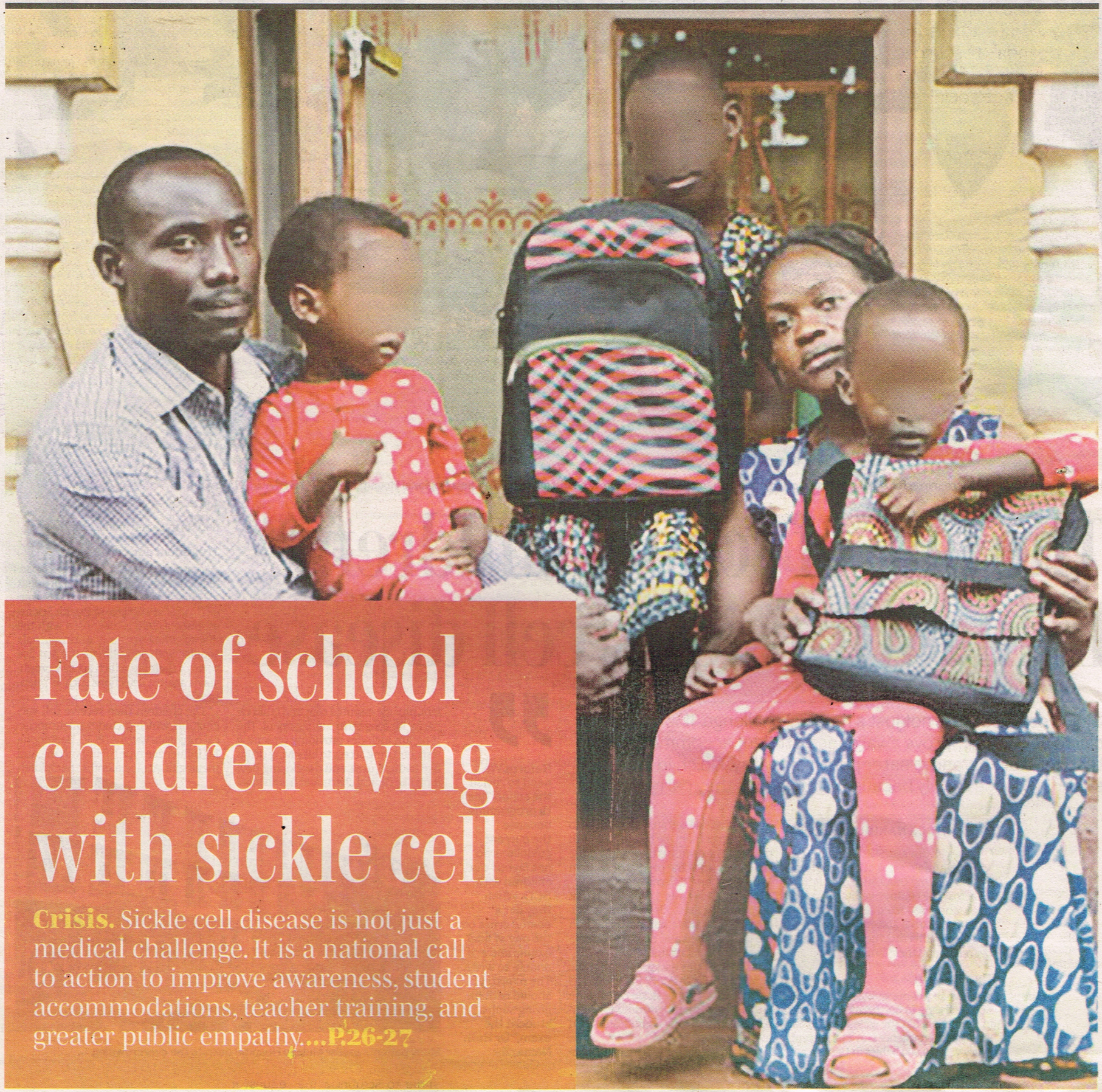


Fate of school children living with sickle cell

Crisis. Sickle cell disease is not just a medical challenge. It is a national call to action to improve awareness, student accommodations, teacher training, and greater public empathy.....P.26-27

Health workers conduct screenings for sickle cell disease and other conditions at a community health camp held at Jinja Regional Hospital. (PHOTO BY TAUSI NAKATO).

