

## **ACTION PLAN FOR SICKLE CELL PROJECT**

**The sickle Cell Project** is conceived as an advocacy programme to reduce/eradicate the scourge of sickle cell disease.

Sickle Cell Disease (SCD) is a hereditary disease seen most often among people of African ancestry. Nigeria being the most populous black nation in the world, unfortunately, has the highest incidence of SCD in the world.

SCD is caused by a gene mutation that leads to the production of sickle haemoglobin, which affects the function of the red blood cells in the body. This mutation is inherited from the parents of an individual in an autosomal recessive pattern. It is a very painful, agonizing, deforming and life-threatening disease.

Because of the autosomal recessive nature of this disease, the good news is that the eradication or bringing to minimal level of the disease is achievable if the public can be well informed. Most critical of the life saving measures for sickle cell disorder (SCD) is awareness and information management.

I know the pain and the horrors associated with people living with Sickle Cell Disorder because I have been there myself. I am a survivor of this disease. I have seen people die not from sickle cell disease, but from poor medical care, mismanagement, delay, lack of information and poverty.

To this end the Sickle Cell Project aims to:

1. Work with national and private medical institutions to establish functional and vibrant sickle cell clubs in Nigeria, starting with Abuja in collaboration with Federal Staff Hospital, Gwarinpa, Abuja and, through these clubs, provide opportunities for sharing experiences, learning from, encouraging and supporting one another
2. Create public awareness on:
  - Sickle cell disease
  - Importance of genotype testing
  - Management of SCD
3. Provide healthcare support for those living with SCD.
4. Extend the advocacy campaigns to various institution of learning, worship centres and communities with targeted talks and real life presentations.
5. Through all the efforts above, establish the fact that **SCD is not a death sentence.**