UKEREWE SICKLE CELL DISEASE PROJECT (USCDP)

PROGRESS REPORT

FOR THE IMPLEMENTATION OF PHASE ONE

July 2024 – April 2025

UKEREWE DISTRICT - TANZANIA

Community Training on Sickle Cell Disease

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EXECUTIVE SUMMARY

This report summarizes the progress made in the first nine months of the Sickle Cell Disease (SCD) Project Phase One implemented in Ukerewe District, Tanzania. The primary aim of the first phase of the project is to provide comprehensive care and management of sickle cell disease to children in Ukerewe through infrastructure strengthening, capacity building, community outreach, and improved clinical services. In addition, the project is establishing a patient registry with baseline data, both hard copy and using the Kobo data collection software, for follow up of all patients and evaluation of the project during the second phase.

Key achievements in Phase One include training of 55 clinical personnel from Nansio Hospital and other health facilities across Ukerewe Island; training of 67 LVC volunteer ambassadors on sickle cell disease and how to work to create awareness in the community; establishing and operating of three dedicated SCD clinics resulting in assessment of 217 of children seeking care; new diagnosis and treatment of 170 children between the ages 8 months to 17 years, 35 % under the age of 5 years.

During this first phase, the project secured availability of hydroxyurea for all children diagnosed with SCD, referred 14 children for severe SCD, provided blood transfusion to 10 and referred four for splenectomy. Collaboration with government health services and research community were initiated.

During the remaining part of the startup phase of the establishment of the SCD program in Ukerewe the routine reporting system will be finalized, and the project database be up and running for the impact evaluation that will be planned in detail (June 2024) with research partners at regional SCD specialist center for the second phase 2025 – 2028. The project will also ensure continuation of steady supply of all essential drugs for all enrolled patients and address the shortfall in the budget caused by higher-than-expected cost of drugs and the high demand for SCD services among children 0 -15 years.

INTRODUCTION

Sickle Cell Disease (SCD) remains a significant public health challenge, particularly in Ukerewe District with high morbidity and suffering among children 0-15 years. Enhancing early diagnosis and continuing management of sickle cell disease will substantially decrease children's suffering. This SCD Project was launched in July 2024 with the aim of improving early detection and diagnosis, increasing access to treatment, and creating significant community education and awareness.

Phase One of this project is funded by the Einhorn Family Foundation, managed by the Lake Victoria Children (LVC) in collaboration with Ukerewe District Council and district medical services, and the SCD clinical expert research team at Bugando hospital. The medical/clinical components of the project have been implemented at the Nansio Hospital on Ukerewe, and the education and awareness components have been implemented across the island and in 42 health facilities.

Objectives of USCDP Project

- To Increase awareness and understanding of sickle cell disease in Ukerewe community
- To Improve the health infrastructure and support the health system in Ukerewe district to better identify and manage sickle cell disease and its complications
- To build the capacity of health professionals to provide high-quality SCD care
- To develop and maintain relationships with stakeholders on a joint research agenda, to evaluate the program and ensure best practices are adopted through evidence-based research and investigation.

Phase One Start-up

Project Introduction

- The project secured approval from the Government – Ukerewe District Council. This has made it easier to engage with stakeholders including local health ministry, Nansio Hospital, Bugando Medical Center, and allowed the project to be implemented with ease.
- Finalized the recruitment of a project manager hired through LVC.

