

Africa Centre hosts Sickle Cell Screening

By Iyamide Thomas

On Monday 4 July 2011 all roads led to the Africa Centre in Covent Garden. No not because it was America's Day of Independence, but because 4 July is also UK Sickle Cell Day (now you know!) and the Africa Centre in collaboration with the Sickle Cell Society was hosting the screening of a film called 'The Family Legacy'.

The historic venue (now threatened with relocation) was a fitting place to host this latest screening not only for its central London location but also for the mere nostalgia it must have evoked in many of the Africans and Caribbeans who attended the event and who are from the two communities most affected by sickle cell disease. Sickle cell disease is a serious inherited blood condition that can cause anaemia and extreme pain. It affects approximately 15,000 people in the UK and in addition to the individuals who have full blown sickle cell disease, an estimated 240,000 'healthy' people carry one copy of the sickle cell gene.

Not just the usual Baby Drama

The Family Legacy is a moving British-Nigerian film about the impact the birth of a baby with sickle cell disease has on a marriage and a family. It was commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme to help raise awareness of sickle cell disease and testing. The film has been shown among the high risk target communities in an innovative dissemination strategy that includes barber and hairdresser shops, restaurants, family homes, churches and SKY TV. However, this recent screening at the Africa Centre was 'not just the usual baby drama'! It was unique in that the question and answer session that followed was conducted with an illustrious panel made up of Professor Elizabeth Anionwu CBE a co-founder of the Sickle Cell Society and who was the first ever UK sickle cell nurse specialist, Dr Lola Oni OBE a Specialist Nurse Consultant in sickle cell and Service Director of the Brent Sickle Cell & Thalassaemia Centre, Mr Olu Alake – President of 100 Black Men of London, Ade Solanke – Script Writer of Family Legacy, Jane Thorburn – Director, Family Legacy and Ahmed Sesay a sickle cell service user. The session was moderated by Iyamide Thomas, Regional Care Advisor of the Sickle Cell Society who served as an expert adviser in the production of the Family Legacy. Cast members present included African Voice's very own Golda John and also actress Joy Elias-Rilwan (remember the comedy

'Desmond's?'). Don't you just wish you were among the 64 strong audience which (to 'add insult to injury'!) also included Nollywood film producer Obi Emelonye ('Mirror Boy') and Professor Gus John. Another interesting attendee was an elderly Englishman by the name of Doig Simmonds who together with two colleagues had made a film on sickle cell anaemia in Nigeria in 1964. The audience was very diverse, made up of old and young and an almost even split of the sexes, so thankfully we got the men!

After Professor Anionwu set the scene with a rather humorous account of what sickle cell awareness was like in the early days, the post film discussion covered the many issues raised by the film such as stigma, blame, myths and beliefs often associated with sickle cell disease. Cecilia Shoetan, Director of Barking, Dagenham and Havering Sickle Cell Support Group raised the very important issue of religious beliefs and how these sometimes affect compliance with medication or accessing of medical care. Professor John asked about sickle cell and its impact on education, whilst Obi Emelonye and Olu Alake recounted their experiences of being tested for the sickle cell gene. (Interestingly both accounts had some humorous aspect to it). For both men and women, knowing whether you carry the gene is extremely important as each time two carriers have a baby together, there is a 25% chance their child could inherit sickle cell disease. To find out whether you are a carrier so that you can make informed decisions when starting a family you can request a special blood test from your GP or NHS Sickle Cell and Thalassaemia Screening Centre.

The Family Legacy sessions have proved an excellent way of raising awareness of sickle cell disease and testing in an informative yet entertaining way. The discussion at the Africa Centre (which by the way included delicious African food) had agreeably been a resounding success. As a follow-up request I have already arranged testing for one male attendee. Raising awareness among men remains one of the Screening Programme's top priorities as 50% of men whose expectant partners have been found to carry a copy of the sickle cell gene do not accept their invitations to be tested!

If you missed our unique Family Legacy Screening at the Africa Centre the good news is we are planning to do another during Black History Month in October. Of course you will just have to watch this space. Useful Websites: www.familylegacy.org.uk
www.sicklecellsociety.org
sct.screening.nhs.uk
Iyamide Thomas is Regional Care Advisor, at the Sickle Cell Society, UK



Panellists L-R: Iyamide Thomas, Dr Lola Oni, Ade Solanke, Olu Alake, Professor Elizabeth Anionwu, Jane Thorburn and Ahmed Sesay



Iyamide Thomas of the Sickle Cell Society introduces actress Golda John



Cross section of crowd listen attentively to Obi Emelonye's contribution