

# Managing life with sickle cell

BY TONNY ABET

**WAKISO.** Tracy Katusiime, 22, a teacher from Wakiso District was born with sickle cell disorder. She says she takes at least two different types of medicines each day due to the condition.

"My parents got to know my status when I was five years old. That's when I started experiencing episodes," she narrates. "But before, I didn't experience the symptoms of sickle cell. I did not have yellow eyes."

Katusiime recalls they first took her to St Francis Hospital Nsambya and then they went to Mulago Hospital.

"They (my parents) took me to Nsambya Hospital, but it [the pain] persisted. Then I was taken to my mother's family doctor. So, it is this doctor who told my mother that I might be having sickle cell," she says.

"The doctor advised my mother to take me to Mulago [Hospital]. Knowing what having sickle cell [disease] meant at that time, it was very hard for my mother so she gave me to my aunt. It's my aunt who took me to Mulago [Hospital] for the test and they found I had it," she adds.

When the results came out they didn't reveal it to her immediately.

"It took me like two years and I was now in Primary Two, that is when I got to know that it was sickle cell [disease]. I just thought it was being special... they would limit me from playing with my friends and by then we didn't have medicine, we only had folic acid, there was nothing like hydroxyurea," she recalls.

She adds: "There was nothing like hydroxyurea to stop the crises (pain episodes). I remember when I was still young whenever I was playing, they would tell me not to laugh too much, and if I was crying, they would also tell me to stop crying."

Katusiime says the disorder has affected her academic performance.

She also says the pain episodes have serious emotional and mental health effects. However, she notes that with the introduction of hydroxyurea, the pain episodes have significantly reduced, improving her productivity at work and general quality of life.

"I started going to Mulago Hospital clinic in 2008. By then, at Mulago, they would give us diclofenac and folic acid. But right now, we have hydroxyurea, you can take even a year without getting into crises/pain episodes," she reveals.

"I am taking two hydroxyurea tablets daily, and I have to take

folic acid daily and take folic acid, three in a month and do multivitamins every day. There are many medicines you have to use," she continues.

"Hydroxyurea is so good; I have been using it for six years. I have not had any of those serious side effects. It is not like panadol that they give you when there is a headache. Here, they first test your liver and your kidneys to find out if they can manage it," she adds.

However, she says access to hydroxyurea is still hard for people upcountry and that sensitisation is not focusing on the right people amid a lack of social support for the persons living with the disorder.

"Some people still buy hydroxyurea at Shs3000 yet in Kampala it is Shs800. Why doesn't the government fix the price at Shs500 to make everyone access? We are doing newborn screening for sickle cell but their main target is on mature people. Let them put more focus on young people to sensitise them so that they do not produce children with sickle cell. Most of the decisions about relationships and sex are made in school, let them go to school and sensitise and screen them before they fall into the ditch. We are very neglected," she says.