Inception planning / progress meetings

- Creation of Ukerewe Sickle Cell Disease project (USCDP) management team consisting of Alex Magaga, chair of LVC; Dr. Karin Euler, Canadian physician, project/medical advisor; Deo Dominik, Project Manager, and Cathy Cleary, Canadian project advisor
- Confirmed the USCDP Advisory Committee consisting of the USCDPMT in partnership with Dr. Mariam Claesson, Kaseza Lukumbuzya, and Dr Ronald Waldman.
- Mwanza - Bugando Medical Center (BMC) with Dr Ambrose, SCD expert, on 23rd August 2024
- Ukerewe District with District Medical 0fficer (DMO) – 31st August 2024
- Project progress meeting with USCDP management team 12th September 2024
- Project Progress meeting with the USCDP management team 27th September 2024

- Project Progress meeting with the USCDPMT team and Dr. Mariam Claesson 2nd October 2024
- Project Progress meeting with the USCDPMT team and Advisory Committee on Feb 4th, 2025

Development of project implementation tools and getting approval

- Designed and developed project performance framework (PMF)
- Designed and developed a year 1 project implementation plan (PIP)

Phase One – Training Component

Training of Clinicians

The training aimed at improving the knowledge and skills of healthcare professionals in Ukerewe District to manage Sickle Cell Disease (SCD) effectively. The training focused on enhancing patient care, particularly for children 0-16 years, and ensuring effective disease management and support for individuals living with SCD. Ultimately the training equips healthcare professionals to identify, diagnose, treat and follow up, and deliver improved services to individuals living with SCD in Ukerewe District.

A total of 55 (28M/27F) Doctors, Nurses, Clinical Officers, Assistant Medical Officers, RCH in charge, and Lab Technicians from different health care facilities in Ukerewe Districts were introduced to the SCD project and trained on comprehensive sickle cell disease management. These clinicians are the core implementers of this project.

Training of LVC Community Ambassadors

This training aimed to empower LVC volunteer Ambassadors with the knowledge and skills necessary to serve their communities effectively by providing a comprehensive understanding of Sickle Cell Disease including its causes, symptoms, potential complications, management, myths and misconceptions and stigma. The purpose was to promote better health-seeking behaviors and compliance among affected individuals and their families as well as to reduce myths, misconceptions, and stigma.

A total of 67 (40M/27F) LVC Ambassadors were trained on SCD and serve as core implementers of the community component of this project as they are closest to the communities and best placed to provide education and support to families with children living with sickle cell disease.

Phase One – Community Outreach

LVC Ambassadors were tasked with providing education to communities at large and to individual families to identify and refer possible SCD child patients.

From October 2024 to March 2025 data collected by LVC Ambassadors has been tracked using Kobo tool. Reports are submitted and the analysis is ongoing. Community Ambassadors have managed to reach the community as explained through data charts below:

Household visits

After training, LVC ambassadors (67) were able to visit 10 households per month (on average) out of the planned 20 households per month. LVC ambassadors are volunteers and are not paid for their community work, working it into their time between income earning and caring for their families. To date in Phase One, LVC ambassadors have visited 2,907 households resulting in a total of 8,721 community members reached and provided with education on sickle cell disease. As a result of their engagement, the three SCD clinics faced higher than expected demand for SCD services.

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HOUSEHOLD VISIT OCTOBER-MARCH 2025

SN	DISTRICT	OCT	NOV	DEC	JAN	FEB	MARCH	TOTAL
1	Ukerewe	663	523	482	317	446	476	2,907

Community Meetings

As a group, LVC Ambassadors were able to host 246 community meetings, resulting in 4,920 community members reached and provided with awareness and education on sickle cell disease. These included both formal and informal meetings within their own and surrounding communities/villages.

COMMUNITY MEETINGS OCTOBER-MARCH 2025

SN	DISTRICT	OCT	NOV	DEC	JAN	FEB	MARCH	TOTAL
1	Ukerewe	56	52	28	27	46	37	246

The total number of **13,641** beneficiaries were reached through both home visits and community meetings conducted from October 2024 to March 2025. Referrals were made at this time to upcoming SCD clinics, which began in January 2025, for any children who present with SCD-like symptoms. LVC Ambassadors also worked with families to identify other health issues and make referrals to the nearest health facility.

