Mandatory sickle cell tests at birth

Solution. With 20,000 babies born each year carrying the sickle cell burden - and thousands dying before their fifth birthday - the government's mandatory screening aims to nip the tragedy in the bud, cut the disease off at birth, and give Ugandan children a fighting chance from day one ...P.4-5

13% ▲

Affected. At least 13% (6 -7 million people) of the Uganda's population carry the sickle cell trait.

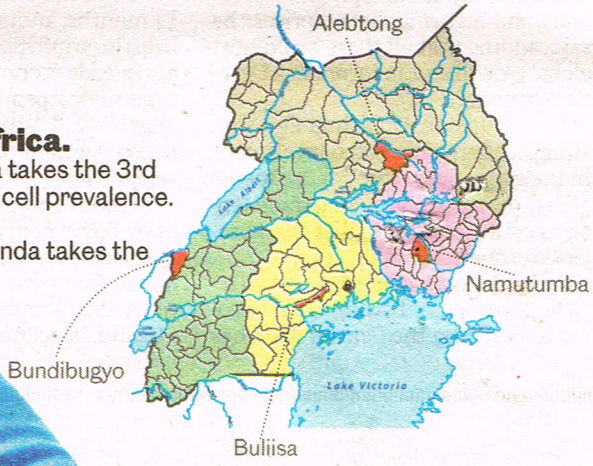
9,000 ▲

Mortality. An estimated 6000 – 9000 children die before 5 years.

3rd

Ranking - Africa. In Africa, Uganda takes the 3rd position in sickle cell prevalence.

Global. In the world, Uganda takes the 5th position.



Most affected. High burden districts are Alebtong, Namutumba, Bundibugyo and Buliisa, with prevalence of 24 %.

Uganda launches must-do sickle cell screening at birth

Newborn screening will now be mandatory at birth, and children diagnosed with the disease will be followed up to manage complications such as organ failure.

BY SYLVIA NAMAGEMBE

The government has rolled out a must-do nationwide sickle cell screening for newborns to reduce the disease's contribution to Uganda's under-five deaths.

Sickle cell disease (SCD) remains a major contributor to child death in Uganda, with data from the Health ministry showing that 20,000 babies are born with the condition every year.

The figures also show that an estimated 6,000 to 9,000 of the babies die before their fifth birthday, mainly from preventable complications.

Dr Diana Atwine, the Health ministry permanent secretary, said the early screening will enable immediate linkage to care and prevent deaths caused by complications from late detection.

Lifesaving Sickle Cell Care Programme is launched in Kayunga in 2024. PHOTO/HEALTH MINISTRY

"We are targeting reducing under-five mortality, and children with sickle cell disease take a large portion of those numbers, which will be worse than HIV/AIDS and drain a lot of our resources. They require constant blood transfusions in competition with other disorders like leukemia," she said.

Newborn screening will now be mandatory at birth, and children diagnosed with the disease will be followed up to manage complications such as organ failure.

Dr Atwine said the laboratory capacity has been strengthened, and the rapid diagnostic tests (RDTs) similar to those used for HIV/AIDS will be used to record results immediately on child health cards.

During the launch at the Ministry of Health headquarters yesterday, Dr Atwine revealed that hydroxyurea, previously scarce, has been added to the essential medicines list, with efforts underway to ensure it is available even at lower-level health facilities.

Hydroxyurea is a crucial oral medication identified by theWorld Health Organization as a key disease-modifying agent for sickle cell disease. It reduces pain crises and blood transfusion needs by increasing fetal hemoglobin.

She added that the National Medical Stores (NMS) will begin supplying sickle cell RDT kits to public facilities starting February 2026 for free screening, while the private sector has been encouraged to make testing widely accessible.

"When we do the early screening, we link these children to early care so that

we prevent complications and deaths through early vaccination, penicillin as prophylaxis, and disease-modifying therapy, like hydroxyurea. Mothers are also counseled to recognise danger signs early," Dr Atwine said.

The 2014 National Sickle Cell Trait and Disease survey report shows that districts in the South-western region had the lowest prevalence of the trait, being less than five percent in nine and less than three percent in two. The high burden districts of Alebtong, Namutumba, Bundibugyo, and Bulisa have a prevalence of 24 percent.

