MAKING A DRAMA OUT OF SICKLE CELL DISEASE

By Iyamide Thomas - Regional Care Advisor, Sickle Cell Society

As Africans and African-Caribbeans, many of us will probably have heard of sickle cell disease, since it is a condition that affects us more than other ethnic groups in the world. Out of 15 million people in the world believed to have sickle cell disease, approximately 10 million live in Africa. Sickle cell disease is particularly common in West African countries such as Ghana and Nigeria. The first written account of sickle cell disease was published in 1874 by an African called Africanus Horton, a medical doctor who was born in Sierra Leone in 1835 of Nigerian parents. It is therefore rather ironic that as Africans and African-Caribbeans, 'sickle' 'cell' 'disease' are three words we often run away from! There are a lot of myths, wrong beliefs and stigma about sickle cell disease and much of this is due to lack of education and awareness about the condition.

So, what is Sickle Cell Disease?

Sickle cell disease is a serious, inherited blood condition that affects the haemoglobin in our blood. Haemoglobin gives blood its red colour and also carries oxygen around the body. People get sickle cell disease if they are born with two unusual genes for haemoglobin, one from their mother and one from their father. People born with one unusual gene for haemoglobin and one normal gene are known as 'carriers' (or have the 'trait'). Someone with sickle cell disease has 'sickle haemoglobin' which causes their round red blood cells to change to a banana or 'sickle' shape when they give up their oxygen. The cells become stiff and get stuck going through the narrow blood vessels, stopping oxygen from reaching various parts of the body. This causes severe pain known as a 'crisis'. Over time, major organs such as the kidney or liver can be damaged. Sadly, death can sometimes result. Sickle cell affects mainly people who originate from Africa, the Caribbean, Asia, the Mediterranean and Middle East because the sickle gene developed as nature's protection against malaria. About 13000 people in the UK have sickle cell disease. Some people see sickle cell as a 'black' disease and so are ashamed of it. This is wrong as sickle cell disease can affect 'white' people too, though less frequently. Whoever it affects, it is nothing to be ashamed of!

Princess Deun of Arize talk-show and Iyamide Thomas

Making a 'Drama' out of Sickle Cell Disease

A special blood test will let you know if you carry the gene for sickle cell. In the United Kingdom there is a National Health Service Sickle Cell and Thalassaemia Screening Programme which offers screening to all pregnant women (antenatal screening) and new born babies (neonatal screening). If the woman carries the gene for sickle cell then the baby's father is invited to be tested too. If they are both carriers then there is a 25% chance that whenever they have a child it will be born with full blown sickle cell disease. You can get tested for the gene at any time of your life and it is even better to do this before you plan to have a child. This can be done through your GP or nearest sickle cell centre. 1 in 4 West Africans and 1 in 10 African-Caribbeans carry the sickle gene so it is important to know if you might pass it on to a child. There are approximately 240,000 people in the United Kingdom who are carriers and each year 350 babies are born with sickle cell disease.

To increase awareness of sickle cell disease and testing especially among the high risk community, the NHS Screening Programme has produced a drama on DVD called 'The Family Legacy'. It is a moving British-Nigerian drama about the impact of sickle cell disease on a marriage and a family. **The Family Legacy** is firstly being shown in Lambeth, Southwark and Lewisham where many West African and Caribbean people live. It is being shown at community groups, events, and workshops. Further screenings at local cinemas, family homes, hairdressers and barbers' shops are also planned. Watch out for posters and information about local screenings in your area so you can attend one of the many interactive sessions being held. However, if you really cannot wait to watch this exciting movie you can go to www.familylegacy.org.uk and watch it today! After that do complete the on-line survey and let us know what you think.

Junior's Story

The Family Legacy also contains bonus footage, including interviews with people affected by sickle cell disease such as Junior who tells his story:

"My name is Junior Kebbay. I am 29 years old and live in South London. I was born in the UK and my parents are from Sierra Leone. Just before starting a family in 1974, my parents went for screening since my mum already knew from Sierra Leone that she was a carrier. The test confirmed her status, whilst my dad was told he did not carry the sickle gene at all. This was good news since it meant none of their children would be born with sickle cell disease. Two of my older sisters were both diagnosed as carriers and when I was born in 1980 my parents were told I was also a carrier. At age two I fell sick and my ankles were swollen and painful. My mum rushed me to the GP and his diagnosis was that I might have sickle cell disease since painful swelling of the hands and feet was common in young children with sickle cell disease. A blood test confirmed I had sickle cell disease and my parents were shocked, especially since my father had been told he was not a carrier! In those days there was very little awareness of the condition even among health professionals and the screening tests were not well developed or interpreted. The Sickle Cell Society had just been formed in 1979 to try and raise more awareness of the condition. Growing up with sickle cell anaemia was difficult as I couldn't play football with my friends or go swimming, since exertion and the cold would trigger my crises. I took daily penicillin and folic acid. I still get admitted when I have very painful crises but I have good family support. The awareness of sickle cell has improved over the years. I myself have been called to talk to nurses to educate them about living with the condition. I am now a trustee of the Sickle Cell Society, which has done a lot to improve care for people with sickle cell disease and there are now clinical standards of care for adults with sickle cell disease in the UK. The Society's lobbying resulted in the formation of the NHS Sickle Cell and Thalassemia Screening Programme in 2001. Screening for sickle cell is now vastly improved. The antenatal screening which is offered to all couples gives them much more accurate information and counseling and allows them to make informed choices, something my mother and father didn't have because of a poor screening system in the past".

Junior Kebbay

Scene from Family Legacy

For further details about the Family Legacy please contact Iyamide Thomas on 07841-558611 or iyamide.thomas@sicklecellsociety.org

Useful Websites

www.familylegacy.org.uk (DVD drama)

www.sicklecellsociety.org (Sickle Cell Society)

www.sickleandthal.org (NHS Sickle Cell and Thalassaemia Screening Programme)

NHS Screening Programmes

Sickle Cell & Thalassaemia