximise independent living.

Currently the organisation supports the affected client group during episodes of hospitalisation; however this is generally in terms of advocacy and social. The launch of this new initiative will allow us to implement a range of activities which will support clients more intensely during periods of hospitalisation and agree a package of support for discharge and thereafter.

A number of our clients live by themselves with little or no external/family support, therefore our service will offer a range of interventions so as reduce the feeling of isolation especially during periods of being unwell, to include alternative modes of recovery i.e. massage, access to cognitive behavioural therapies and psychological support.

The service will be targeted to the affected client group, which affects approximately 102 adults in the three areas Wolverhampton, Walsall and Dudley.



Objectives

Discharge Planning

- To reduce hospital length of stay and unplanned re-admission to hospital
- Improve the co-ordination of services following discharge from hospital
- Tailored to the individual client leading to an increase in patient satisfaction

Home Support

- Practical assistance to include help with shopping, cleaning, laundry or food preparation
- Facilitate where appropriate help with personal care

Companionship

- Visit
- Lifestyle match

Volunteer engagement programme

- New volunteering opportunities
- Collaborative work between staff and volunteers in the provision for home support

“It’s good to know that the service is always there when I need them, especially in times of need e.g. hospitalisation, and that I don’t feel pressured to be in contact with them constantly.”

Case Study

The case study focuses on a service user who has two children with Beta-Thalassaemia Major. It came to our attention that the parent may need some extra emotional support as at the time they were going through bereavement after losing their young baby. A visit was conducted with the parent and they asked about bereavement counselling. An initial referral had been made to an outside agency but the parent did not feel comfortable speaking with a stranger.