COMMUNITY TO FACILITY REFFERALS OCTOBER-MARCH 2025

SN	DISTRICT	OCT	NOV	DEC	JAN	FEB	MARCH	TOTAL
1	Ukerewe	67	42	35	45	36	65	290

LVC Ambassadors referred 290 clients/children with SCD symptoms to their local community health facilities for SCD screening. The health facility staff then assessed the patients and referred as identified to the Nansio Hospital Sickle Cell Disease clinic.

Phase One: Preparing for SCD Clinics

Procurement of medication and medical equipment

After much research and investigation, the Ukerewe Sickle Cell Disease project succeeded in coordinating the procurement of essential medicine and medical equipment**,** including hydroxyurea and sickle cell rapid test kits (hemotype SC)**,** to support early diagnosis and effective treatment of up to 200 patients by the end of phase one.

Hydroxyurea

Securing hydroxyurea in Tanzania is very difficult. We were able to make connection through Dr. Ambrose, SCD expert at Bugando SCD centre in Mwanza region. We procured a total of 220 boxes of hydroxyurea made in India, imported through Tanzania suppliers and provided at a cost of 40,500 for a box of 100 tabs, at a total cost of 8.9 million TS. The medication is more expensive than originally estimated and we are working to find suppliers providing hydroxyurea at lower cost, and to mobilize additional funding to compensate for this budget increase during the first phase of the project. We face a funding shortage of 9.92 million TSH for hydroxyurea for the remaining five months of Phase One, May - September 2025. Children under age 5 are to receive medication free of charge according to national policy; however, there are no supplies of hydroxyurea to be found, and government health facilities do not carry this medication on Ukerewe Island. During the second phase of the project, we will work with partners to ensure sustained continuous supply of SCD essential drugs and explore opportunities to merge or integrate Ukerewe SCD services with government and specialized SCD programs to ensure sustainable, predictable treatment and care.

Hemotype SC – sickle cell rapid test kits

A total of 2,000 Hemotype Sc kits were purchased from USA supplier, Silver Lake company, through Tanzanian connection, facilitated by Dr Ambrose. Purchase of 40 boxes with 50 tests each. These tests are made in India, and we have been able to access them though an American Research NGO at a lower cost because of our planned research agenda.

Hydroxyurea and the Hemotype SC test kits were distributed to 5 designated health facilities (Nansio Hospital, Kagunguli Health Center, Nakatunguru Health Center, Muriti Health Center, Bwisya Health Center) ensuring that screening and management services could be carried out efficiently and without interruption. In addition to Nansio Hospital, four health centers were chosen as they have laboratory facilities.

Creating Awareness to increase demand for services

LVC Ambassadors were tasked with letting the communities know about the SCD clinics to be held at Nansio Hospital. As noted, this was done with individual family meetings and larger community meetings. They worked closely with local health care facilities to prescreen individuals who would then be advised to attend the clinic.

