WHAT CAN WE DO TO PREVENT CRISES?

1. Maintain a clean environment always
2. Maintain good personal hygiene
3. Protect yourself from mosquito bites
4. Take a malaria prevention medicine as prescribed by the doctor
5. Protect yourself from infections
6. Avoid extreme cold and extreme heat and from exposure to cold weather and rain.
7. Avoid strenuous physical exertion
8. Follow your doctor's advice
9. Seek prompt treatment whenever you are sick
10. Drink plenty of water/fluids
11. Take one folic acid tablet daily
12. Attend the nearest sickle cell clinic for proper care
13. Join a Sickle Cell Club and attend meetings regularly

WHAT CAN SICKLE CELL PROGRAMMES DO TO CONTROL THE DISORDER?

1. We can help prolong their lives and drastically reduce the number of their illnesses and crises by testing all new born children for sickle cell anaemia and if positive, counselling the parents about proper care right from the start.
2. We can reduce the suffering of affected people and their parents by making professional genetic counselling and good medical care available to all.
3. We can intensify research to find drugs that will prevent or make crises less severe.
4. The establishment of sickle cell centres to promote and co-ordinate counselling, diagnosis, proper care, health education, training and research into the disorder is essential for achieving objectives (1) to (3) above.
5. We can ensure that Stem cell transplantation is accessible and affordable to interested persons.

WHAT ARE SOME OF THE SERVICES AVAILABLE TO AFFECTED PEOPLE?

In Lagos area Sickle Cell Clinics are available at:

- Lagos University Teaching Hospital (LUTH),
- Lagos State University Teaching Hospital (LASUTH)
- General Hospitals Lagos and Gbagada
- Massey Street Children's Hospital

Outside Lagos, get in touch with the nearest teaching or State specialist hospital. These services are expanding. For more information, contact Sickle Cell Foundation Nigeria or Sickle Cell Clubs in your area.

WHAT ARE THE SERVICES AVAILABLE AT THE SICKLE CELL FOUNDATION NIGERIA?

1. Genetic counseling for the affected persons and caregivers and pre-marital counseling for sickle cell carriers.
2. Haemoglobin laboratory for blood tests
3. Automated Exchange Blood Transfusion service
4. Prenatal diagnosis for sickle cell disorder
5. Leg Ulcer treatment
6. Stroke prevention programme for children with Sickle cell disorder (2 to 16 years old)

WHAT CONTRIBUTION CAN YOU MAKE TO HELP PERSONS WITH SICKLE CELL DISORDER IN YOUR COMMUNITY?

1. Make donations for the treatment, care and welfare of affected persons
2. Join your local Sickle Cell Club and become an active member
3. Help start a Sickle Cell Club in your locality or in your school

Issued by:

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With the support of

SICKLE CELL ANAEMIA

THE FACTS

SICKLE CELL FOUNDATION NIGERIA
"Bringing Hope to the African Child"

THE FACTS

WHAT IS SICKLE CELL ANAEMIA?

Sickle cell anaemia is a lifelong hereditary disorder of the blood which results in anaemia, occasional body pains and some serious infections in childhood. To have it, one has to inherit the unusual variant sickle haemoglobin, known for short, as Hb S, from each parent and thus end up having HbSS. The usual or normal haemoglobin (Hb) is known as Hb A.

WHAT IS HAEMOGLOBIN?

Haemoglobin or Hb for short, is the red substance in the blood. It is responsible for carrying oxygen from our lungs to different parts of our bodies.

WHAT IS ANAEMIA?

Anaemia means a shortage of haemoglobin. The blood is therefore not able to carry as much oxygen as it should. The anaemia of sickle cell is due to the rapid breakdown of Hb S. It is not due to lack of iron and does not require treatment with iron-containing drugs or blood tonics. These can be harmful to the patient.

WHAT IS SICKLE CELL TRAIT?

Sickle cell trait is said to occur in a person who inherits only a single dose of the sickling gene (or seed) for Hb S from one parent and for Hb A from the other parent. This individual thus possesses the Hb AS. He does not have the symptoms of sickle cell anaemia but he is a carrier who can transmit the Hb S to his or her children. The presence of the normal Hb A suppresses the adverse effects of Hb S and thus protects such persons from suffering from the symptoms of sickle cell anaemia. These carriers of the sickle cell gene ie persons with sickle cell trait), are healthy, require no treatment and live a normal life span. One in every 4 Nigerians (25%) has the sickle cell trait -Hb AS. In order to find out whether one has sickle cell anaemia (SS), the trait (AS), or is free (AA), a laboratory blood test is necessary.

ARE THERE OTHER UNUSUAL OR VARIANT HAEMOGLOBINS?

Yes, very many, but Hb S is the most common of these all over the world. The second commonest variant haemoglobin in Africa is termed Hb C. It originated from Northern Ghana and Burkina Faso where about 1 in 5 of the population (20%) are carriers of the C gene (ie C trait); i.e. they have Hb AC. Hb C is also found in Nigeria especially in Western Nigeria and among the black populations of America, Europe and the Caribbean.

Some persons in these areas do therefore have HbSC disorder from inheriting Hb S from one parent and Hb C from the other. The symptoms of Hb SC are similar but much less frequent and much less severe than those of Hb SS. The term Sickle Cell Disorder is generally used to refer to a person with Hb SS or Hb SC or Hb S – betathalassaemia (SBthal).

HOW COMMON IS SICKLE CELL ANAEMIA IN NIGERIA?

Very common. About two of every hundred children born to Nigerian parents would have Hb SS. Our large population ensures that we have the largest number in the whole world.

WHAT ARE THE SIGNS OF SICKLE CELL ANAEMIA?

Usually, none in the first 6 months of life. After that, pale skin or eyes due to anaemia. Yellow eyes (Jaundice). Bone or abdominal pains or swelling. Swelling and pain of the hands and feet in young children.Fever, chest infections and rapid breathing. Pain crises are commoner in the rainy season or in cold weather. As the child approaches the age of puberty, he may remain small for his age and signs of puberty and menstruation may be delayed for some years.

Eventually, normal development occurs by the time they reach the end of their teenage years. Good nutrition will promote faster growth. In teenagers and adults, the pain crises occur less frequently but leg ulcers around the ankles may occur. They (SS) cannot cope well with strenuous competitive sports because of their anaemia.

Please note that not everyone develops all the above symptoms. Some are not even suspected of having the condition until they have reached their late teens or until a blood test is performed. Many remain well for very long periods and hate to be treated as objects of pity. They are as intelligent and capable as anyone else.

WHAT IS THE OUTLOOK FOR PEOPLE WITH SICKLE CELL ANAEMIA?

Good medical care and environmental sanitation, personal cleanliness, prevention of infection, balanced nutrition and prompt treatment of infections have made it possible for many children to survive and lead long and happy lives. At school age the child begins a less dangerous period of life. He is of normal intelligence and can perform very well at school.

They often succeed with careers in the professions and other areas. It is wise to avoid careers requiring strenuous physical activities. They can look forward to marriage and child-bearing. It is best for females to reduce the risk of child-bearing by limiting their children to no more than two. They should consult their doctors or contact Sickle Cell Foundation Nigeria for information about access to birth control.

WHAT ARE SOME OF THE COMPLICATIONS ARISING FROM THE DISORDER?

Though they can live long useful lives into old age, some complications such as bone pains, stroke, infection, severe anaemia especially in infancy and childhood often arise and can lead to premature death if not prevented or promptly and correctly treated.

They succeed with careers in the professions and other areas. It is wise to avoid careers requiring strenuous physical activities.