

## LEAD DEBATE ON SICKLE CELL ANAEMIA (PREVENTION, CONTROL AND MANAGEMENT) BILL, 2020 (SB. 166)

**Sponsor: Sen. Egwu, Samuel Ominyi (*Ebonyi North*).**

Mr. President, Distinguished Colleagues, permit me to first express my gratitude to you for the opportunity to lead the debate on the general principles of this all important Bill.

This Bill which was read for the First Time in this Hallowed Chamber on Thursday, 14<sup>th</sup> November, 2019, seeks to provide for the prevention, control and management of sickle cell anaemia and for other purposes connected therewith.

Mr. President, Distinguished Colleagues, the prevalence of Sickle Cell Anaemia in Nigeria has risen to an alarming proportion, yet little is known about it and far little is done about it. The endemic nature of this disorder in Nigeria has further compounded the problem of our health sector which is already in crisis. This is regrettable because Sickle Cell Anaemia is definitely preventable with minimal efforts and national consciousness.

As we know, Sickle Cell Anaemia is a genetic blood disease due to the presence of an abnormal form of hemoglobin. It describes a group of inherited red blood cell disorders. It is hereditary, transferable to children when parents who are carriers (AS and SS) marry either out of ignorance or negligence. Sickle Cell Disease has major social and economic implications for the affected child as well as the family. Recurrent sickle-cell crises interfere with the patient's life, especially with regard to education, work and psycho-social development. The disease is among the top-ten non communicable diseases causing significant disability, morbidity and mortality.

Mr. President, Distinguished Colleagues, the 2014 and 2015 reports of the World Health Organization (WHO) and Ministry of Health on Sickle Cell Anaemia in Nigeria are frightening. The reports state that Nigeria has the highest prevalence of Sickle Cell Disease (SCD) in the world with about 40million Nigerians carrying the genes. Nigeria is the most Sickle Cell Disease endemic country in the world with over 150,000 babies born with the serious condition every year, majority of whom die before the age of 10 with an annual infant death of 100,000. It was estimated that only five per cent of the children with Sickle Cell Disease live past the age of 10 in Nigeria, compared to over 96 percent surviving into

adulthood in the United Kingdom and the United States. The very few that live above the age of 10 are subjected to constant pain, suffering, hardship and eventual premature death resulting from the regular crisis associated with the disease.

Mr. President, Distinguished Colleagues, the purpose of this Bill is to curb these preventable massive deaths and avoidable hardships by placing a statutory duty on the Federal Government of Nigeria to engage in and encourage the prevention, control and management of the occurrence, spread and effect of Sickle Cell Anaemia. It will enable the Ministry of Health to direct, coordinate and supervise the prevention, control and management of the disease by performing the functions outlined in section 3 of the Bill. It will also empower the Ministry to accredit reputable public and private hospitals and medical clinics across the country, including the rural areas, to function as accredited participants in the prevention, control and management of the disease in Nigeria. It also empowers the Ministry of Health to receive donations, literature and other relevant materials from persons, organizations and bodies or governments and ensure proper utilization of such resources for the prevention, control and management of the disease.

The passage of this Bill will ensure that experts and other stakeholders are committed to the prevention and control of sickle cell disease in the country through adequate sensitization and counseling to prevent persons who are carriers (AS and SS) from marrying other carriers, while facilitating uniformity and standardization of care for those living with the disease. It will ensure that these campaigns, sensitization and services are taken to the rural areas across the nation where majority of the citizens are ignorant of this disease and do not carry out the relevant tests to ascertain their genotype before getting married. Proper sensitization of the rural dwellers and accessibility of the blood testing services, which this Bill seeks to enhance, will lead to an appreciable reduction in the number of fresh cases in a short time.

Mr. President, my Distinguished Colleagues, the passage of this Bill will attract no significant additional cost to the government because it is not setting up any new body or Commission; its implementation is to be carried out by the Federal Ministry of Health. It will however lead to achievement of better results through better utilization of resources, stronger political will, greater mutual accountability and more research in the area of Sickle Cell Disease and these efforts will culminate in reduced morbidity and mortality caused by the disease.

I therefore urge my distinguished colleagues to support the second reading and eventual passage of this Bill. By doing so, we would have played our part in bringing to an end the wanton, unfortunate and preventable hardships and deaths which hundreds of thousands of innocent young Nigerians are subjected to on yearly basis.

Thank you.