Phase One - Sickle Cell Disease Clinics

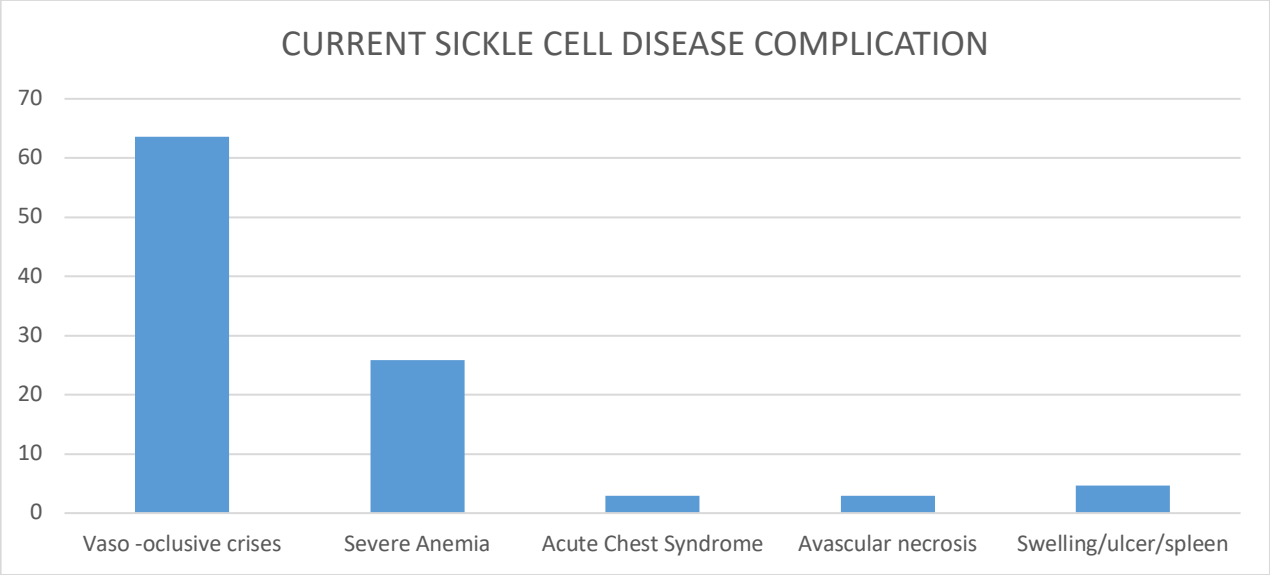
Ongoing functional sickle cell disease clinics have taken place in January, February, and March of this year at Nansio Hospital. These clinics were operated in partnership with BMC's experts on SCD including Dr. Ambrose, Dr. Kabyamera, along with their interns and students. In addition, several clinicians from Nansio Hospital who have been trained under Phase One of this project are also members of the SCD clinic team. The objective of these clinics is to provide comprehensive care: to assess, diagnose, manage and follow up sickle cell disease (SCD) cases. The clinic aimed to provide expert consultation, laboratory investigations, treatment plans, and patient education on SCD management, as well as to assess the prevalence and severity of SCD among child patients. Outlined below are the results of these clinics:

CLINICS	**HB SS**	**HB SC/Trait**	**HB AA**	**TOTAL SCREENED**
First clinic	125	17	8	150
Second Clinic	20	6	6	32
Third Clinic	25	6	4	35
TOTAL	**170**	**29**	**18**	**217**

A total of 217 Patients were attended by doctors: 114 males and 103 females were newly diagnosed cases of 170 HbSS, 29 HbSC, and 18 HbAA.