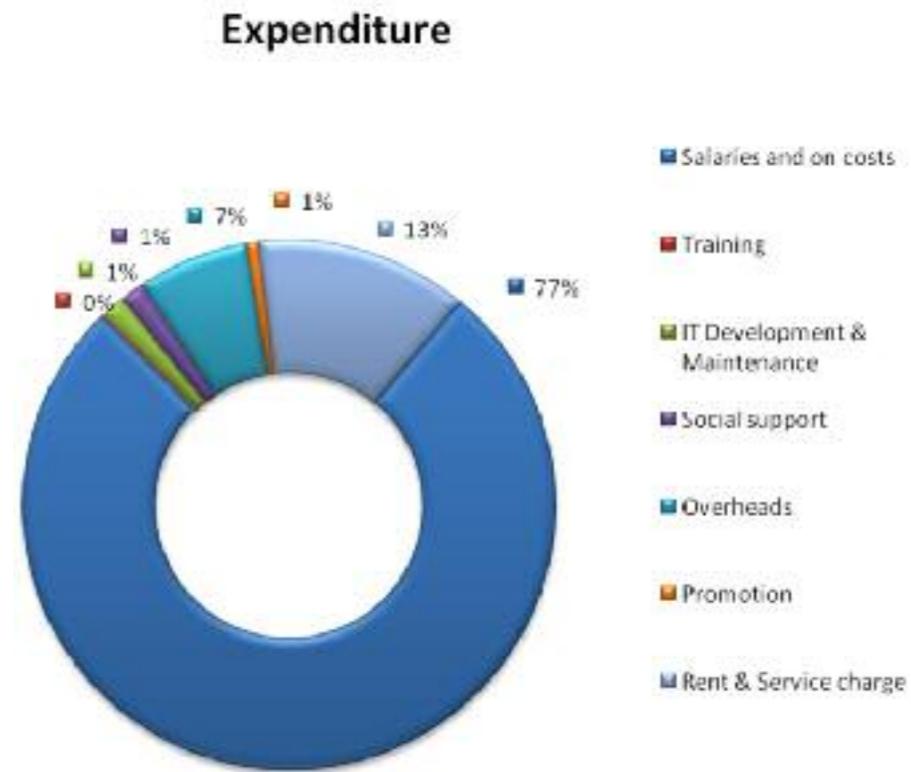
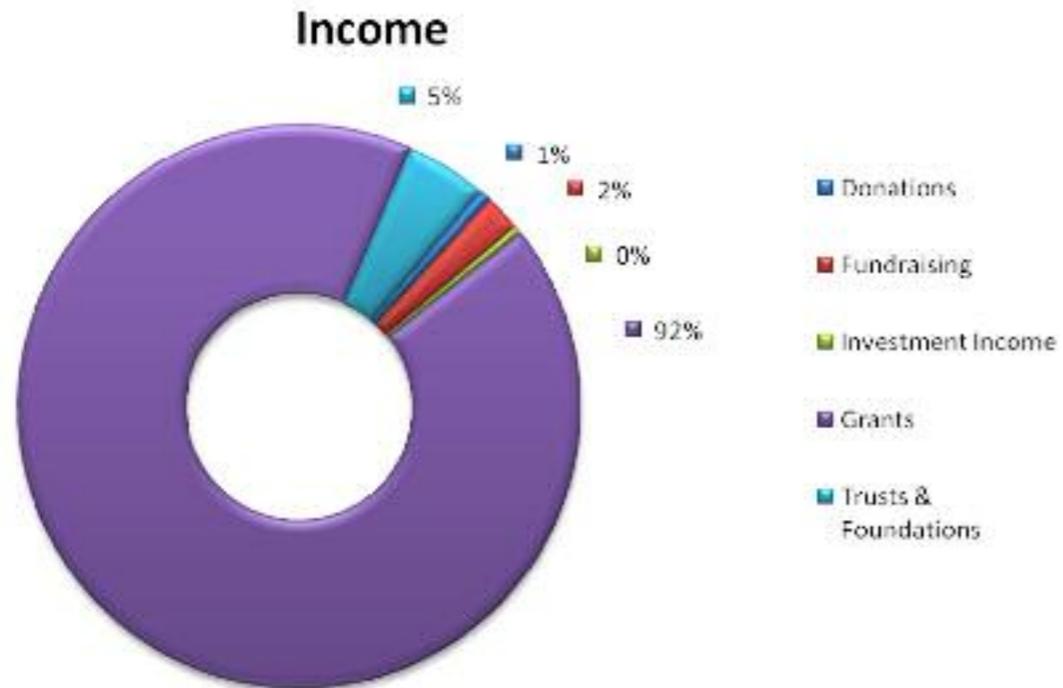
We worked with the parent on a one to one basis, offering regular visits and home support to help the parent to manage their grief. During this process we also explored other areas where support may be required. The parent highlighted that they would need some support financially to help towards the cost of the funeral. Through the support of the Project, an application for financial assistance from the Department of Work and Pensions was submitted. The total cost of the funeral was covered, which took a lot of the financial worry and strain away from the family as a whole, which in turn contributed to the positive and emotional wellbeing of the family.

This family had also identified further needs for financial support to help improve the quality of life for the two children with Beta-Thalassaemia Major.

A Family Fund application was completed to enable the family to purchase essential items for the affected children, which was also successful.

“As a result of the Projects support I was able to remain independent and not ask my family for any financial support which may have put more strain on them also. I lost my son and I was very depressed at that time. Through the work and support of the Project I was able to go on a holiday which helped me both mentally and emotionally”

Accounts



A full set of accounts have been prepared, and are available from our website (www.sctsp.org.uk) or by contacting the office on (01902) 444076/77.

Future Developments

1. To grow new business streams

2. To develop new markets

3. To continue to measure and promote the quality of new and existing services

4. To build strategic partnerships within the sector and engage with local and national decision making agencies in relation to the development of haemoglobinopathies

The Sickle Cell & Thalassaemia Support Project (Wolverhampton) would like to thank the following individuals and organisations for their continued support:

Organisations

Wolverhampton City Council
Wolverhampton City Primary Care Trust
Dudley Metropolitan Borough Council
Dudley Primary Care Trust
NHS Walsall Community Health
Walsall Hospital NHS Trust
Lloyds TSB Foundations

Donations

Andus
JP Stores
Fox Hotel
Select & Save
Castlecroft Stores
Super Stop
Jeremy Watson
Home from Home
Newhampton Road Post Office

Home from Home
Bradmore Wines
Ideal Eyes
Bruford Arms
Warstones News
Bills National Stores
Bradmore Post Office and News
JP Stores
UNISON



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