



A Project to Enhance Newborn Screening for Sickle Cell Disease and Conduct a Prospective Cohort Study Based on a Pilot Screening Program in Northern Ghana

This project aimed to establish newborn screening for sickle cell disease (SCD) in the Tamale Teaching Hospital using point of care testing and linking newborns and infants diagnosed through this program to clinical care. Using a mixed methods approach, key lessons learned from the pilot newborn screening program were documented. Children were then followed up on as a cohort to document their progress in the early years of life and collect evidence to inform policy on universal screening for SCD in Ghana.

In addition to screening, this project has helped build referral pathways and improve caregiver counseling and has enabled the collection of high-quality prospective data for national-level decision-making in policy, practice, and future programmatic activities related to newborn screening. At the end of the project, screening transitioned into routine hospitals services and long-term care of the enrolled children is still being provided, ensuring sustainability of the initiative. This project demonstrates a scalable model for newborn screening for sickle cell disease in low-resource settings.

Project Details



Location
Tamale, Ghana



Setting
Single center,
Tamale Teaching Hospital



Condition/Disease
Sickle Cell Disease



Focus Areas
Access, Equity, Timeliness



Target Age Group
Birth to 5 years

System Levels Change

Participants

8592 Children

22 Health Care Workers

17200 Caregivers

UN Sustainable Development Goal

Goal 3: Good Health and Well-Being

WHO Building Blocks

Access to essential medicines

Health information systems

Health service delivery

Health workforce

GICC CureAll

Yes



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Key Findings

The following are key findings from this Global Scholars Project implementing a newborn screening program for sickle cell disease in northern Ghana.

- 8,592 infants and young children were screened/tested over the 2-year project period, benefiting thousands of infants, their families, and health care workers.
- 98 children were identified with SCD, representing a prevalence of 1.4 %. 71 of these were HbSC (72.4%), and 27 were HbSS (27.6%). This is in sharp contrast to findings from southern Ghana that show a majority of children with HbSS.
- 91 of the 98 children were successfully linked to the SCD clinic, where they currently receive care. This will most likely positively impact their disease course in the long term.
- 1277 children were identified to have the HbAC variant, a carrier state that could perpetuate the disease burden in subsequent generations. This was important because in routine practice, the sickling test is still used to screen for SCD in Ghana. This type of test does not identify the C hemoglobin variant and hence underestimates the true trait rates and gives false hope to families.
- All tests were determinable, except for 30 (0.35%) invalid tests, underscoring the importance of quality assurance. These were promptly discussed with the manufacturer to improve future testing and storage conditions.
- Parental interest in genotype testing increased as a result of newborn screening activities.



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- The project's findings were disseminated at multiple scientific meetings worldwide, thereby increasing visibility for the SCD program in Tamale and the Global Scholars Program.
- Multiple collaborators from Ghana and abroad were hosted who were interested in conducting a study on our project and attended several stakeholder meetings to discuss the future of SCD diagnosis and management in Ghana.
- The PI was nominated to the national technical working group for SCD. This group worked on the guidelines for the diagnosis and management of SCD in Ghana, which were launched in December 2025.
- Through the Ghana Ministry of Health, Tamale has been selected as part of the first cohort of facilities to continue newborn screening using the same point-of-care test used during the Global Scholars Project implementation. This is significant because it helps meet sustainability requirements and enables continued generation of data for policymakers.



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