

# Expanding Access to Blood Disorders Care in East Africa

Following a successful joint project between Kenya and Tanzania in 2021–2023, this project expanded its reach to include Uganda and Rwanda, and continued to strengthen haemophilia care whilst exploring integrated approaches to haemophilia and sickle cell disease. Supported by the Novo Nordisk Foundation (NNF) and Novo Nordisk Haemophilia & Haemoglobinopathies Foundation (NNHF), the project built on over a decade of work supported by the NNHF across the four countries and focused on leveraging each country's strengths, providing a platform for learning, encouraging positive competition, and fostering collaboration.

Desmond, who is living with sickle cell disease in Kawangware, Kenya, and his mother.



Since the Project began in 2024,  
**2,246** people with haemophilia,  
and at least **2,227** people with sickle cell disease  
directly benefitted from its activities

# Impact highlights

## KEY ACTIVITIES



**538**

people retested or newly diagnosed so far



**28**

treatment centres established/strengthened



**667**

HCPs trained; including 41 HCPs who received advanced and specialised training



**600**

youth empowered

## KEY OUTCOMES



Benefitted **2,246** people with haemophilia, and at least **2,227** people with sickle cell disease



**28%** increase in diagnosis rate, averaged across the four countries



Up to a **10-hour reduction** in travel time to receive care

## KEY ADVOCACY UPTAKES



National registry and treatment guidelines endorsed in Rwanda



Procurement of reagents by Mulago National Referral Hospital in Uganda



Centre of Excellence for haemophilia and sickle cell disease established by Kenya Medical Training College



National treatment guidelines endorsed in Tanzania



Leonard Ssengooba, a parent of a child with haemophilia, listens attentively during a training session for patients, parents, and caregivers in Uganda.

# Strengthening care centres and enhancing knowledge capacity

The two activity pillars were establishing integrated care facilities for haemophilia and sickle cell disease, and strengthening services and knowledge in haemophilia.

Learnings from the previous project with Kenya and Tanzania emphasised that integrating haemophilia and sickle cell disease (SCD) care leads to improved efficiencies due to shared resources, medical personnel and training opportunities. The project teams continued to pursue this approach, with 13 of the 28 strengthened centres offering integrated care for both haemophilia and SCD.

Efforts to strengthen haemophilia care also continued with 667 healthcare professionals trained, and 41 of these receiving in-depth training. In addition to training sessions in Kenya and Tanzania, trainees also travelled to South Africa and India, enabling them to gain skills in orthopaedic surgery that had not been available in the region, advanced coagulation techniques, and management practices in low-resource settings. The project also enabled the introduction of Point of Care Ultrasound machines at Kenyatta National Hospital in Nairobi, Kenya, Muhimbili National Hospital in Dar es Salaam, Tanzania, and Mulago National Referral Centre in Kampala, Uganda, resulting in timely identification of bleeds and more efficient use of factor concentrates.

Whilst training abroad offers valuable insights into optimal care systems, strengthening in-country training opportunities is a key step for countries seeking to become self-sufficient in haemophilia care. Kenya has made strides towards this goal, with Kenya Medical Training College (KMTC) establishing a centre of excellence to serve as a national and regional hub for training, focusing on training for both haemophilia and sickle cell disease. With 85% of Kenya's mid-level healthcare workers trained at KMTC, the long-term impact will be far-reaching. Furthermore, healthcare professionals from the project countries are now equipped to train other regions of Africa, such as Dr Samuel Ntambi from Uganda, who has trained lab technicians from Liberia, The Gambia and Sierra Leone. The enhanced training capacity generated by this project expands opportunities for healthcare professionals to access training within East Africa, which reduces the reliance on South Africa as a training hub.

Further ensuring the standardisation of care across all centres, Rwanda and Tanzania have now joined Kenya in having their national treatment guidelines endorsed by authorities.

The new and strengthened centres have achieved an average reduction of 7.5 hours in round-trip travel time for care access across all four countries, with Uganda reporting the greatest improvement of 10 hours for people with haemophilia and SCD living in Mbarara.

Joint training for lab technicians from Mulago National Referral Hospital and Kawempe National Referral Hospital in Kampala, Uganda.

