

Shine the light on Sickle Cell Disease

Daniel Roy Odur ,Executive Director of Uganda Sickle Cell Rescue Foundation highlights the burden of Sickle Cell disease In Uganda and advocates for increased awareness of the disease to help those affected.

On September 1st, 2023 Uganda will join the rest of the world to mark the month of sickle cell awareness under the theme “Building and strengthening global sickle cell communities, formalizing new born screening and knowing your sickle cell status”. This month is dedicated to promoting and increasing public knowledge and raising awareness on Sickle Cell Disease (SCD), while highlighting the challenges faced by the people living with the condition.

Sickle cell disease causes progressive organ damage and episodes of severe pain and acute illness. These episodes result from the sticky and stiff red blood cells which clog tiny blood vessels.

In Africa, Uganda has the fifth highest sickle cell burden and this condition affects every tribe, religion and social class. Sadly, the greatest majority of our population is not aware. The Ministry of Health indicated that 13.5% of our population is carriers of this condition. The prevalence of the condition varies by region and district. Being a carrier means that a person has a chance of having a child with sickle cell if they have a baby with another carrier. Such unions continue to add to the sickle cell burden in Uganda.

Currently about 25,000 babies are born with sickle cell disease every year. Up to 80% of those born will die before their fifth birthday without proper medical care. We know from the developed world that newborn screening, penicillin prophylaxis, and comprehensive care are associated with a 70% reduction in early deaths from SCD. However, these are yet to be effectively replicated in Uganda. The Ministry of Health has already rolled out newborn screening in high burden areas, but uptake is still low. As parents, it is our responsibility to request a sickle cell test when our babies have been born. Early identification of SCD through newborn screening is the first step in active management of this disease condition

In the same spirit, the Ministry of Health with the team of researchers from Makerere University shared results from a Hydroxyurea study, where they highlighted that this drug is safe in Uganda. However, that drug is not yet being supplied by the Government, we are relying on donations and the market cost is very prohibitive. As we mark the sickle cell awareness month, we need to remind the government of the need to avail hydroxyurea to the thousands of Ugandans living with sickle cell disease. Early diagnosis with prescribed medical care can offer that possibility, establishment of a sickle cell one stop center will enhance care and treatment

Daniel Roy Odur, Executive Director of Uganda Sickle Cell Rescue Foundation, ed@uscfruganda.org.



Courtesy of Tobi Awodipe

With just some basic early health care and regular follow up, babies could have a chance. Babies don't have to die. This will ensure that people living with sickle cell will become productive members of society, having families, jobs and contributing to the development of Uganda

This year's theme “Building and strengthening global sickle cell communities, formalizing new born screening and knowing your sickle cell status”, especially highlights two important aspects in the fight against sickle cell disease. First, breaking the silence and the need for awareness. The Uganda Sickle Cell Rescue Foundation, working with Roofings group, BMK group and Ministry of Health have closely worked together to raise awareness, offer free SCD screening and, counselling. However, more needs to be done. We are still faced with issues where schools refuse to admit students because of sickle cell and cases where husbands still blame their wives for bringing sickle cell into their homes. This therefore calls for concerted efforts to increase awareness of this condition in Ugandan communities.

Living with SCD is worsened by limited and hard to access formal support programs to help patients and families cope with the physical and psychosocial burden of sickle cell. People living with SCD are stigmatized and suffer discrimination from others who do not understand the disease. This results in the isolation of persons with SCD from family and the community. In our recent activities that were supported by Roofings group Ltd in Makindye Sabagabo, Mbarara University and Bundibugyo, 68.7% of the people interviewed randomly said they cannot marry a person with SCD.

As we mark this awareness month, let us show some compassion to people living with SCD. Let us all avoid the stigma and discrimination. Above all, let us all take a sickle cell test today.