

Accelerating access to blood disorders care in Kenya and Tanzania

In 2020, the Kenya Haemophilia Association and Tanzania's Muhimbili National Hospital embarked on a journey to reduce inequities in access to blood disorders care. The first initiative co-funded by the Novo Nordisk Foundation and Novo Nordisk Haemophilia Foundation (NNHF), this project sought to improve healthcare infrastructure, influence policy and pave the way for a regional approach to improving access to care. Here we highlight some of the project's activities, achievements and learnings.

With an overall aim of achieving national policies for bleeding and blood disorders, the project's goals fall into three main themes:



Improving medical capacity and infrastructure



Building strategic alliances to engage authorities and policymakers



Increasing diagnosis and creating registries

Eunice Bella Aluoch, mother to a 16-year old boy living with haemophilia, from Kisumu County, Kenya.



Since the project began in August 2020,
1,400 people
with haemophilia directly benefitted
from its activities

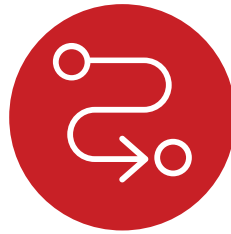
IMPROVING MEDICAL CAPACITY AND INFRASTRUCTURE

Before this project, a person living with haemophilia in some areas of Tanzania faced a 48-hour journey to receive care and diagnosis. Today, the average journey time has reduced almost tenfold, to 5-hours. The 21 joint Haemophilia and Sickle Cell clinics established or strengthened in both Kenya and Tanzania offer diagnosis and treatment thanks to trained multidisciplinary teams and a dedicated clinic space – described as ‘one-stop shops’ for care by Eunice Bella Aluoch, a mother from Kisumu Country in Kenya

1,300
healthcare professionals
trained, of which 195
received in-depth training



Up to
18-hour
reduction in travel time to
care and diagnosis (one-way)



**National
treatment
guidelines created
or endorsed**



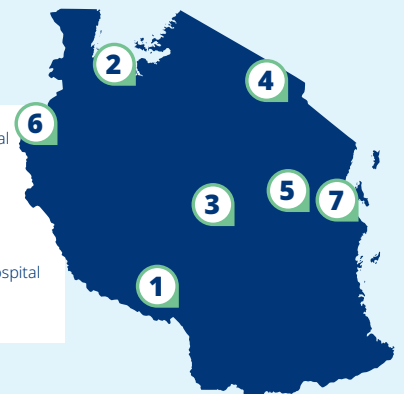
The National Treatment Guidelines, which are being disseminated in Kenya and in the final endorsement stage in Tanzania, mean that healthcare professionals now have an established protocol. This framework empowers them to deliver standardised care to individuals with haemophilia, streamlining the organisation of care and ensuring consistent treatment regimens and methodologies.

All of this was made possible due to the collaboration between each country's Medical Advisory and Scientific Committee (MAC) and Ministry of Health. With MAC conducting facility needs assessments and training, they could ensure the treatment guidelines addressed the needs of healthcare facilities and people with haemophilia whilst being aligned with the Ministry's strategic plan for blood disorders.

21 centres established or strengthened

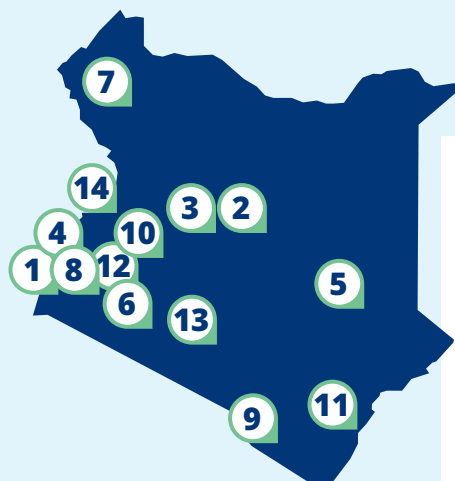
Tanzania

1. Mbeya Zonal Referral Hospital
2. Bugando Medical Centre
3. Benjamin Mkapa Hospital
4. Kilimanjaro Christian Medical Centre
5. Morogoro Regional Referral Hospital
6. Maweni Regional Referral Hospital – Kigoma
7. Muhimbili National Hospital



Kenya

1. Bungoma
2. Meru
3. Laikipia
4. Kakamega
5. Garissa
6. Narok
7. Turkana
8. Kisumu
9. Taita Taveta
10. Nakuru
11. Mombasa
12. Kisii
13. Kenyatta National Hospital, Nairobi
14. Moi Teaching and Referral Hospital



“Now we have a one-stop shop; we have a clinic, there's Factor VIII, there's a lab. Everything is done here, it's cheaper, it's easier.”

– Eunice Bella Aluoch, mother to a 16-year old boy living with severe haemophilia A, Kenya. Click on the image to watch the video.

BUILDING STRATEGIC ALLIANCES TO ENGAGE AUTHORITIES AND POLICYMAKERS

1,050

monthly consultations now take place with people living with Sickle Cell Disease in Kenya and Dar es Salaam



Dr Patrick Amoth, Director General for Health in Kenya, at a centre opening in Kisumu County. Improved care, together with the financial relief provided by the National Health Insurance Fund, will help people living with haemophilia and sickle cell disease to be active members of society and ensure, in Dr Patrick Amoth's words, "no-one is left behind".

