

INFORMATION
BROCHURE



SICKLE CELL FOUNDATION NIGERIA
"BRINGING HOPE TO THE AFRICAN CHILD"

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**“No one is useless in this world who
lightens the burdens of another.”**

—Charles Dickens



Profile

The Sickle Cell Foundation Nigeria (Limited by Guarantee RC 258517), is a non-governmental and non-profit making organization dedicated to the proper care and control of sickle cell disorder in Nigeria. The Sickle Cell Foundation Nigeria (SCFN) was registered in November 1994 to address important issues, such as, capacity building, research, policy development, policy implementation, monitoring and evaluation necessary for the sustained management and control of sickle cell disorder (SCD) in Nigeria. The SCFN operates a Private Public Partnership (PPP) with the Nigerian government through its affiliations with the Lagos University Teaching Hospital & College of Medicine, the Lagos State Ministry of Health, the Federal Ministry of Health and the Sickle Cell Clinics supervised in Delta, Edo, Kano and Lagos States. In addition, the SCFN is a DPI.NGO, indicating her merited association with the Department of Public Information (DPI) of the United Nations.

Vision

To alleviate the burden of sickle cell disorder in Nigeria and to ensure that all affected persons can live normal pain-free lives.

Mission

To develop a world class National Sickle Cell Centre and to drive the search for effective solutions to the problems associated with sickle cell and related disorders in Nigeria and beyond.



The National Sickle Cell Centre, Lagos

The Sickle Cell Foundation Nigeria (SCFN) was registered in November 1994 to address important issues, such as, capacity building, research, policy development, policy implementation, monitoring and evaluation necessary for the sustained management and control of sickle cell disorder (SCD) in Nigeria.

In accordance with WHO recommendation, the SCFN has developed the National Sickle Cell Centre, the first comprehensive sickle cell centre in Africa. It is situated opposite the Lagos University Teaching Hospital (LUTH) in order to foster an effective and sustainable collaboration with a teaching hospital and medical research centre. Proudly and significantly, all funds for its development were raised in Nigeria.

Background

Over 40 million Nigerians are healthy carriers of the sickle cell gene (Hb AS), while over 150,000 children are born each year with sickle cell anaemia (Hb SS). This is by far the largest burden of SCD anywhere in the world and most of these children would die in childhood from lack of access to early diagnosis and proper care.

Sickle cell centres are ideal institutions for addressing the problems of SCD as shown by their establishment in the USA over 40 years ago. Since then, the average life-expectancy of persons with sickle cell anaemia in America rose from 14 years in 1974 to 53 years in 2003 and to 60 years in 2014. The interventions that have made this possible were derived from research funded and carried out in America. This is what Nigeria should be doing – leading in research to improve treatment and care for sickle cell disorder.

Programmes

Our programmes can be broadly categorized under three headings namely:

1. Clinical (Diagnostic & Treatment) Services
2. Training & Capacity Building
3. Research

1.1 1.1 Clinical Services – improving the standard of health care of persons with sickle cell disorder

With partner support, we supply free drugs to, and oversee the running of 16 **dedicated Sickle Cell Clinics** located in Kano (6 clinics in one hospital); Benin (5 clinics in one Centre); Lagos (3 clinics in two hospitals) and Asaba (1 clinic). These clinics have, as expected, recorded improvement in the quality and longevity of lives of their patients. The goal of this intervention is to demonstrate to the host State governments and other stake holders, the positive impact of dedicated Sickle Cell Clinics on the lives of persons with SCD and hopefully, encourage them to expand the coverage of these Clinics within their States. Hence, we look forward to greater partnership support to enable us expand these facilities to every State in Nigeria.