Value	Frequency	Percentage
HbSS	170	78.3
HbSC/Trait	29	13.3
Hb AA	18	8.3

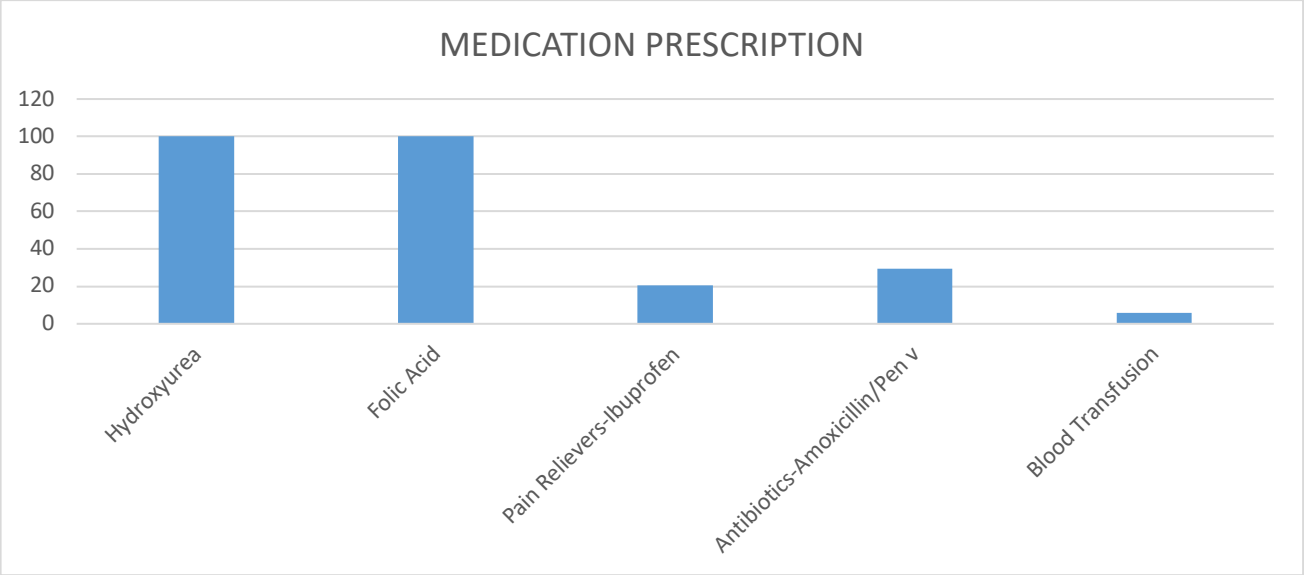
Most reported / noted symptoms:



Value	Frequency	Percentage
Vaso-occlusive crises (VOC)/Pain Crisis	108	63.6
Severe Anemia	44	25.9
Acute Chest Syndrome	5	2.9
Avascular necrosis	5	2.9
Swelling (hands/feet)/Ulcer/spleen	8	4.7

Treatment and Interventions

Pain management strategies were provided, including medication and non-pharmacological approaches. Of all patients, 170 are on Hydroxyurea therapy, 100% are taking Folic Acid and those who are in severe pain and/or with infections are on antibiotics and pain medication.



Value	Frequency	Percentage
Folic Acid	170	100
Hydroxyurea	170	100
Pain Relievers-Ibuprofen	35	20.5
Antibiotics (specify):-Amoxicillin/Pen v	50	29.4
Blood Transfusion	10	5.8

- 10 patients with severe anemia received blood transfusions and were admitted for more than 2 days at Nansio hospital. Each required 1-2 units of blood.
- Antibiotic prophylaxis was recommended for infection prevention (Amoxicillin and Pen V)
- Counseling education was offered to 100% of parents/caregivers who attended the clinic
- Referrals for Specialized Care were provided whereby 4 patients were referred to Bugando Medical Center with splenectomy complications.
- LVC is partnered with Canada Africa Community Health Alliance, a Canadian NGO that raises funds for LVC Emergency Children's Medical Fund. While this is a small fund and spread across all children's medical emergencies, some funds were allocated to financially and socially support 2 children requiring surgery at Bugando Medical Center.

Lessons Learned

- **Male involvement and family separation:** We learnt that men's involvement in and awareness about SCD is key to reducing stigma and the misconception that sickle cell is caused by women, the mothers/wives. This common perception leads to men leaving their families who live with SCD, with the added challenge of decreased income within the family. More emphasis on the involvement of the men will help ensure increased knowledge about SCD and help families to deal with the disease together rather than pulling them apart.
- **Education on SCD to teachers and school management teams:** 80% of the parents that we talked with urged us to bring education and awareness to the school system – both teachers and students. This adds to community awareness and provides teachers with information on how to manage when children with SCD are sick and/or missing school.
- **Effect of Hydroxyurea:** During clinics 2 and 3 we heard from an estimated 90% of parents who reported positive improvements in their children after attending initial SCD clinic and beginning hydroxyurea medication. This will be further evaluated during the follow up of these children in Phase Two of the project.
- **LVC Ambassadors Improve Treatment Adherence:** Having the LVC Ambassadors providing education and awareness in the community, and monitoring SCD patients improves treatment compliance. It has been found that patients receiving LVC ambassador support were very likely to attend follow-up visits/clinics and report any challenges they were having.
- **Lack of health insurance prevents many families from seeking proper SCD care**. Most families with SCD patients reported not being able to afford regular hospital visits/clinics due to financial constraints. After the introduction of Phase One, which provides SCD education, diagnosis and treatment at no cost to the patient**,** check-in and follow-up rates increased**,** indicating that cost reduction encourages treatment.

