

PHOTOS BY BRIDGET AHURIRA



Delegates pose with Dr Atwine, the permanent secretary of the Ministry of Health (seated, third-left) during the launch of the exercise in Kampala yesterday

NATIONWIDE TASK

Sickle cell disease, an ailment transmitted through genes, has dogged many families countrywide. Communities share in lost hours, finances, exhaustion and sometimes, premature death the disease brings to loved ones. Can the Government find a sustainable solution?

By Annabel Oyera and John Musenze

The loss of her two daughters to sickle cell disease (SCD) has not only left Dr Hope Fortunate Achiro with a grief few parents can imagine, but also fuelled her determination to fight the life-threatening blood disorder in Uganda.

Speaking during the launch of nationwide mandatory newborn screening for SCD at the Ministry of Health headquarters in Kampala yesterday, Dr Achiro recounted the heartbreaking story of her daughters – Gloria and Mariah – and the enormous toll the disease took on her family physically, emotionally, and financially.

“The cost of sickle cell disease is immense. From a parent’s perspective, it is overwhelming,” she said.

Repeated severe illness forced Achiro to take her daughters to India on the advice of their paediatrician, where she spent over a year seeking treatment. Tragically, Gloria and Mariah passed away in January and November 2023, at ages 16 and 14, respectively.

“They experienced frequent, severe illness and unimaginable pain. Both girls required repeated blood transfusions, oxygen therapy, and intensive care. Their education suffered – Gloria, our sweetheart, was stuck in Primary Four. Mariah, full of life, was constantly restrained from playing, running, swimming or even jumping,” she said.

The disease also disrupted Achiro’s

GOVT MANDATES SICKLE CELL SCREENING FOR NEWBORNS

career. She highlighted how she often had to leave work abruptly to care for her daughters, sometimes showering at the hospital before heading to the office, only to rush back when the children’s condition has worsened. Her year in India exhausted her sick leave and ended in the heartbreak of losing both children.

She said local medical bills alone exceeded sh10m, while treatment in India cost about sh1b, half of which she raised publicly, with the remainder supported by President Yoweri Museveni.

“Sickle cell disease tests love, family and relationships. Social events became nearly impossible. Every day was a challenge, balancing care and work. Watching your children suffer and ultimately die in your arms is indescribable,” Achiro said.

WHAT IS SICKLE CELL DISEASE?

SCD is a genetic blood disorder caused by an inherited abnormality of haemoglobin, which carries oxygen in red blood cells. Children inherit the disease (SS) when both parents carry the gene. Those with only one copy (AS) are carriers, generally healthy, but able to pass the gene to their children.

Health experts say the disease causes chronic anaemia, severe pain crises, infections, organ complications and reduced life expectancy if untreated. Signs in children include frequent hospitalisations, fatigue, delayed growth, jaundice and vulnerability to infections.

COMPULSORY TESTING

Following Achiro’s testimony, Dr Diana Atwine, the permanent secretary at the Ministry of Health, officially launched the nationwide

UGANDA’S EFFORTS

In October last year, health minister Dr Jane Ruth Aceng announced that Ugandan pharmaceutical company Qcil would soon begin manufacturing hydroxyurea for sickle cell disease. She said having the drug produced locally would make treatment more accessible.

mandatory newborn screening programme for SCD.

The programme will screen all newborns in hospitals and lower-level health facilities using rapid diagnostic test kits. Results will be recorded on child health cards, and follow-up care will be provided. Missed screenings at birth will be addressed during routine immunisation visits.

“This landmark initiative underscores the Government of Uganda’s commitment to early detection, prevention, and improved health outcomes for children affected by sickle cell disease. It is mandatory for every child born in a government hospital, and it is already ongoing, so we ask all parents to give their children this chance,” Atwine said.

She stressed that addressing SCD is central to reducing under-five mortality, noting that 6,000-9,000 children with the disease die each year before their

fifth birthday. Newborn screening and premarital counselling, she said, remain the most effective preventive measure.

“Many countries with a high SCD burden have significantly reduced prevalence through mandatory premarital testing. Early screening links children to care, reduces complications, and empowers parents with knowledge,” Atwine said.

Prof. Sarah Kiguli, the chairperson of the National Sickle Cell Task Force, urged all parents and couples planning to marry to screen for the disease.

“Screening must go hand in hand with long-term care because sickle cell disease affects people across the lifespan, not just children. Early identification allows life-saving interventions, including prevention of crises, vaccinations against other infections, and initiation of hydroxyurea therapy,” Prof. Kiguli said.

Dr Miriam Ajambo, a senior medical officer in the department of clinical services, said the average total cost of care for a child with SCD is about sh8.3m, covering hydroxyurea, blood transfusions,

vaccinations, infection prevention, and family counselling. She added that the only curative options, like bone marrow transplant and gene therapy, remain unaffordable for most families.

Sheikh Muhammad Waiswa, the Deputy Mufti of Uganda, who represented believers, encouraged believers to know their status before marriage.

“Faith institutions will mobilise communities, educate families, and reduce stigma. Early detection is a moral responsibility, as well as a medical one,” he said.

Achiro echoed this message: “Test before you fall in love. If both partners are carriers, seek counselling. Prevention is cheaper and easier than a cure.”

Uganda has one of the highest SCD burdens globally, ranking third in Africa after Nigeria and the DR Congo, and fifth worldwide. Approximately 20,000 children are born with SCD annually, about 55 per day, while more than six million adults carry the sickle cell trait, representing 13% of the population.

According to the 2022 demographic survey, districts with the highest prevalence include Alebtong, Namutumba, Bundibugyo and Buliisa, where nearly one in four residents is affected. Northern, eastern and central regions carry a disproportionate burden, while Mbarara in western Uganda has the lowest prevalence at 0.2%.

TREATMENT, CURE

Although treatment exists, it is expensive and emotionally draining.

In 2008, seven-year-old Miriam Mulumba became the first Ugandan to be cured of the condition, but through a bone marrow transplant. Several others have also been treated using the same method.

This year, however, Jude Byamukama became the first Ugandan to be cured of sickle cell disease through gene therapy. Byamukama’s treatment did not come cheap; it cost a whopping \$2.1m (about sh7.5b) and involved a process known as stem cell harvesting and cell editing.



Dr Achiro has lost two children to the disease