Hans (right) and Liam (left), two brothers from Mauritius aged 7 and 3 years respectively living with haemophilia A.

NNHF Half-Year Report

1 January - 30 June 2026

novo nordisk haemophilia & haemoglobinopathies foundation

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1. Introduction

This **Half-Year Programme Report** presents an overview of the activities, progress, and key developments across programmes supported by the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation (NNHF) during the first half of 2026, **from 1 January to 30 June.** It highlights key developments from NNHF-funded projects across **Africa, the Americas, and Asia**, along with updates from **global programmes**.

The report outlines programme objectives, implementation status, and key achievements, illustrating how NNHF and its partners continue to strengthen diagnosis, improve access to care, build sustainable health systems, and empower patient communities affected by haemophilia, sickle cell disease, and thalassaemia. It also highlights advocacy efforts and progress towards long-term sustainability and local ownership.

During the reporting period, NNHF's programme portfolio remained broad and diverse across regions and maturity stages. New initiatives were launched while several partner countries advanced decade-long collaborations. Coordinated efforts by patient organisations, multidisciplinary healthcare teams and ministries of health strengthened national care ecosystems and improved sustainable access to diagnosis and treatment, driving progress toward systemic change.

As of June 2026, NNHF has supported 265 projects, 74 fellowships, and 33 awards across 88 countries. This report offers NNHF partners and ambassadors a consolidated snapshot of progress achieved during the first half of the year and insight into how individual country programmes contribute to NNHF's broader regional and global objectives.

Discover the impact we are making together. In Mozambique, **haemophilia training** for more than **180 healthcare professionals** strengthened diagnosis, referrals and access to multidisciplinary care closer to home. **In Nigeria**, a **national leadership forum convened 74 stakeholders** and led to a new technical working group on inherited blood disorders. Across several regions, partners are sharing expertise across borders to strengthen haemophilia and haemoglobinopathies care. **These examples reflect just part of the progress captured during the first half of 2026, with further developments highlighted throughout the report.** Scroll through the report to explore developments from across countries and regions.

Every page shows how your support drives policy change and expands care. For more information visit www.nnhf.org or reach out to info@nnhf.org.