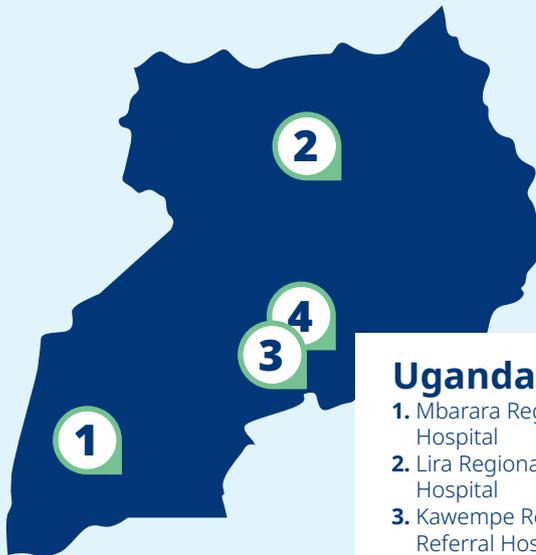


# 28 centres established or strengthened



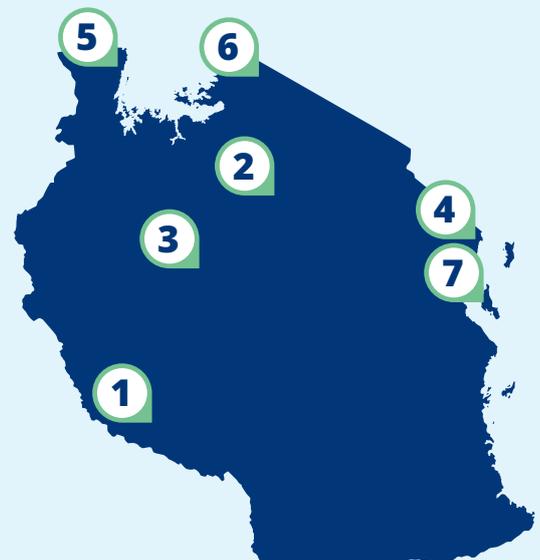
## Kenya

1. Kitui County Referral Hospital
2. Homa Bay County Referral Hospital
3. Lodwar County Referral Hospital
4. IRC Kakuma Hospital
5. Kilifi County Referral Hospital
6. Kwale County Referral Hospital
7. Kakuma-sub County Referral Hospital
8. National Spinal Injury Referral Hospital
9. IRC, Dadaab Refugee Camp
10. Busia County Referral Hospital
11. Kapenguria County Referral Hospital
12. Marsabit County Referral Hospital
13. Migori County Referral Hospital
14. Mandera County Referral Hospital



## Uganda

1. Mbarara Regional Referral Hospital
2. Lira Regional Referral Hospital
3. Kawempe Regional Referral Hospital, Kampala
4. Mulago National Referral Hospital, Kampala



## Tanzania

1. Rukwa Regional Referral Hospital
2. Manyara Regional Referral Hospital
3. Tabora (Kitete) Regional Referral Hospital
4. Tanga (Bomboo) Regional Referral Hospital
5. Kagera Regional Referral Hospital
6. Mara Regional Referral Hospital
7. Ijiti District Hospital (Zanzibar)

## Rwanda

1. Kibuye Referral Hospital, Karongi District
2. University Teaching Hospital of Butare (CHUB)
3. University Teaching Hospital of Kigali (CHUK)



# Improving diagnostic outcomes through capacity building and registries

Through training for lab technicians and strengthening of laboratory capacities, 538 people with haemophilia have been diagnosed so far since the project began (261 in Kenya, 15 in Rwanda, 164 in Tanzania and 98 in Uganda). With an improved infrastructure and skills in place, this number is anticipated to grow significantly over the coming months. In addition, Rwanda experienced the largest increase in diagnosis rates at 36%, and established a national electronic patient registry in collaboration with the Rwanda Biomedical Centre. This initiative aims to streamline patient management, facilitate advocacy and research, and improve healthcare outcomes for all patients.

Whilst impressive, overall diagnosis rates for haemophilia remain low, ranging from 6% in Uganda to 21% in Kenya. Therefore, the project teams are ramping up efforts to address this through targeted screening campaigns such as family tree tracing, and implementing activities to strengthen laboratories, including lab technician training at Kawempe National Referral Hospital in Uganda. This facility is home to Africa's busiest labour ward and is therefore ideally placed to conduct maternal and newborn screening.



Lab technicians in training at Muhimbili National Hospital in Dar es Salaam, Tanzania.

# Sharing learnings in pursuit of systemic change

Throughout the project, the four countries have shared their advocacy challenges, learnings and successes. For example, addressing the challenge of irregular reagent supply for diagnosis, Uganda successfully advocated for government funding for reagents at Mulago National Referral Hospital in Kampala, which should now be available on a rolling basis. Additionally, the government of Tanzania has pledged to include funding for haemophilia and sickle cell disease in its new fiscal budget for 2025/2026. Targeted advocacy activities have also played a key role in the project's significant successes such as the KMTC partnership and the creation of the national registry in Rwanda where the treatment guidelines were developed, approved and endorsed in 2024. Rwanda has also leveraged on the materials utilised by other countries, for example by adapting materials from Kenya and Tanzania for the training of healthcare professionals at Kibuye Hospital.

Additionally, the national patient organisations in each country have been strengthened through opportunities to share knowledge, train youth, and provide board leadership training. These initiatives aim to foster the organisations' succession planning and enhance their leadership and advocacy capacities.

An important project highlight was the East Africa Blood Disorders Leadership Forum, held in Nairobi in October 2024. Over 100 delegates from governments, patient organisations, NGOs and the healthcare sector of 12 countries attended the Forum – the first event of its kind focused on bleeding and blood disorders in the region. Drawing on collective experiences and fostering innovative solutions for the future of blood disorders care, panellists and speakers at the event included Ministry representatives and MPs from the East African Legislative Assembly.



# Expanding networks for improved care in bleeding and blood disorders

The four countries, with the support of the NNF and the NNHF, have made significant progress in advancing haemophilia and sickle cell disease care. A solid network and a culture of healthy competition has been established, in which project teams continue to share their challenges, insights and successes both formally and informally. The project's learnings extend beyond the four countries, with the NNHF actively supporting similar coalition projects in other regions across Africa.



Looking ahead, the four countries aim to consolidate the many interventions already in place, ensuring that existing infrastructure is functional, fostering knowledge sharing between trained healthcare professionals and those yet to be trained, securing government commitment and continuing to improve the pace of increasing their diagnosis rates.