

Sickle Cell Foundation Nigeria

Achieves Groundbreaking Bone Marrow Transplant: First non-profit organisation in Africa to lead a comprehensive Bone Marrow Transplant initiative for sickle cell disorder, in partnership with Lagos University Teaching Hospital (LUTH).



October 2024, Lagos, Nigeria – Sickle Cell Foundation Nigeria (SCFN) has achieved a historic breakthrough by completing the first-of-its-kind Bone Marrow Transplant (BMT) in Nigeria and West Africa, using advanced technology and expertise. In partnership with LUTH, the organisation established a state-of-the-art, advanced-technology Bone Marrow Transplant Centre in Lagos. This ground-breaking procedure marks a new era in healthcare for persons living with sickle cell disease in Nigeria, reducing the need for expensive medical tourism and providing accessible, life-saving treatment to thousands of Nigerians affected by the disorder. As Nigeria holds the world's largest population of persons with sickle cell disorder, this groundbreaking achievement underscores the country's significant role in leading the charge to address this global health issue.

Understanding Sickle Cell Disorder and its Cure

Sickle Cell Disorder (SCD) remains a significant public health challenge globally, affecting nearly 100 million people and accounting for over 50% of deaths among those with the most severe form of the disease. In Sub-Saharan Africa, where approximately 70% of sickle cell births occur, inadequate management has led to a high mortality rate before the age of five. In Nigeria, 150,000 babies are born annually with SCD and over 100,000 die before their fifth birthday. In addition, an estimated 50 million people carry the sickle cell trait and are at risk of passing it on to their offspring. With the average life expectancy of individuals in Nigeria living with SCD at only 20 years, the need for an effective cure has never been more urgent.

Bone marrow transplant (BMT) is currently the only established cure for the disease. For many years, this cure has been limited and unavailable in Nigeria, the sickle cell capital of the world, forcing families to seek BMT procedures abroad at exorbitant financial and socio-cultural costs. Recognising this critical gap, Sickle Cell Foundation Nigeria, embarked on a journey to establish Nigeria's first state-of-the-art Bone Marrow Transplant Centre.

*“The **SCFN/LUTH Bone Marrow Transplant Centre** is the first of its kind in West-Africa, and we are proud to offer a safe, quality, and accessible cure for sickle cell disorder here in Nigeria,” said Dr. Annette Akinsete, CEO/National Director of SCFN. “We have always believed that Nigerians deserve access to world-class healthcare at home, and this is now a reality.”*

Our BMT Journey




The First Effort (2009 - 2011): Thirty years ago, Professor Olu Akinyanju OON, established Sickle Cell Foundation Nigeria as an entity to address all aspects of sickle cell disease - from advocacy, training and research to prevention, treatment, care and support. Eager to bring the cure for the disorder to Nigerians in Nigeria, the Foundation partnered with the Mediterranean Institute of Haematology (IME) in Rome. This collaboration enabled 50 Nigerian children with SCD to undergo free successful bone marrow transplants in Italy. Unfortunately, this partnership was discontinued in 2015 due to funding constraints in Rome.

A Second Chance (2016): Undeterred, SCFN remained committed to its mission to make available international-standard BMT in Nigeria. In 2016, Prof. Olu Akinyanju, and Dr. Annette Akinsete, CEO/National Director of SCFN, met with Prof. Adetola Kassim. Prof. Kassim is an internationally-renowned professor of medicine, and Head, Centre of Excellence for Sickle Cell Disease at Vanderbilt University in Tennessee, USA. Together, they sought to bring the technology and expertise needed for BMT to Nigeria.

"We are proud to have played a part in this groundbreaking initiative with SCFN and LUTH," said Prof. Kassim, Professor of Medicine (Haematology/Oncology) & Clinical Director, Adult Stem Cell Transplant Program at Vanderbilt University Medical Centre, Nashville, USA. "The success of this global collaboration represents a major step forward in ensuring that the latest medical technologies and treatments are accessible to all, regardless of location."