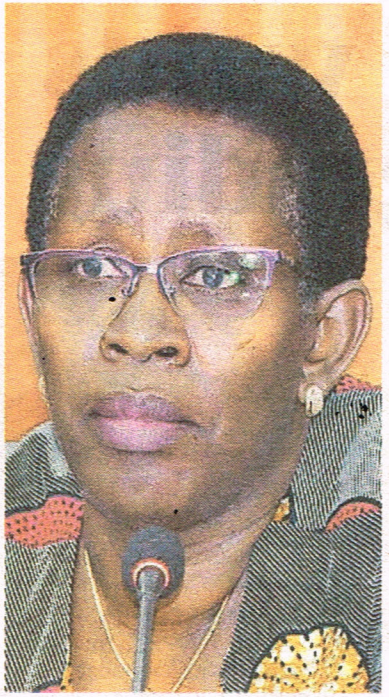
The survey report shows that prevalence of the SCD in East-Central (Busoga, Bugweri, Bukedi, and parts of Teso) stood at 1.5 percent, Mid-North – Acholi and Lango (1.3 percent), Mid-Eastern (1.2 percent), North East (1 percent), and Central (0.8 percent). Kampala had the disease prevalence of 0.7 percent, both Mid-Western and West Nile (0.5 percent), and South Western (0.2 percent).

In Africa, Uganda ranks third in the disease prevalence, with about 13 percent of the population, approximately six to seven million people carrying the sickle cell trait, and fifth in the world.

The 2024 annual health performance report indicates that sickle cell disease takes the 12th position among the leading causes of admissions in health facilities at 1.5 percent. This also contributes 15 percent of under-five deaths.

The figures also show a growing burden, with laboratories identifying 34,729 positive cases of 500,000 tests conducted over the past decade, representing seven percent.

Dr Deogratious Munube, a consultant pediatrician and pediatric hematologist-oncologist at Mulago Hospital, said



Reason.

"We are targeting reducing under-five mortality, and children with sickle cell disease take a large portion of those numbers, which will be worse than HIV/Aids and drain a lot of our resources. They require constant blood transfusions in competition with other disorders like leukemia," Dr Diana Atwine, the Health ministry Permanent Secretary

newborn screening is critical to improving child survival.

He noted that Uganda has a high prevalence of the sickle cell trait, partly driven by malaria, and many children presented with fever, particularly with malaria, later turn out to have undiagnosed SCD.

"Studies have been done in Mulago and other places where it shows that children who present with fever and are diagnosed with malaria about 25 percent of those children actually have undiagnosed sickle cell disease. Therefore, early diagnosis allows for follow-up, prevents admissions, reduces mortality, and ensures children can grow, attend school, and survive into adulthood," he said.

He stressed that counseling and follow-up are critical, noting that symptoms often appear between three and six months after birth.

"Every child born with sickle cell disease in Uganda deserves to be diagnosed at birth and given a chance to live. With the right policies, care practices, and financing, Uganda can become a continental leader in newborn screening," Dr Munube added.

About sickle cell disease

Sickle cell disease is a group of inherited disorders that affect the haemoglobin, which causes sickle-shaped red blood cells. Haemoglobin is the protein in red blood cells that carries oxygen. Healthy red blood cells are round and move easily all over the body, but in SCD, the red blood cells are hard and sticky. They are shaped like the letter C, looking like a farm tool called a sickle.

Dr Deogratious Munube, a pediatrician and pediatric hematologist-oncologist at Mulago

20,000
BORN WITH SICKLE CELL EVERY YEAR

Scientists say these abnormally shaped red blood cells, or sickle cells, clump together and can't move easily through the blood vessels. Due to their stickiness, they can get stuck in small blood vessels and block blood flow, stopping the movement of healthy oxygen-rich blood. This blockage can cause pain and can also damage major organs.

Who is at risk?

Dr Munube explains that sickle cell disease (SCD) is inherited, meaning it is passed down from parents to children through genes.

"People who carry one sickle cell gene, what we call the sickle cell trait (HbAS), do not suffer from sickle cell disease or its complications themselves," he said.

"However, they can pass the gene to their children as each pregnancy has a 25 percent chance of resulting in a child with sickle cell disease. The risk becomes very high when both parents carry the trait. In such cases, their child has a significant chance of being born with sickle cell disease," he said.

Dr Munube added, "If one partner has sickle cell trait (a carrier) and the other has no sickle gene, there is zero risk of birthing a child with sickle cell disease. However, there is a 50 percent chance that each child will inherit the trait (carrier) and a 50 percent chance of being totally unaffected."

He stressed the importance of premarital screening and family history.

"Individuals with a known family history of sickle cell disease or sickle cell trait pose a high risk as well.

Marriage or pregnancy between two carriers is strongly discouraged unless proper genetic counseling is done. Some families do not know they carry the trait because they appear healthy. That is why mandatory newborn screening is essential for identifying at-risk children early and linking them to care before symptoms appear."