Recommendations

- Strengthen outreach of sickle cell screening programs for early diagnosis.
- Improve access, availability, and affordability to essential SCD medications and pain management options.
- Enhance training for healthcare providers in SCD management.
- Enhance training for LVC Ambassadors in SCD information.
- Develop a follow-up system for continuous patient care and monitoring.
- Strengthen laboratory capacity for early and accurate diagnosis.
- Enhance patient education programs to increase awareness, self-management skills, and early screening programs to reduce community misconceptions and stigma about SCD.
- Advocate for community-based support programs for SCD patients and families including men's involvement.
- Investigating how to assist patients to access health insurance.

7. Conclusion

Phase One of this project reminds us that children are living with ongoing pain when treatment could be made available to reduce their pain, severe complications, and risk of dying from SCD. It emphasizes the importance of treating children with SCD and improving their health and over-all quality of life, and it reinforces the importance of continuous care and follow-up of SCD patients. Despite initial challenges accessing medications, significant progress was made in diagnosis, treatment, and patient/community education. Continued efforts are needed to ensure that the children who are being diagnosed and treated continue to have access to this life saving healthcare. The foundation has been established on Ukerewe island through the combination of community outreach and provision of services. Drawing on lessons learned, much can be accomplished to improve healthcare infrastructure, medication access, and community awareness concerning SCD in Ukerewe District, and to evaluate the impact of the program on the cohort of about 200 children to be followed during Phase Two.

