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Sickle cell screening urged for newborns in Africa

Sickle cell disease disproportionately affects babies in Africa, but many go undiagnosed due to lack of screening. Newborn screening is needed to save lives and improve care.

By Syriacus Buguzi | Jun 17, 2022

Newborn screening lies at the heart of the fight against #sicklecell disease. Routine newborn screening is needed to save lives and improve care #WorldSickleCellDay

Routine newborn screening for sickle cell disease could have a profound impact in stemming complications and averting loss of life among people diagnosed with the condition.

Yet access to the procedure remains a distant dream in countries across sub-Saharan Africa, a region which carries over three quarters of the global burden of sickle cell disease, according to research published in PLOS Medicine.

More than 300 000 babies globally are born every year with sickle cell, a hereditary condition which causes red blood cells to become sickle shaped. These unusually shaped cells do not live as long as healthy blood cells and can block blood vessels, sometimes resulting in painful swelling or even stroke.

In many countries, families of children with sickle cell grapple with complications of the life-threatening disease, often without knowing the diagnosis, as health systems remain ill-equipped and underfunded to rollout the much-needed newborn screening services.

Such was the case for Chilufya Pikiti, whose son was finally confirmed to have sickle cell disease after three months of repeated testing for malaria and HIV at various hospitals in Zambia in 2009. Pikiti shared his story as part of the online streamed S-WORD webinar series organized by Novartis in December 2021 to discuss important topics relating to sickle cell in sub-Saharan Africa.

Newborn screening, which was central to the discussions, entails primary screening for sickle cell disease at birth and enrolment into care programs before the onset of symptoms that could later develop into chronic complications.

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>
> **Lawrence Osei-Tutu**, a specialist in clinical paediatric haematology and oncology at Komfo Anokye Teaching Hospital in Ghana

At the age of six months, Pikiti's first-born son, who was initially healthy at birth, began developing bouts of fever and excessive crying. By the time he was nine months old, "we had been in and out of hospitals without knowing the right diagnosis", says Pikiti.

As a last resort, Pikiti was advised by his older brother to try a sickle cell test for his son at a university teaching hospital in the country's capital, Lusaka, where sickle cell disease was eventually confirmed.

“But this came after repeated testing, with health workers not even suspecting he could have sickle cell,” says Pikiti, whose predicament as a parent has ignited his zeal to create public awareness about life-threatening blood disorders through the Zambian Childhood Cancer Foundation, where he is a founding member.

Pikiti’s story, however, represents a bigger challenge on the continent, with medical experts attributing the misdiagnosis of sickle cell and delays for treatment to poor geographical access to expertise and laboratory tests.

Lawrence Osei-Tutu, a specialist in clinical paediatric haematology and oncology at Komfo Anokye Teaching Hospital in Ghana, says a typical parent with a child suffering from sickle cell disease reports to hospital when the child is aged six months, with complications such as painful swelling of hands and feet.

“Children with sickle cell disease are prone to dying from infections even before their first birthday,’’ Osei-Tutu tells the webinar. “As they grow from nine months to one year, that’s when they develop anaemia.

“Unfortunately, when these anaemic symptoms are unchecked, the blood continues to travel at a very high speed in various parts of the body and that can lead to a sequence of events that could eventually lead to stroke at the age of two years.”

The scaling up of newborn screening would help in planning for the comprehensive care of affected children, including antibiotic treatment to keep them free from life-threatening infections.

“It’s important to have tests that are simpler and quicker, to help us in screening sickle cell disease,” says Osei-Tutu, explaining that newborn screening would also help in creating a database of children and families with sickle cell disease to inform related programs and policies. But sickle cell disease should not be looked at in isolation because it affects people’s social and economic life, Charles Kiyaga, sickle cell program coordinator in Uganda’s Ministry of Health, tells the webinar.

With first-hand experience conducting nationwide screening services for sickle cell in Uganda, Kiyaga says families of children with undiagnosed sickle cell are likely to face dilemmas due to lack of awareness about the disease.

“Early screening alleviates social troubles related to the disease, such as broken families and marriage,” he says.

Kumasi, Ghana: A sickle cell screening program for newborns at Kumasi General Hospital. Early diagnosis and education of the parents of a sickle cell baby is considered vital for treatment of this disease.

Existing programs

If governments incorporated newborn screening into routine child health services at hospitals and provided the necessary funding to sustain sickle cell programs, it would help caregivers better manage the disease and improve patients' quality of life, Kiyaga believes.

To successfully roll out newborn screening services for sickle cell in Africa, strategies should leverage existing programs—not be introduced as standalone projects—says Kiyaga. "It can anchor along existing programs such as early infant screening for HIV," he explains.

In Tanzania, which has the fourth-highest birth prevalence of sickle cell individuals in the world, Arafa Salim Said, who was diagnosed with sickle cell eight months after birth, still counts herself among the lucky few in the country, despite being diagnosed a bit late.

"Although I wasn't screened when I was a newborn, I can say I am lucky because I received the right treatment even after being diagnosed at eight months, unlike in most families that are unaware, and are not privileged enough to deal with complications in their affected children," she tells SciDev.Net.

"I am aware of families in rural areas that end up believing that their children have been bewitched when they discover that they have a yellowish coloration of eyes or are pale. That tells you the kind of care and treatment they end up receiving," Arafa, the founder of the Sickle Cell Disease Patients Community of Tanzania, tells SciDev.Net.

She adds that beyond screening, there was also a need to intensify awareness campaigns. "Being informed, along with newborn screening services, could improve acceptance of the disease. Even if the baby is screened and found to be a carrier of a sickle cell, and not actually having the disease, it would help the family prepare the child's future in terms of managing marital choices."

Sickle cell disease

SCD is a global health problem, yet sub-Saharan Africa bears the highest burden of disease. That is why Novartis launched a comprehensive effort to improve and extend the lives of people in this region of the world. The Novartis Africa Sickle Cell Disease Program, an end-to-end effort that encompasses screening, diagnosis, treatment, education, research and advocacy, was first launched in Ghana in 2019 and now includes Uganda, Tanzania, Kenya and Zambia. This unique program features agreements with local governments and their health departments to address the local needs of SCD patients.

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