2. Selected Programme Updates

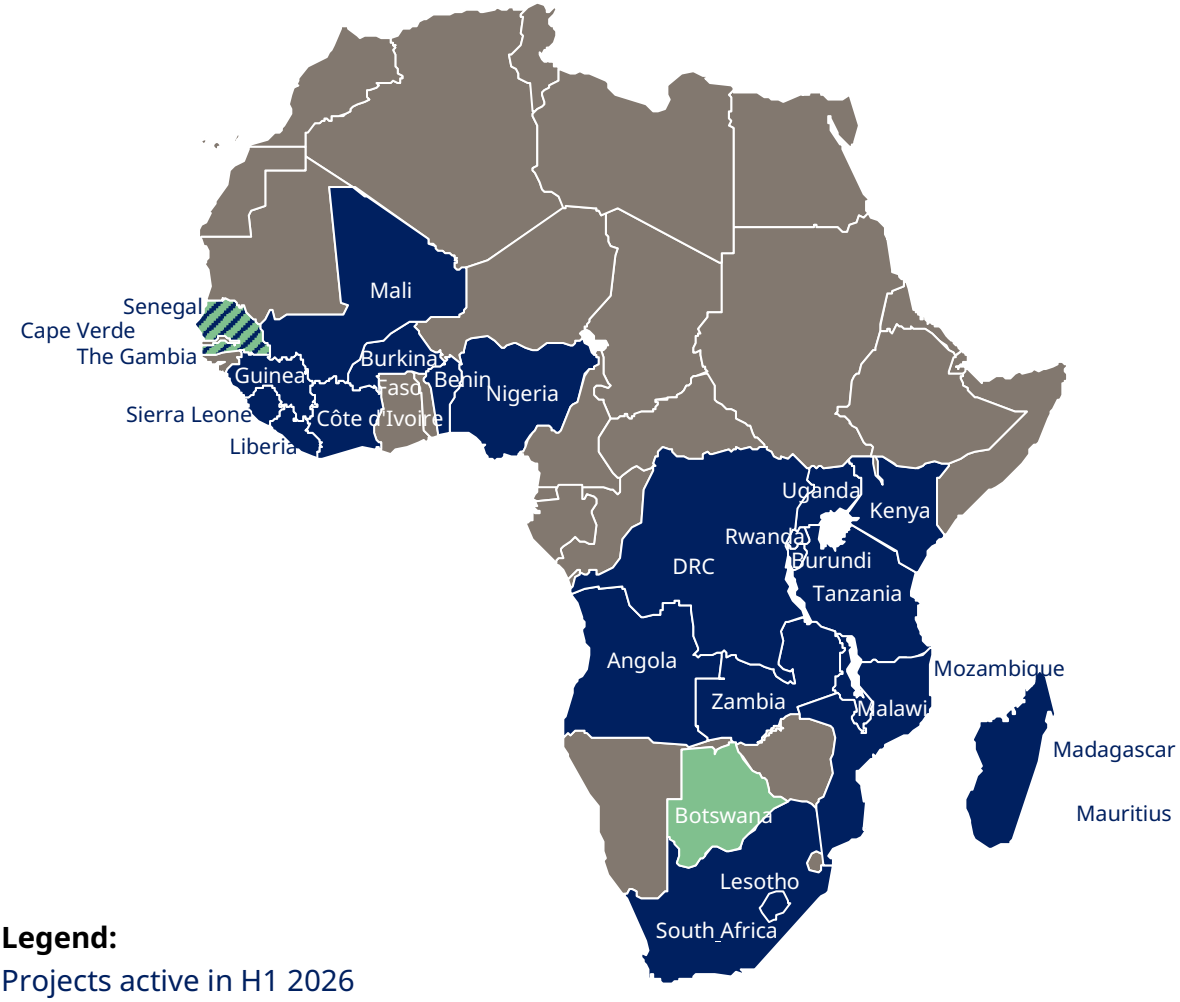
1 January – 30 June 2026

Programmes approved since 2005:

- 265 projects (5 new projects since H2 2025)
- 74 fellowships
- 33 awards

in 88 countries

3. Africa



Legend:

Projects active in H1 2026

Projects completed in H1 2026

3.1. Africa CDC 1 Project

- Programme title **Reduced burden of haemophilia and sickle cell disease across Africa through equitable access to prevention, diagnosis, treatment, and care**
- Phase Formalisation
- Partners
    - **Africa Centres for Disease Control and Prevention (Africa CDC)** (technical partner):
      Dr Adelard Kakunze, Programme Officer NCDs, Injuries and Mental Health, and Joseph Mwaniki, Technical Officer, Grants Management
    - **Africa Public Health Foundation** (grant holder):
      Victor Kubende, Grants Management Lead, and Milou Biesebroek, Resource Mobilisation Lead
- Duration 2 years
- Activity start date Q3 2026
- ***This project is supported by a grant from Novo Nordisk Foundation***

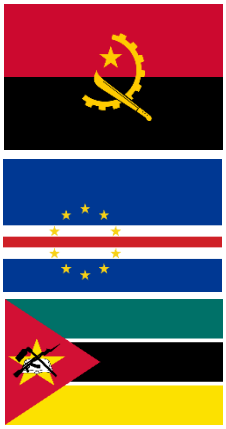
Objectives

- Establish a unified continental policy and governance framework for haemophilia and sickle cell disease that is formally endorsed by the African Union and adopted by Member States as the basis for national planning and investment
- Aim for haemophilia and sickle cell disease service inclusion in national universal health coverage (UHC) benefit packages and financed through sustainable domestic mechanisms in at least 10 AU Member States, reducing dependence on out-of-pocket payments and donor funding
- Aim for reliable, affordable, and equitable access to essential medicines and diagnostic commodities for haemophilia and sickle cell disease across participating countries through strengthened supply chains, pooled procurement, and regulatory harmonisation
- To establish interoperable, disaggregated national and continental data systems that generate credible burden estimates, monitor service coverage, and track clinical outcomes to inform planning, resource allocation, and accountability
- To increase awareness and knowledge among governments, policymakers, healthcare workers, patients, and communities, driving evidence-based policy action and reducing stigma and diagnostic delays

Status

- The project was approved at the NNHF Council meeting in May 2026 and is currently working on the formalities to sign the project partnership agreement and soon commence activities.