Training and Capacity Building (2016 - 2023): To ensure a solid foundation for the BMT Programme, Sickle Cell Foundation Nigeria sponsored the training of haematologists, paediatricians, radiologists and adult physicians from LUTH in various areas of BMT at the Vanderbilt University Medical Centre in 2016, 2021 and 2022. In 2023, SCFN also sponsored the training of nurses from LUTH to India, in various aspects of BMT nursing.



Partnerships and Funding (2016 - 2023): Acknowledging that meaningful progress can only be achieved through strong partnerships, SCFN entered into collaborations with Vanderbilt University Medical Centre for BMT Training and with LUTH for Technical expertise, laying the groundwork for building a sustainable and world-class BMT programme.

Through SCFN's strategic fundraising efforts and with the generous support from the Chairman of SCFN Board of Directors, Chief Tunde Afolabi, MFR, NNPC/Chevron, civil works began on the designated site in LUTH - the Olikoye Ransome-Kuti Children Emergency Centre. SCFN also received significant funding and support from the Lagos State Government, private sector organisations and several individuals. By 2021, SCFN had reconstructed, fully-furnished and equipped the centre, ensuring it met international standards. The state-of-the-art SCFN/LUTH BMT Centre was formally declared open in January, 2022 by the Governor of Lagos State, Mr. Babajide Sanwo-Olu, represented by the Hon. Commissioner for Lagos State, Prof. Akin Abayomi.

The story of the SCFN/LUTH Bone Marrow Transplant programme will not be complete without recognition of the role of Lagos State Government, whose significant donation kick-started the development of the state-of-the-art BMT Centre. This speaks to the power of partnerships.

The First Successful Transplants (2024): Last month, the first two patients, one paediatric and one adult, were admitted to the SCFN/LUTH BMT Centre. Following weeks of preparation, including chemotherapy and blood transfusions, bone marrow stem cells were harvested from family donors and infused into the patients. After weeks of meticulous care, both patients have now been discharged from the hospital and are under observation.

*"Our **Bone Marrow Transplant experience** has been remarkable, filled with hope and certainty. I felt confident in the exceptional care we received at the Sick Cell Foundation Nigeria/LUTH BMT Centre. From the moment of admission to discharge, the medical staff provided round-the-clock attention," said the mother of one of the discharged patients. "The post-transplant care has also been thorough and attentive, with regular check-ins, adjustments to medication, and detailed follow-up tests. I truly couldn't ask for a better experience. The cost of treatment abroad was simply too high. I am deeply thankful to SCFN for their dedication in making this cure possible and accessible, turning hope into a reality for us and so many others. It's hard to put into words how grateful I feel."*

The success of these procedures is testament to the relentless efforts of Sickle Cell Foundation Nigeria, the technical and medical expertise of LUTH's team, the constant supervision of our Visiting Consultant Prof. Kassim, and the growing capacity of Nigeria's healthcare system.

"Partnering with SCFN on this historic project underscores our shared commitment to improving healthcare outcomes for Nigerians living with sickle cell disorder," said Prof. Wasiu Adeyemo, Chief Medical Director, LUTH. "This BMT Centre is a major leap forward in offering accessible treatment for those who need it most."

Looking Ahead

SCFN's journey is far from over. The bone marrow transplant procedure, while groundbreaking, remains expensive, and SCFN aims to make it accessible to those in need.

Many individuals living with SCD live below the poverty line and face significant barriers to care. This underscores the critical need for multi-sectoral collaborations and funding support to create a sustainable model for treating SCD in Nigeria.

To address these challenges, SCFN is currently developing the Access to Care Programme, a digital platform that connects sponsors with patients in need of financial support, while transparently tracking funding and treatment progress. With hundreds of inquiries for BMT, of which 127 patients potentially qualify for the procedure, the demand for BMT is clear.

SCFN continues to seek partnerships with government bodies, private organisations, and philanthropists to expand the program. Together, we can make this life-saving cure more accessible for all Nigerians living with sickle cell disorder.

About Sickle Cell Foundation Nigeria

Sickle Cell Foundation Nigeria is a global non-profit leader championing the prevention, care, cure and control of Sickle cell disease through clinical services and programmes. The Foundation 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.

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