

Sickle cell disease: Mandatory newborn screening is a milestone

Uganda has marked a major public health milestone with the launch of a mandatory national newborn screening programme for sickle cell disease; a transformative intervention aimed at saving lives and strengthening the future of the country's children.

This progress has been driven by sustained leadership and collaboration within the national health system, particularly by the Ministry of Health, the National Sickle Cell Programme Office, and other technical and diagnostic institutions. Updated national guidelines introduced in 2025, alongside the establishment of a national sickle cell registry and the Sickle Cell Health Passport, have improved standardization of care, patient tracking, and coordination across health facilities.

Another key achievement has been the decentralisation of services through the creation of more than 10 regional Centres of Excellence for sickle cell care. Previously, families depended heavily on central referral hospitals, but the new centres now allow children and families, especially in high-burden regions such

and demonstrates how resource-limited settings can optimize service delivery through innovation. With the introduction of the point of care Gazele HB electrophoresis machine from Nicosam Health care Uganda limited, and Rapid Diagnostic device from Mircoheam scientific across health facilities in Uganda, more people will get to know their sickle cell status in a timely manner.

Access to treatment has likewise improved, particularly with the increased availability of Hydroxyurea in public health facilities.

This has led to reduced pain crises, hospital admissions, and complications among patients. Growing advocacy and awareness efforts by civil society organisations, including Catherine Phil Sickle Cell Support Initiative, have contributed to a cultural shift toward early testing, informed health decisions, and better community understanding of the disease.

Despite these advances, significant challenges remain. The high disease burden continues to strain the limited number of trained hematologists and specialized clinics, particularly in rural areas. Blood transfusion shortages persist, even though sickle cell patients consume nearly 30 percent of the national blood supply, affecting timely treatment for severe anaemia and stroke prevention.

The cost of comprehensive care also places a heavy financial burden on families, often consuming 20–30 percent of household income, especially in rural communities. Cultural stigma and misconceptions, including beliefs linking sickle cell disease to curses or witchcraft, further hinder early diagnosis and proper care. Moreover, a growing transition gap exists as more children now survive into adulthood but struggle to access specialised adult sickle cell services.

Mandatory newborn screening is therefore essential for improving survival, reducing complications, and enhancing quality of life. Early identification enables immediate preventive care, parental education, prophylactic treatment, and regular follow-up. Beyond medical benefits, the programme represents a national investment that will reduce childhood mortality, lower long-term healthcare costs, and foster healthier communities.

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as northern and east-central Uganda, to access specialised care closer to home. Additionally, integrating sickle cell management into Non-Communicable Disease (NCD) services has strengthened service delivery at regional and district levels, ensuring continuity of care throughout a patient's life.

Diagnostic capacity has also improved through innovative approaches such as the hub rider sample transport mechanism, which efficiently moves samples from lower-level facilities to regional and Kampala laboratories for confirmatory testing. This system has reduced turnaround times

Daniel Roy Odur, Executive Director, Catherine Sickle Cell Support Initiative.

The Editor welcomes 450-word comments on topical issues. Prefor