The fate of school children living with sickle cell disease

Sickle cell disease is not just a medical challenge. It is a national call to action to improve awareness, student accommodations, teacher training, and greater public empathy. No child should suffer in silence simply because of the genes they carry.

BY BEATRICE NAKIBUUKA

Sickle cell disease (SCD) remains one of Uganda's most silent epidemics, affecting thousands of children across the country, yet its impact is often underreported and misunderstood. It is a social and educational barrier, deeply affecting the lives of young Ugandans and their families.

The statistics

One in 10 people in Uganda has the sickle cell gene. In northern Uganda, one in five people has the gene, and the national gene prevalence is at 13.3 percent. Every year, 20,000 babies in Uganda are born with sickle cell anaemia, and 30 to 45 percent of them die before their fifth birthday. The disease is the leading cause of admissions at the paediatric ward in Mulago National Referral Hospital.

Today, there are over 5,000 patients that are attending the sickle cell clinic in Mulago Hospital alone, but many children are undiagnosed and do not even contribute to these statistics.

It is against this background that the Ministry of Health (MoH) in Uganda has launched a national sickle cell disease (SCD) screening programme for newborns to ensure early identification and management.

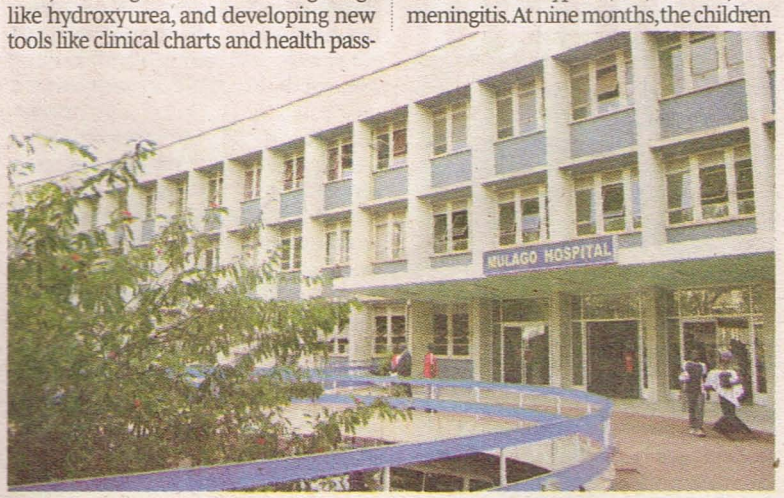
The initiative, aims to screen every infant, provide essential care, and build capacity for long-term management. The program includes providing screening tests, ensuring access to lifesaving drugs like hydroxyurea, and developing new tools like clinical charts and health passports to track and manage the disease.

> **Reform.** We need to revisit the school health programme because the current guidelines do not favour the children with SCD. When they get a painful crisis on the day of final exams and are unable to write. The ministry should rethink giving such a student the exam," Dr Ruth Namazzi.

Treatment and care

According to Dr Ruth Namazzi, a paediatric hematologist at the Department of Pediatrics and Child Health of Makerere University College of Health Sciences, when a child is diagnosed with the disease, they get daily antimalarials coupled with penicillin for the first five years of their life, which act as a prophylaxis against infections such as pneumonia.

"The children then receive full vaccination, which includes pneumococcal conjugate vaccine (PCV), Haemophilus influenzae type b (Hib) vaccine, and meningitis. At nine months, the children



Many patients prefer Mulago Hospital despite the overcrowding.

start taking hydroxyurea, get nutritional support including folic acid, and get crisis management, stroke prevention, and transfusions where necessary. The caregivers are given education on the things that trigger painful crises, symptoms, how to manage, and where to seek care."

Joining the school community

Due to the increased comprehensive care and treatment given, more children with SCD are surviving beyond the age of five years and this necessitates them to go to school.

However, sickle cell disease (SCD) affects school attendance and children who are affected by the disease can be absent for a month in every term because of the frequent hospital admissions.

"Since they are chronically absent, this affects their academic performance, and social and emotional challenges like stigma. These challenges stem from physical symptoms, the need for frequent medical appointments, and a lack of understanding, all of which impact their quality of life, concentration, and overall school functioning," she says.

The disease is associated with a high economic burden when it comes to treatment, poor quality of life, and effects on cognition and the ability to concentrate in school due to the painful crises.

