

## **Moravian Women's Association – Home and Overseas Paper – June 2014 - OSCAR**

**The MWA has given £1,000 to OSCAR.**

### **What is OSCAR?**

**OSCAR** is based in Birmingham and is the Organisation for Sickle Cell Relief & Thalassaemia Support, a voluntary organisation and registered charity established in 1972 primarily to promote greater awareness of Sickle Cell and Thalassaemia Disorders (**SCDs**).

### **What are SCDs?**

Sickle cell anaemia is a genetic (inherited) blood disorder in which red blood cells, which carry oxygen around the body, develop abnormally. Rather than being round and flexible, the sickle red blood cells become shaped like a crescent (or sickle).

These abnormal red blood cells can then clog sections of blood vessels leading to episodes of pain which can be severe. These episodes are called a sickle cell crisis. They can last from a few minutes to several months, though on average most last five to seven days. The abnormal blood cells have a shorter life-span and are not replaced as quickly as normal; this leads to a shortage of red blood cells, called anaemia. Symptoms of anaemia include tiredness and breathlessness; especially after exercise.

### **Complications**

Symptoms of sickle cell anaemia can have a significant impact on quality of life. Potential complications can be life-threatening, including:

- Stroke - where the supply of blood to the brain becomes blocked
- acute chest syndrome – where the lungs suddenly lose their ability to breathe in oxygen; often as a result of infection
- increased vulnerability to infection
- pulmonary hypertension - where the blood pressure inside the blood vessels that run from the heart to the lungs becomes dangerously high

However, following improvements in preventative treatment, many complications associated with sickle cell anaemia can be avoided and most people with the condition live much longer than previously.

### **What causes sickle cell anaemia?**

Sickle cell anaemia is caused by a genetic mutation that affects normal development of red blood cells. A genetic mutation is when the instructions found inside all living cells become scrambled in some way meaning one or more of the processes of the body do not work in the way they should. It is estimated that around 250,000 people in England have the sickle cell "trait"; most of whom have African-Caribbean ancestry.

Having the sickle cell trait itself will not cause a person to develop sickle cell anaemia. But if two people with the trait conceive a child then there is a one in four chance that child will be born with sickle cell anaemia.

Thalassaemia is a related condition.

### **What are OSCAR's aims?**

People affected by SCD may be disadvantaged due to social exclusion or lack of support. OSCAR aims to reduce social isolation, to educate clients, their families and carers to help manage their conditions more effectively and to maximise their quality of life, i.e. to help people live as positively as possible with SCD.

OSCAR also campaigns on behalf of individuals and their families, to provide services that are accessible and sensitive to the cultural and religious needs of clients and their families/carers.

OSCAR aims to raise awareness, education, publicity and campaign on matters relating to SCDs such as stroke, diabetes etc. It aims to undertake research and provide information relating to SCDs.

### **OSCAR's Vision**

SCD blood disorders are incurable. Whilst OSCAR looks forward to a life without SCD, its vision is to create the circumstances where people can "*live life to the full with SCD*".

### **How does OSCAR help?**

OSCAR runs a Youth Outreach Unite (YOU) Project aimed at children and young people aged 10-18 years old who are living with full condition of SCD, or have family or friends living with SCD, or are living with SCD traits.

The YOU Project provides opportunities for young people to come together from different backgrounds and communities within Birmingham to socialise and make friends, build networks, receive information and guidance based on individual need, have access to social, educational and recreational trips and activities. It also provides mentoring, training and workshops on nutrition, health, managing SCD and coping strategies.

The YOU project offers drop in on a weekly basis, programmes during half term holiday periods, outreach within the community and advocacy support in relation to health and education welfare.

The aim is for young people to become experts in living with their condition, improve skills and knowledge especially in a crisis, help raise awareness of genetic blood disorder, develop emotional resilience, improve well-being and self-esteem, and develop strong and close support networks.

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