3.2. Angola, Cape Verde & Mozambique Project - PALOP 1



- Programme title **Strengthen diagnosis in the capital cities, expand haemophilia care in the regions and build a regional coalition between the PALOP countries**
- Phase Execution
- Partners
    - **Angola**: Liga dos Amigos dos Doentes Hematológicos de Angola (LADHA) – Mr Kaunda da Gama, President and Dra Victoria Pediatric Hematological Institute – Dr Francisco Antonio Domingos
    - **Cape Verde:** Associação Caboverdiana de Hemofilia e de Outras Coagulopatias Congénitas (ACHCC) – Dr Conceição Pinto and Dr Carla Lima from Hospital Agostinho Neto
    - **Mozambique**: Mozambique Institute for Health Education and Research – Dr Sergio Noormahomed and Dr Nelia Zacarias Manguele and supported by Dr Patrícia Silva
- Duration 4 years
- Activity start date Q1 2025

Objectives

- Increase diagnosis rate from 4.9% to 8% in Mozambique, 5.8% to 8.5% in Angola and 36.1% to 50% in Cape Verde
- Strengthen care in the capital cities of Mozambique and Angola and establish care in selected regions
- Patient community education and empowerment
- Establish treatment centre in Cape Verde
- Establish national haemophilia patient organisation in Cape Verde, and create a communication and knowledge exchange between them and the patient organisations of Mozambique and Angola
- Create a blood disorders coalition comprising Angola, Mozambique, Cape Verde and other PALOP countries to facilitate knowledge exchange and amplify advocacy efforts
- Explore sickle cell disease landscape, build strategic alliances and define strategy for Mozambique and Angola

Status

Mozambique

- **Strengthen care and diagnosis in the capital and the regions of Mozambique**
    - A nurse from Maputo Central Hospital completed a one-month specialised training programme at Hemocentro UNICAMP in Brazil,

enhancing her knowledge and practical skills in the integrated management of haemophilia and sickle cell disease and strengthening coordinated care, patient education, and follow-up services.
    - To strengthen haemophilia diagnostic capacity in Nampula Province following the procurement of a coagulation analyser by Nampula Central Hospital, project partners Mozambique Institute for Health Education and Research (MIHER) and Maputo Central Hospital supported a 5-day specialised laboratory training programme in May 2026. 5 laboratory technicians were trained in coagulation testing, quality control, sample processing, and interpretation of laboratory results, enhancing the hospital's capacity to accurately diagnose and monitor people with haemophilia.
    - Complementing the laboratory training, Dr Virgílio Nhantumbo and Dr Belmiro Paraque from Maputo Central Hospital delivered a 3-day clinical training programme on haemophilia diagnosis, treatment, and management. A total of 82 healthcare professionals were trained, including 45 general practitioners, 12 paediatricians, 10 surgeons, 8 nurses, 1 haematologist, and 6 dentists. The training strengthened multidisciplinary care teams' capacity to identify, diagnose, and manage haemophilia, supporting earlier diagnosis, improved referral pathways, and more coordinated patient care across the province.
    - A 3-day basic multidisciplinary training on haemophilia diagnosis and management was conducted from 27 to 29 April 2026 at Beira Central Hospital, led by Dr Nélia Manguele and Dr Amisi Débora Feza from Maputo Central Hospital. The training reached 81 healthcare professionals from the paediatrics, internal medicine, surgery, orthopaedics, dentistry, nursing, pharmacy, and haematology departments, strengthening their capacity to recognise, diagnose, and manage haemophilia. The programme also enhanced multidisciplinary collaboration and coordination in haemophilia care.
    - Concurrently, from 27 to 30 April 2026, 18 laboratory technicians at Beira Central Hospital received hands-on training led by Dr Vânia Monteiro from Maputo Central Hospital in sample processing, basic coagulation testing, operation of the coagulation analyser, and interpretation of results. The training strengthened the hospital's diagnostic capacity, equipping technicians with the practical skills required to support haemophilia diagnosis and improve patient management.
- **Enhance haemophilia awareness in Mozambique**
    - To commemorate World Haemophilia Day, a national webinar on haemophilia was conducted featuring presentations by Dr Belmiro Paraque, Dr Etelvina Elija, and Dr Helder Nhampule, moderated by Dr Faizana Amodo. In observance of World Sickle Cell Day, a second national webinar on sickle cell disease featured presentations by Dr Belmiro Paraque and patient advocate Mayra Augusto, moderated by Dr Virgílio Nhantumbo. Together, the webinars strengthened awareness and understanding of haemophilia and sickle cell disease among

healthcare professionals, patients, caregivers, and the broader community.

Cape Verde

- **Treatment centre strengthening and patient community empowerment**
  - A 1-day awareness-raising workshop was conducted in June 2026 at Agostinho Neto University Hospital (HUAN) to strengthen the haemophilia treatment centre at the facility. The workshop brought together 7 healthcare professionals, including a paediatrician, a haematologist, two laboratory technicians, a nurse, and a physiotherapist, strengthening the capacity of the centre's basic multidisciplinary care team to support the diagnosis and management of haemophilia.
  - Eight people with haemophilia participated in a 1-day patient education session held at the Agostinho Neto University Hospital (HUAN), focusing on haemophilia management, treatment adherence, and psychosocial support. The session empowered participants with knowledge and self-management skills, supporting improved treatment adherence and quality of life.