Dr Namazzi therefore, advocates for an integrated school health intervention that would support children with the disease.

"We need to revisit the school health programme because the current guidelines do not favour the children with SCD. There are times when they get a painful crisis on the day of final exams and are unable to write. The ministry should rethink giving such a student the exam they miss so that they do not have to repeat the whole year."

She also notes that until today, many children with SCA face stigma at school and it is perpetrated by the teachers and the learners. There is always a myth that stops them from going to school because most people in the community say they would die by the age of 14. About 40 percent of the people in Uganda do not know about the disease.

"The target keeps shifting. Those who pass the 14 year bar are reminded that they would die at 20 which is very wrong. We get reports that these children are excluded from some school activities and the school nurses do not attend to them after their working hours yet the painful crisis can happen any time."

One woman's experience

Her mother had always told her that she is not defined by sickle cell disease and was always confident that she can brave through every storm until her primary three teacher shuttered her confidence.

Ruth Mukiibi Nankanja (51) started school at a time when there was no sportswear and both boys and girls were required to take off their uniforms during the PE classes that were usually held in the morning. She then brought a medical letter to her teacher asking that she remain in her uniform during the PE classes.

"The teacher announced before the whole class that I was not going to be part of the classes anymore because I had sickle cell disease. That I had to remain in class and watch over other pupils' uniforms."

20,000
BABIES BORN WITH SCD ANNUALLY.

SECRECY

Teachers play a vital role, yet many lack the knowledge to support children with SCD but according to Mudi Kangave, the national chairperson of the private teachers' platform in Uganda, many parents do not disclose the medical conditions of their children and by the time a crisis happens, they are unprepared.

After the announcement, her classmates avoided her. They refused to talk or sit with her and kept reminding her that children with sickle cell disease died early. There was another child at her school who had the disease, and she died when she was in Primary Six.

"This worsened the stigma. Children kept reminding me that I was going to die just like my colleague. My mother had told me to be strong, but from that time, I stopped telling people that I had SCD because I feared being isolated, and I wanted to fit in."

Nankanja recalls hard times at university when she would get joint pains and when asked she would say she fell or twisted her ankle. One time, she got a very painful crisis but had to lock herself in the room struggled to reach her painkiller without anyone's help.

"I always had everything I needed in case of a crisis but because I had not told anyone, I self-administered the painkiller. The first attempt was in a wrong place and the skin bulged. I still have a scar from that incident. On the second attempt, I administered the injection and in a few minutes, I got relief and sought the help of a nurse."

She missed a paper during her final exams at campus because of a crisis but recalls that getting to do it was a wearisome process that required her to go up to the senate with medical forms.