It takes a multi-sector, collaborative approach to influence policy – particularly when it comes to rare conditions like haemophilia. Embedded since the project's inception was the partnership between the haemophilia and Sickle Cell Disease communities. With both conditions being blood related, there is crossover between the treating physicians and other healthcare professionals, and the training curricula in which they are included. This meant efforts could be amplified: by establishing clinics treating both conditions, including them in the same training sessions, and covering them with the same policy, the beneficiaries would be higher in number compared with any initiative targeting only one condition. The collaboration is already proving effective in elevating haemophilia's position on the healthcare agenda: haemophilia was raised by Ministry of Health representatives multiple times in relation to integrated NCD care during a Sickle Cell conference in Tanzania, whilst keynote speaker Prof Tshilolo from Democratic Republic of Congo praised this approach, which has also proven successful in his country.

In total, six strategic alliances have been formed or strengthened including the Kenyan haematological Technical Working Group (TWG), formed by the Ministry of Health with project partner Dr Kibet Peter Shikuku as the co-chair. The Kenya Haemophilia Association also created a strategic partnership with Non-Communicable Disease Alliance Kenya (NCDAC-K), where two KHA members were co-opted to the Board, and a working partnership has been formed with the Kenya Medical Training College which has started generating haemophilia awareness across the country's counties, with a long-term view to begin including haemophilia in the training curriculum.

In addition, haemophilia is now recognised as a disability by the National Council for Persons with Disability (NCPWD) in Kenya, allowing them to access benefits such as tax exemptions, express services in government offices, access to



6 strategic alliances formed or strengthened



Budget allocation approved in Tanzania



Entitlement to disability benefits in Kenya



Bleeding and blood disorders included in Kenya's National Non-Communicable Diseases strategy

government procurement opportunities and waivers for government levies. In Tanzania, Parliament approved a Ministry of Health budget allocation to Muhimbili National Hospital to include the provision of haemophilia care in 2023/2024.

These accomplishments represent pivotal moments in the partners' quest to establish a comprehensive national government policy for blood disorders. The project played a crucial role by providing a platform for showcasing the partners' credibility and demonstrating the mutual advantages derived from this collaboration. Through the inauguration of clinics, as well as through joint high-level workshops and meetings, they effectively showcased a pathway to achieving their common objective: reducing inequities in healthcare.

INCREASING DIAGNOSIS AND CREATING REGISTRIES

At the project's inception, Tanzania had a mere 2% diagnosis rate, while Kenya fared slightly better with 15%. To address this head-on, an impactful awareness and screening campaign was integrated into the project.

Comprising family tree screening, sensitisation sessions for primary healthcare professionals, and a media engagement campaign, the various initiatives combined targeted tactics with those aimed at reaching a broader audience.

Each centre's inauguration brought with it an opportunity to generate noise and media interest, giving exposure to government figures and bringing recognition to the hospitals involved. These events helped accelerate the efforts of the screening campaign: new or reconfirmed diagnoses total 226 in Tanzania and 314 in Kenya, an overall 65% increase in the number of people diagnosed or with a reconfirmed diagnosis since the project started.

Diagnosis is not only the first step to care for those who need it, it also provides a source of data. With accurate patient numbers, governments are more likely to allocate budgets and approve policies. Healthcare professionals can track treatment regimes, schedule appointments, monitor treatment consumption and make informed decisions based on patient history, as well as generate data for publications. By capturing this data in newly created registries, which have been launched in Kenya and in the final launch stage in Tanzania, an accurate epidemiological picture of blood disorders will be captured for the first time.

540
individuals
received a
diagnosis

65%
increase in the
number of people
with a confirmed
diagnosis

2
national
registries
created



First Lady of Kenya's Kisumu County, Dorothy Nyong'o, visits the new lab at Jaramogi Oginga Odinga Teaching and Referral Hospital.

Seven year old Sahin with his grandmother receives treatment during a consultation at Morogoro Regional Referral Hospital, Tanzania whose clinic was strengthened through this project. Sahin is living with haemophilia A. © Amini Suwedi/Novo Nordisk Haemophilia Foundation/Fairpicture



LEVERAGING LEARNINGS TO CREATE AN INTERNATIONAL NETWORK

Despite diverse healthcare systems, political structures and cultures, bleeding disorders communities around the world face shared challenges, and benefit from sharing experiences and success stories. The partnership of Kenya and Tanzania meant Kenya brought significant experience in patient organisation strengthening and could support Tanzania on this topic, whilst Tanzania brought experience relating to accessing Sickle Cell Disease care. The two countries shared their knowledge through weekly virtual meetings, as well as onsite visits where not only the project team were present to learn from each other, but also representatives from authorities, hospital management and the sickle cell disease patient organisations.

Testament to the value of leveraging learnings internationally is the project's next phase, which is being co-funded by the Novo Nordisk Foundation: A joint initiative between Kenya, Tanzania, Rwanda and Uganda to elevate the standards of haemophilia and sickle cell disease care across the four countries.