

**2011**

**Sickle Cell Disease- A Request for Partnership**

**Case History**

December 2005, when I visited my home, I went to pay the usual homage to aunties, uncles and all the important relatives. This is important for me; it sustains my roots to the land of my birth and the connection to where I belong. My mother expects me to do the full rounds so that she is not blamed for monopolising her son. This visit unlike all others would become a turning point for me. I saw a 12-year-old cousin who was pale and suffering bouts of pain. I was told she would miss school and because of this; quite often unable to complete her school assignment. The family was not sure what evil spirits were tormenting her. As I walked into the room she was in severe agony complaining of pain all over the body, jaundiced and pale. She was literally dying of severe anaemia (Low haemoglobin), was jaundiced and had swollen limbs. My cousin has sickle cell disease (SCD) and was experiencing one of several severe vaso-occlusive (bony) crisis and haemolysis (red cell destruction).

**The Burden of Disease**

SCD is an inherited blood disorder that requires two copies to show the full illness and a single copy from either parent is called a carrier stage. The carrier stage offers protection against malaria and a survival advantage. Africa has the highest prevalence of the disorder with over 75% of the world's patients living in Sub-Saharan Africa. In Nigerians 1 in 4 of the population carries the gene and 1 in 100 have the full illness and that would make it at least 1.5million SCD. However just like my cousin a large number of families are unaware of their status or have the wrong result; others have no idea where to seek help or advice. The majority diagnosis is made when the child falls sick and some may die not knowing this was the reason and may in fact attribute evil spirits instead.

The technology to make the diagnosis from birth is now standard practice in the western world including Brazil but no single African country has implemented a full scale newborn screening (diagnosis at birth). Nigeria does not have newborn screening even though this is one of the most effective ways of educating families, empowering mothers to take care of their children and teach patients self-care. The introduction of Newborn screening has been shown to increase patient survival, as well as improved the overall quality of life.

## **First Steps**

In 2009 we secured an EC-UNDP grant (N-253) to establish a pilot project by instituting newborn SCD screening from birth using new technology referred to as High Performance Liquid Chromatography (HPLC). This has now been established in Abuja. With the support of international community and universities in the UK and US, through Nigerian Diaspora; additional equipment has been donated to Kaduna, Katsina, Oyo and Anambra states. The initial programme has built a team of specialists' counsellors including doctors; nurses and technologists have received training at the national sickle cell centre, Lagos.

## **The Challenge**

The need for funding to continue the screening programme such as un-interrupted supply of reagents, capacity building, training of lab staff and other health professionals, capacity to sustain community mobilisation, counselling and patient follow up. There is a need to enhance the knowledge base not only in specialists' centres but also in secondary and primary care centres and support the professional development education and training of community extension workers.

## **The Way forward**

We are therefore proposing to continue this work by building on the expertise and contacts achieved through this project. Our aim is to develop a robust programme that is capable of leading to a national policy on newborn sickle cell screening that is adopted by state governments and has the support of the private sector and well meaning Nigerians.

## **The Proposal**

Our organisation, Collaboration for Health Advancement, Innovation and Research (**CHAIR**) is a group of Diaspora professionals working with delivery partners in Nigeria on health related initiatives. Our respective organisations abroad support the work and contribute the expertise of some colleagues to our projects including institutional financial and material support.

We are seeking to establish a long term health partnership with corporate bodies and individuals, to work with us on the Sickle Cell Cohort Research (SCORE) project as we strive to achieve excellent health services for the benefit of the Nigerian child, patients with SCD and their families.

## **The Request**

We are requesting long-term sponsorship by your company (**3-5 years**) in support any of the following activities Health promoting awareness events to mark the annual global sickle cell day (19<sup>th</sup> June) to cover conference venues, accommodation; workshop and seminars; PR activities –publicity, community surveys. Partners will be acknowledged in all publicity material.

Support the purchase of HPLC machines and the cost of reagents for the diagnostic equipment for one year or more

The management and administrative office support, specialist scientific staff to provide expert advice to individuals with SCD, patient support groups, the public and professionals.

Accommodation for international and national experts during seminars, research meetings

The long term goal is to ensure that the SCD diagnosis, management benefits from ongoing findings from research and other national developments in care. To work collaboratively with the national sickle cell network and other civil and private initiatives for the benefit of the Nigerian SCD patient.

SCORE board

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