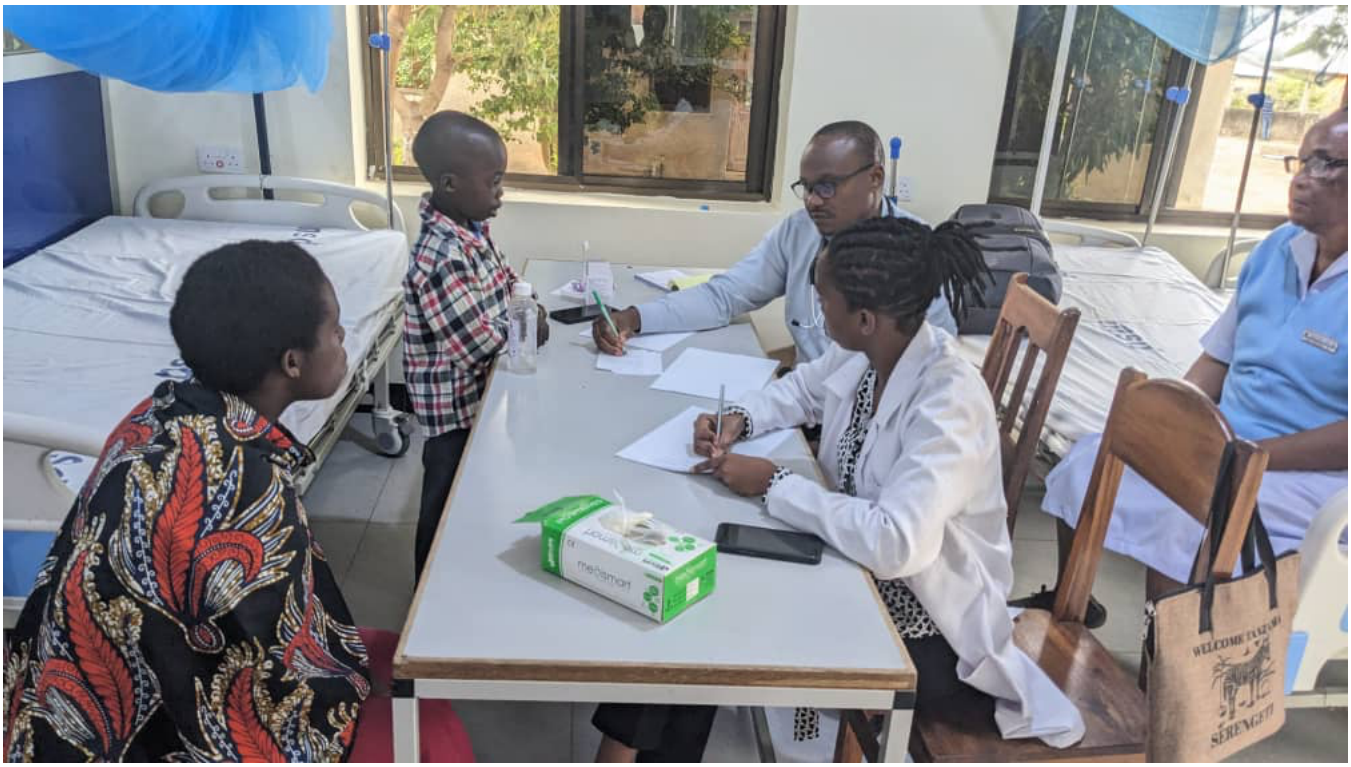
Budget Update, as of April 2025

Income:

DESCRIPTION	AMOUNT (TSH)
Income	
Grant Received (July 2024)	**57,217,980**
Grant received (October 2024)	**24,671,832**
Other Funding Sources*	**0**
Total Income	**81,889,812,**

* Other funding and in-kind sources:

- In addition to attending all SCD clinics, Dr. Ambrose and the SCD expert team at Bugando Medical Center provided all the training along with much guidance and support during Phase One of the project.
- Dr. Karin Euler donated the funds to purchase a motorcycle to increase the project manager's capacity to move easily around the island visiting LVC ambassadors, health centers, and communities.
- CACHA children's Emergency Medical fund provided financial support to 2 children suffering severe SCD complications and needing to be transferred to BMC for splenectomy procedures.



Category	July	August	September	October	November	December	January	February	March	Comments/notes	Total (Tsh)
Personnel cost (salary)	0	0	1,350,000	1,350,000	1,350,000	1,350,000	1,350,000	1,350,000	1,350,000	The salary for the Project Manager includes NSSF, PAYE	9,450,000

Administrative cost	0	500,000	625,000	625,000	625,000	625,000	625,000	625,000	625,000	LVC administration cost	4,875,000
Project set-up phase and inception meetings	0	410,000	0	0	0					Inception Meeting with Ukerewe health management team and LVC board members, included venue cost, refreshments	410,000
Training-clinician training (training preparation cost, per diems, accommodation, meals, venue, stationery)	0	0	14,540,000							The cost included -55 Participants half per diem and full per diem @150,00=9,240,000 - Full perdiem 3 Trainers from BMC@220,000x3 for 4 days= 1,980,000 1-Venue cost for 3 days @50,000=150,000 - Refreshment (Food and drinks) for 60 people for 3 days @15,000=2,925,000 Stationary- lump sum= 245,000	14,540,000
Travel and Transportation	0	0	1,959,000							All Travel costs during project activities and field supervision	1,959,000
Training-LVC Ambassadors (training preparation cost, per diems, accommodation,					9,395,000					The cost included -67 Participants' half per diem @80,000=5,360,000 - Full per diem Trainers from	9,395,000