Sickle Cell Clinic

1.2 Genetic Counselling Service

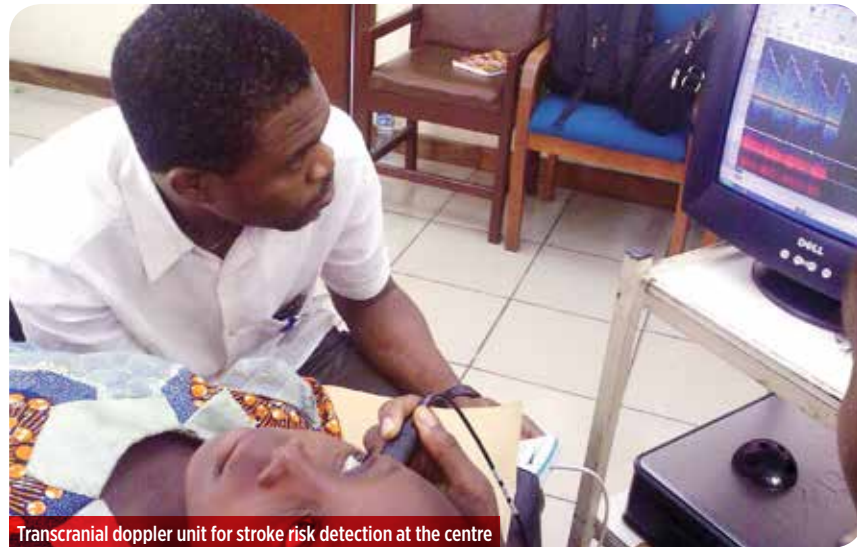
Genetic counselling, with appropriate health education, is crucial to the management of sickle cell disorder. We deliver expert genetic counselling on Mondays to Fridays at the National Sickle Cell Centre. In order to avoid disappointment, prospective clients are advised to call and book appointments ahead of time, for genetic counselling. We look forward to finding partners who will sponsor the expansion and sustenance of this service across the country.



Genetic Counselling in session at The Centre

1.3 Prevention of Strokes

About 1 in 10 children with sickle cell anaemia have a high risk of developing strokes (overt or silent). This debilitating complication can impede their mobility and/or impair their intellectual ability. Happily, strokes can be prevented, if children at risk of developing them can be identified and given preventive treatment. With modern trans-cranial Doppler (TCD) ultrasound scanning, children with a high risk of developing strokes, can be identified and thus protected with stroke prevention treatment. Children aged 2-10 years are most vulnerable but all children aged from 2 – 16 years are invited to have TCD scans once a year at the National Sickle Cell Centre. We look forward to partners who would sponsor our extension of this health and life- saving service across the country.



Transcranial doppler unit for stroke risk detection at the centre

1.4 Prenatal Diagnosis (PND)

Our PND service enables couples who have the possibility of bearing children who have sickle cell anaemia, find out early in pregnancy, the Hb genotype status of their unborn child. Our DNA Laboratory can provide prenatal molecular Hb genotype diagnoses of fetal samples. In most cases, when both parents are healthy S gene carriers (with Hb AS), the child is unaffected (HbAS or HbAA) and their anxiety will thus be allayed. When the fetus (unborn child) is affected, timely interventions, such as genetic counselling and appropriate early care, which go a long way to prevent/ reduce the frequency of illness or premature death, can be provided.

1.5 Laboratory Services

The Reference Haemoglobin Laboratory at the National Sickle Cell Centre offers world standard accurate haematological and Haemoglobin genotype diagnoses, including the proportion of haemoglobin fractions such as Hb A, Hb S, Hb F Hb C etc in each blood sample, thus eliminating the current high risk of obtaining incorrect Hb genotype results. The laboratory results can be emailed to requesting doctors and clinics.



The DNA Laboratory at the Centre

1.6 Exchange Blood Transfusion

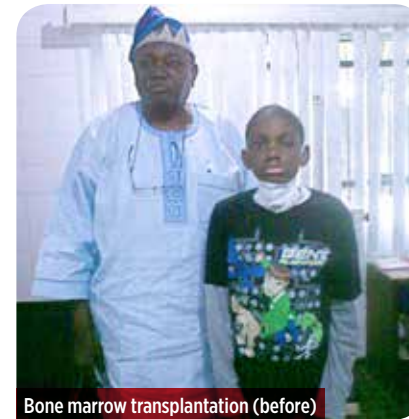
An increasing number of patients with serious complications of SCD have begun to access this life-saving service at our National Sickle Cell Centre. With our recently installed Apheresis machine, the procedure hardly lasts for up to one hour.



