

Mother recounts loss of two daughters to sickle cell disease

BY SYLVIA NAMAGEMBE

KAMPALA. Hope Fortunate Achiro, 40, a pharmacist, lost two daughters to sickle cell disease within just two months in November 2024 and January 2025.

Ms Achiro had travelled to India on her doctors' advice as her daughters' conditions worsened, spending about a year seeking treatment. Despite the effort, she watched both girls die from the disease and its complications.

"My two daughters were always in unimaginable pain. Blood transfusions, oxygen, and ICU admissions became the norm for them and could not engage in any physical activity. Their education was so adversely affected that Gloria, at 16 years, was only in Primary Five, held back by sickle cell disease," she narrates.

Ms Achiro says the emotional toll of watching her children suffer was devastating. One of her daughters lost her speech a month before she died, while the older told her she was "tired and wanted to go" shortly before losing consciousness.

Caring for the two chronically ill children reshaped Achiro's career and family life.

"I used to leave the hospital, shower, go to work in Entebbe, then return in the evening because if one child wasn't sick,

the other was," she says.

During the year spent in India, Ms Achiro exhausted her sick leave and eventually lost her job.

"Sickle cell disease will test your love and your family dynamics. Social events became a luxury because my priority was always hospital care."

The financial burden

Beyond the emotional pain, the financial burden was overwhelming. Ms Achiro says medical bills exceeded Shs10 million per month, and treatment in India cost about Shs1 billion, forcing her to exhaust her sick leave and eventually lose her job.

"My medical bill was over Shs10 million every month. In India, I spent about Shs1 billion on treatment. Half of the funds came from government support, while the rest was raised through public contributions," she adds.

Today, Achiro is using her experience to call for greater awareness and prevention of the disease.

"Sickle cell may have taken my daughters, but it turned me into a fighter to make sure no child and no parent goes through what we did. It is so absurd that someone like me who has a medical background with both parents being medical professionals failed to give a priority to this disease testing," she laments.

She believes the disease can be dra-



Ms Hope Fortunate Achiro, a pharmacist who lost two daughters to sickle cell disease. PHOTO/ SYLVIA NAMAGEMBE

cally reduced through widespread testing and raising awareness.

"We can win this fight in 10 years or less. It is cheaper and easier to fight than HIV, malaria or TB. It just requires awareness and action. To the ladies, let love not make us blind and not screen for this disease that can cost our future happiness. Look at me, at my age, with no more children."

Ms Achiro challenges the govern-

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Hope Fortunate Achiro, 40, a pharmacist who lost two daughters to sickle cell disease

ment to strictly enforce teenagers and adults testing to curb the sickle cell burden.

"Schools, universities and religious institutions should make sickle cell testing a requirement just like HIV testing before marriage. Early testing is the most powerful tool to prevent such a heartbreak as I suffered."

ABOUT SICKLE CELL

Sickle cell disease is an inherited blood disorder causing red blood cells to become sickle-shaped, leading to severe pain "crises," strokes, and high mortality.

At least 80 percent of the cases occur in sub-Saharan Africa.

New treatment methods include gene-editing (Crispr) and cures.

Challenges include stigma, lack of awareness, and the need for more blood donors.

Facts about sickle cell:

Symptoms & Impact: Causes excruciating, "stab-like" pain crises, severe fatigue, anaemia, and high risk of strokes, with many affected individuals in Africa dying before age five. **Global burden:** Nigeria has the highest population of individuals with the condition, and about 300 babies are born with it in the UK annually. **Treatment & cures:** It is historically managed with blood transfusions.