meals, venue, stationery)										BMC@200,000x2 for 3 days, 1,200,000 1-Venue cost for 2 days @50,000=100,000 - Refreshment (Food and drinks) for 75 people for 2 days @12,000=1,800,000 Stationary-lumpsum= 425,000	
Tanzania Revenue Authority (TRA) compliance in Mwanza and LVC staff accommodation in Mwanza.					359,715					Per diem, transport cost, printing, for LVC staff,2 days stay in Mwanza to issue TRA complies for staff on PAYE, and international procurement of sickle cell rapid test kits	359,715
Procurement of Sickle rapid test kits from USA supplier Silver Lake company (including exchange rate of 2,700 Tsh, Transfer Charges, and VAT)					12,768,419					The cost included -40 Boxes with 50 kits per box. 1 box costs 99 USD = 267,300 Tsh, @rapid kit costs 5,346 Tsh, so 2,000 kits cost 10,692,000 plus Transfer charges, and VAT = 2,076,419	12,768,419
Tanzania Charges (local charges) for Sickle cell rapid test kits during						260,524				Tanzania Food and Drug Authorities charges 26,909 . DHL clearance cost 35,400- TRA	260,524

procurement.										clearance 198,215	
Printing of LVC community ambassadors' reporting tools						180,000				The cost involves the printing of reporting booklet for community Ambassadors for monthly reporting whereby 600 copies produced at a cost of 200Tsh @copy.	120,000
Expenses for engineers for the provision of a quotation for sickle cell ward rehabilitation at Nansio hospital				55,000						Transport refund for the Meeting with DMO and Medical officer in-charge and district engineers to provide quotation for sickle cell ward rehabilitation at Nansio Hospital.	55,000
Fuel and Communication cost				30,000							30,000
Proquarement of 100 boxes for Hydroxyurea drugs first butch and 120 boxes second batch							4.050.000		4,860,000	1 box contains 100 hydroxyurea tabs at a cost of 40,500; 1 tablet costs 405 Tsh. A total of 220 boxes = 22,000 tablets have been procured.	8,910,000
Drugs costs including (Transport Dar to Mwanza, Mwanza to Nansio and fuel cost) first butch and second butch							180,000			The cost included cargo cost from Dar es Salaam to Mwanza, Mwanza to Nansio, including ferry costs and Tax charges	180,000

Sickle Cell Disease first clinic (per diems, drug costs, laboratory CBC costs, transport costs, and stationery)							5,767,800	4,395,000		The cost included : -5 Doctors and a Lab technician half per diem @40,000 for 5 days and 220,000 for specialist from Bugando 2,420,000 - Complete Blood Count for 120 children above 3 years = 1,200,000 1-local transport and logistics 385,000 - cost for other drugs (folic acid, pain killers, pen v, amoxicillin etc.=720,000 Stationary- 100,000	10,162,800
Total Expenses		910,000	18,474,000	2,060,000	24,498,134	2,415,524	7,992,800	6,370,000	6,835,000		73,475,458

Net Income

Description	Amount (TSH)
Total Income	**81,889,812,**
Total Expenses 9 months (July 2024- March 2025)	**73,475,458**
Net Funds remaining April 1, 2025	**8,414,354**
Funds needed for April – September 2025	**39,209,354**
Additional Funding required to complete Phase One	**30,795,000**

Notes and Analysis

- **Income**: Received full funding as projected.
- **Expenditures**:
  - Overall spending exceeds the budgeted amount for Phase One. The main reason for the budget shortfall is the cost of medications. The hiring of a project manager, bringing experts to the SCD clinics, and the cost of tests also contributed to Phase One being underbudget. Lessons have been learned in real time about the actual costs, and the budget for Phase Two will be adjusted to be in line with these actual costs, to cover a cohort of up to 200 children.
  - We are working to find additional funding to bridge the remaining months of Phase One and the beginning of Phase Two, to address the shortfall of 30,795,000 caused mainly by the drug costs since treatment of SCD must continue without interruption. A sustainable procurement and supply system will be developed and be in place before the end of the project in 2028.