Exchange Blood Transfusion Unit at the Centre

1.7 Bone Marrow (Stem Cell) Transplantation

Bone Marrow Transplantation (BMT) is presently, the only known cure for SCD. Unfortunately, it is only regularly available abroad. In order to make it locally available, the SCFN in 2011, agreed with the IME Foundation in Rome and also with LUTH, to transfer BMT technology to Nigeria within 4 years. Since then, as agreed with the IME, 50 Nigerian children with sickle cell anaemia have travelled to Rome for BMT cure, as have 2 doctors and 2 Nurses from LUTH for BMT procedure training. Currently, we are working on developing a functional BMT unit at LUTH, but our major challenge is funding, for which we are appealing to corporate and individual Nigerians.



Bone marrow transplantation (before)



Bone marrow transplantation (after)

1.8 Advocacy, Information, Education & Communication

Advocacy should enable the Federal and State governments enact appropriate policies and allocate commensurate resources to facilitate world standard care for the SCD affected population. We organise programmes that create awareness and provide information and education through presentations or interviews at public fora, or broadcast on radio and/or television or published in the printed media. These are in addition to information dissemination through the distribution of our educational leaflets and audio visual materials, for which partnership support is needed.



Community Outreach Programme Epe, Lagos

1.9 Providing Welfare Services

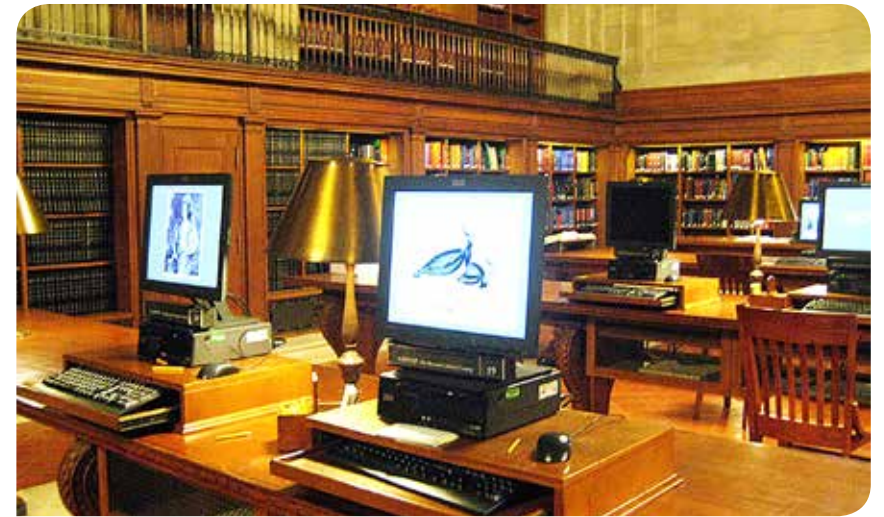
Persons with SCD are particularly vulnerable to the inadequate welfare support available in Nigeria. With partner support and some assistance from staff of the LUTH Social Welfare Unit, we have, as much as possible provided welfare services to needy persons with SCD, mostly in the following areas:

- a. Medical & Surgical Treatment Costs
- b. Educational Grants
- c. Job Skills Training
- d. Business Enterprise Support



1.10 Library Services

The Stanbic IBTC e-Library, which is within the National Sickle Cell Centre, provides access to print and digital resources on sickle cell disorder. The service is highly interactive and is open on weekdays to health care professionals as well as to other persons who desire reliable and accurate information on SCD. Membership of the library is available to the public and confers advantages.



1.11 Conferences and Meeting Facilities

The Union Bank Hall and the Accenture Seminar Room located within the National Sickle Cell Centre, are available for hire for conferences, seminars, workshops, meetings and social events. The venue is secure and has ample vehicle parking space.



The Union Bank Hall

2. TRAINING & CAPACITY BUILDING

The goal of capacity building is that every SCD affected person in any part of Nigeria should have ready access to a health care worker who can offer accurate diagnosis and appropriate treatment to him. Training programmes for capacity building within different cadres of health care workers and other stakeholders include:

- a. Genetic Counselling Training Courses
- b. Update Seminars on the Diagnosis and Treatment of SCD
- c. Understanding Sickle Cell–Seminars for School Children
- d. Practical Training on Prenatal Diagnosis
- e. Practical Training on Laboratory Diagnosis
- f. Training of Sickle Cell Specialist Nurses



Training of Genetic Counsellors

3. RESEARCH

The Foundation coordinates research into important areas of SCD. Research is key to progress in all aspects of SCD. We need to know precisely, the causation of specific complications of SCD and thus discover better remedies for their prevention, amelioration and cure. Funding for sickle cell research in Nigeria is very poor and the situation requires government and public understanding and support from National and International Funding Agencies.