The better experience

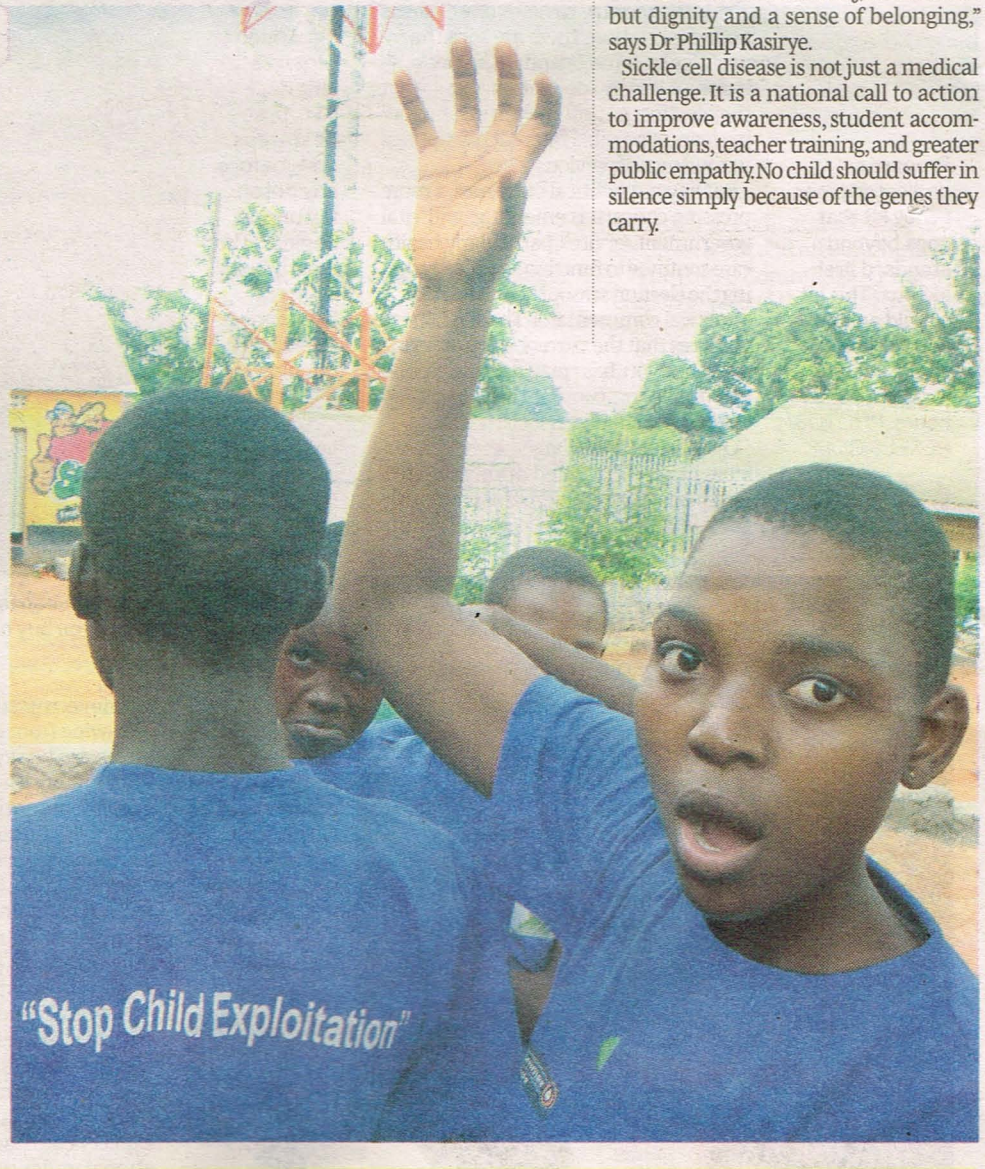
In contrast, Tracy Katusiime (23) believes she got her best support from the school community. As a sickle cell champion, everyone at her school knew about her condition, and many times she got special treatment because of that.

When she joined the secondary level at St Peters' Nsambya, her hip joints became so painful, and so she needed crutches to walk. "I always tell people I have sickle cell even if they do not ask me. It saves me from a lot of trouble."

She adds that, "When the school got to know about it, they made a special arrangement that I had to just go to the library for my meals. Even the security person at the school gate knew about my condition."

In senior three, her classroom was supposed to be upstairs but since she was walking on clutches, it was shifted to the ground floor. When the time came for her to sit her UNEB exams, she was accepted to have her sweater on since the mornings were cold. This is the kind of treatment children living with SCD need to help them get through the school system, but not many of them get this chance.

Children with SCD need to drink a lot of fluids to prevent pain crises, which further increases the need to urinate. "We find ourselves frequenting the washroom, which may be irritating to teachers. Many teachers do not have information about the disease, so they do most of the things out of ignorance," Katusiime says.



Health advocates march to create awareness for SCD. PHOTO/FILE.

Breaking the silence

"There are forms that parents fill when their children are being admitted into schools. However, many of them do not disclose the medical conditions of their children. We sometimes think they are making excuses for not doing some things at school only to find out when the children get painful crises and we do not know where to start from," says Mudi Kangave, the national chairperson of the private teachers' platform.

Dr Joseph Rujumba, a Lecturer in the Department of Paediatrics and Child Health, School of Medicine, Makerere University notes that it is important for children and adolescents to know about their sickle cell status early enough.

"This," he says, "helps them to have the myths confronted early enough to build their confidence. It helps them find peers within the health care, school and community systems. From there, they will find role models and form networks that provide them with information that will help them thrive."

"These warriors need not just medicine but dignity and a sense of belonging," says Dr Phillip Kasirye.

Sickle cell disease is not just a medical challenge. It is a national call to action to improve awareness, student accommodations, teacher training, and greater public empathy. No child should suffer in silence simply because of the genes they carry.