Ugandans urged to prioritise sickle cell testing programme

Uganda is among the countries with the highest burden of the disease, with an estimated 33,000 babies born each year carrying the sickle cell trait or disease.

Parents and care givers from across Lango with their children attend a sickle cell screening and treatment event held at Lira Mayor's Garden on September 28, 2023. PHOTO/FILE

BY MUDANGHA KOLYANGHA

For thousands of families across Uganda, the battle against sickle cell disease is a silent lifelong struggle marked by pain, stigma, and limited access to care.

Health experts are urging married couples and those planning to have children to undergo sickle cell testing, warning that failing to know their status could put future generations at risk.

Sickle cell disease is a serious inherited blood disorder that affects the shape and function of red blood cells, causing them to form a crescent or "sickle" shape. This can lead to severe pain, frequent infections, anemia, and organ damage.

Speaking during a public health awareness campaign organised by Kavule My Home (KMH), a youth-founded organisation at Kavule Primary School playgrounds in Ikiki County last Sunday, Mr Samson Wamani, a health officer attached to Budaka Health Centre IV, urged couples to seek sickle cell testing to reduce the severity and spread of the disease.

He emphasised that testing is the first step in prevention.

"When couples know their sickle cell status before having children, they can make informed decisions and reduce the chances of giving birth to a child with the disease," he explained.

Health workers say when both partners carry the sickle cell trait, there is a 25 percent chance that their child will be born with the disease.

In Budaka District alone, there are 420 registered patients living with the condition, and at least two new cases are reported daily.

"Following the upsurge of the disease, a sickle cell clinic was established to support these patients," Mr Wamani added.

However, despite the high prevalence of the disease in the district, blood shortages remain a major challenge.

Ms Hellen Wanyenze, the assistant district health officer, said the shortage of blood has become a serious obstacle in the fight against sickle cell disease.

Mbale Regional Hospital serves several sub-regions, including Bugisu, Sebei, Teso, and Bukedi. However, Bukedi registers the highest number of sickle cell patients.

Dr Julian Abeso, the head of paediatrics at Mbale Regional Referral Hospital, said the high patient numbers have worsened shortages of both blood and medication.

Ms Eseza Namalwa, who lost a child to sickle cell disease and is raising another who is living with the condition, appealed to the government to provide more support to affected families.

Mr Geoffrey Mapiri, the KMH youth chairperson, said the organisation has been mobilising communities to raise awareness about sickle cell disease through blood donation drives, on-site testing, and community games aimed at supporting affected children.

The Ministry of Health has been rolling out awareness campaigns in both urban and rural areas, urging couples to include sickle cell testing in routine health checks.

However, for some couples, stigma and limited access to testing remain significant barriers.

Health workers are encouraging all people, whether married, engaged, or in long-term relationships, to make sickle cell testing a priority, just like HIV/Aids testing, as part of planning for a healthy family.

SICKLE CELL RANKING

Globally, the prevalence of the sickle cell trait is estimated at seven percent of the world's population, translating to 300,000 to 500,000 children born annually with the disease. Africa bears 80 percent of the global burden, and 50 to 80 percent of affected children die before their fifth birthday. Uganda ranks fourth after Nigeria, the Democratic Republic of Congo, and Tanzania, with 20,000 to 25,000 newborns diagnosed with sickle cell disease each year. (Source: WHO)

"Treatment of sickle cell patients can be expensive and emotionally draining. Testing before starting a family is one of the simplest, most effective steps couples can take," Mr Wamani added.

Despite being one of the most common genetic disorders in Uganda, sickle cell disease remains under-diagnosed, underfunded, and misunderstood.

Mr Henry Kisembo, the chief executive officer of AMAPH Initiative Africa, said the prevalence of the sickle cell trait stands at 25 percent in high-burden regions, yet stigma, low awareness, and limited access to early screening continue to worsen the situation.

"There is need for concerted action to reduce the burden of sickle cell disease through awareness creation, education, and community-based engagement," Mr Kisembo said.

He added that public awareness must be raised on the impact of the disease, its mode of transmission, and the importance of early diagnosis and care. Screening should especially be normalised for young adults and families.

A survey conducted by AMAPH Initiative Africa in partnership with Roman Research, and supported by the Ministry of Health, shows that Uganda is among the top four African countries most affected by sickle cell disease, with an estimated 25,000 children born with the condition annually, and a devastating 80 percent mortality rate before the age of five.

Mr Kisembo further emphasised the need to mobilise youth and academic communities to take ownership of advocacy for improved sickle cell care and education within their communities.

For 40-year-old Ms Betty Mwagale from Budaka District, the journey with sickle cell began with the loss of her first-born son at just two years old.

"He kept falling sick, had high fevers, and cried a lot in pain. We were told it was malaria until he died. Only later did we find out it was sickle cell," she recalled.

Her second child, now six, also has the disease. Although the diagnosis came early, she still struggles to access affordable medication and transport for her son's regular medical reviews.

"Sometimes I have to choose between buying painkillers or feeding the family," she says.

Uganda's health system is still not fully equipped to manage the burden of sickle cell disease. Many health facilities lack screening equipment and trained personnel.

Although the government launched the National Sickle Cell Control Programme in 2014, implementation remains weak due to funding gaps and low public awareness.

"Many children die before they are even diagnosed. Every screening, especially for newborns, can save lives, but it is not routine in most parts of the country. We need to integrate sickle cell screening into maternal and child health services," Mr Kisembo says.

Even so, there is hope. Local organisations such as the Sickle Cell Association and development partners like AMAPH Initiative Africa continue to raise awareness and advocate for improved services. They are also pushing for the government to make premarital sickle cell testing more accessible, especially to young people.

Dr Roseline Achola, a technical officer at the Ministry of Health, said sickle cell is becoming a serious national health burden.

"For those intending to marry, screening for the disease is critical to prevent further spread. This is a serious burden the country is facing," she said.

The highest burden is in northern and eastern Uganda, where 15 to 20 percent of the population carries the trait.