4. THE NIGERIAN SICKLE CELL EXPERT ADVISORY COMMITTEE (NISEAC)

This committee of the Sickle Cell Foundation Nigeria was set up to examine all matters related to SCD and establish the standard of services that will save as well as improve the quality of lives of affected persons. The committee presently has about 30 members spread across the six geo-political zones in Nigeria. Partnership support to meet the cost of the committee's work would be of immense value. Listed below, are the committee's recommendations, which are available on our website and by email request.

1. The Federal and State Governments, as well as the organised private sector in Nigeria and the International Aid Agencies should urgently allocate funds annually for financing appropriate training, service, and research programmes to seriously address sickle cell disorder.
2. The Federal and State Governments should introduce newborn or infant screening for the early diagnosis of sickle cell disorder in Nigeria.
3. Prophylactic anti-infective measures against pneumococcal, meningococcal and other prevalent bacteria and malaria should be freely provided to all infants and children with sickle cell anaemia in order to reduce the high death and illness rates caused by these infections.
4. Adequate safe blood for transfusion should be provided in all States in Nigeria to save and support lives.
5. The training and recognition of a cadre of Sickle Cell Nurse Specialists should be introduced in order to improve our capacity to deliver better health care and education to affected individuals and families all over the country.
6. The committee is seriously concerned that numerous drugs are marketed in Nigeria with unproven claims of curative or palliative properties in the treatment of sickle cell disorder, to the detriment of many affected families who spend scarce resources on their purchase.

5. OUR APPEAL FOR SPONSORSHIP, DONATIONS AND BEQUESTS

We hereby invite you to partner or join us in controlling this national cause by supporting the work of the Sickle Cell Foundation Nigeria. Funding is necessary to enable our dispersed expert committee members meet regularly and engage in effective advocacy, monitoring and evaluation.

You can make a difference by donating regularly (say monthly) an affordable amount to the Foundation. As occurs worldwide, bequests of landed or other valuable property can provide impactful sustenance to the work of the Foundation. We shall be happy to discuss areas of interest, where individual or corporate sponsorship can effectively make a difference.

We are grateful to all our donors, past and present, for their contributions to Sickle Cell work in Nigeria. Donations are tax allowable and given the presence of SCD all over the country, the reflected benefit to substantial donors can be incalculable.

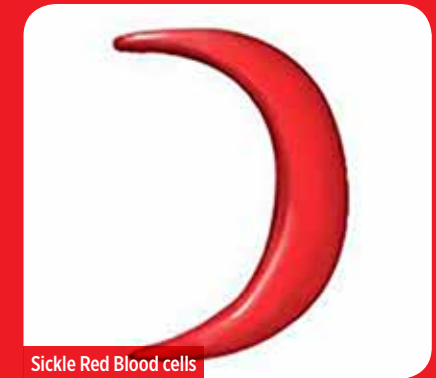
Donation Options

1. Transfer to any of the Sickle Cell Foundation Nigeria accounts below:
 - GT Bank: 0000742248
 - First Bank: 2003071049
 - FCMBank: 0148320013
 - Union Bank: 0007415604
2. By cheque- written in favour of Sickle Cell Foundation Nigeria
3. Electronically via our website – www.sicklecellfoundation.com
4. Cash donations are also acceptable.

Appendix — Sickle Cell in pictures



Normal Red Blood cells



Sickle Red Blood cells



Swollen, painful hand in a child with Sickle Cell Anaemia



Pain is hallmark of Sickle Cell Anaemia



Leg Ulcer in Sickle Cell Anaemia



Stroke in Sickle Cell Disorder

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Mrs. Toki Mabogunje



Mr. Bode Emmanuel



Mr. John Momoh, *OON*



The Hon. Federal Minister of Health



The Chief Medical Director, LUTH

Patrons

Louis Nnamdi Mbanefo, *SAN*
Felix Ohiwerei, *MFR*
Chief Opral Benson, *OON*

Company Secretary

ADCAX Nominees Ltd

External Auditors

Kreston OUC

Solicitors

Adepetun, Caxton-Martins, Agbor and Segun



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