Angola

- **Strengthening diagnosis and care for haemophilia and other bleeding disorders**
  - A 3-day haematology seminar was conducted at Lubango Central Hospital in June 2026, led by specialists from the Pediatric Hematológico Dr. Victoria do Espírito Santo Institute. The seminar brought together 100 healthcare professionals, including paediatricians, nurses, physiotherapists, and laboratory technicians from Huíla, Namibe, Cunene, and Cuanza Sul provinces, to strengthen their capacity to diagnose and manage haemophilia and other bleeding disorders. Watch the training highlights here. The seminar contributed to the diagnosis of 4 new haemophilia cases and 1 case of von Willebrand disease, expanding access to diagnosis and supporting the decentralisation of care closer to patients' homes.
- **Enhance haemophilia awareness in Angola**
  - To increase community awareness of haemophilia, the Associação Liga dos Amigos de Doentes Hematológicos de Angola (LADHA) conducted an awareness session at the Evangelical Baptist Church of Angola (IEBA), reaching approximately 190 congregants. The session enhanced public understanding of haemophilia and helped promote early recognition, reduce misconceptions, and support affected individuals and families.
  - In commemoration of World Haemophilia Day, LADHA organised an awareness and health education session at the Pediatric Hematológico Dr. Victoria do Espírito Santo Institute. The session, led by Dr Feliciano Mangovo, focused on early diagnosis, treatment adherence, patient self-care, and the role of the patient community in reducing stigma and

raising awareness. A total of 58 participants, including people with haemophilia, caregivers, and healthcare professionals, gained knowledge on haemophilia management, self-care practices, and stigma reduction, strengthening community engagement and support for people living with the condition.

- **Sickle cell disease mapping in Angola**
    - A national sickle cell disease stakeholder meeting was convened in March 2026, bringing together 28 participants from patient organisations, healthcare institutions, and the Ministry of Health to discuss priorities for improving care and advocacy. The meeting laid the foundation for the establishment of a technical working group to map sickle cell disease needs, identify gaps in care, and develop a coordinated advocacy plan to guide future interventions.

Healthcare professionals pose for a photo at Lubango Central Hospital during a three-day seminar on haemophilia and other bleeding disorders held in June 2026, which brought together participants from the provinces of Huíla, Namibe, Cunene, and Cuanza Sul.

3.3. Botswana 2 Project

- Programme title **Decentralisation of care and diagnosis in two regions of Botswana**
- Phase Closing
- Partners Botswana Baylor Children's Centre of Excellence at Princess Marina Hospital – Mr Andries Gontshwanetse and Botswana Inherited Bleeding Disorders Association (BIBDA) – Ms Nelly Monametsi
- Duration 2 years, Q3 2023 - Q3 2025

Objectives

- Strengthen haemophilia care in Gaborone to improve haemophilia care and to establish a training hub in the capital
- Decentralise care and diagnosis to Francistown and Maun, decreasing distance to care and diagnosis by up to 1,000km
- Strengthen patient organisation and improve haemophilia awareness to increase diagnosis rate from 24% to 37%

Achievements

- This project has directly benefitted **86 people with haemophilia**.
- **A basic multidisciplinary team was established in the capital, Gaborone, strengthening training capacity and the quality of care.**
    - **1 medical officer and 1 nurse** from Princess Marina Hospital completed a 1-month haemophilia training in South Africa.
    - **1 physiotherapist** from Princess Marina Hospital completed a 1-month MSK and joint care specialised training in Kenya; now a dedicated MSK expert is available in the capital.
    - **2 laboratory technicians** from Princess Marina Hospital received training from a local clinical haematologist, improving haemophilia diagnosis capacity and strengthening the organisation of laboratory.
    - The newly trained multidisciplinary care team has **developed haemophilia treatment guidelines**, currently in use at the main haemophilia treatment centre in the capital and awaiting Ministry of Health endorsement to enable regional training and standardisation of care across the country.
    - 2 patient education camps were conducted through a collaboration between Botswana Inherited Bleeding Disorders Association (BIBDA) and the newly trained multidisciplinary care team. The camps focused on haemophilia self-management, reached more **than 50 people with haemophilia and their families and contributed to strengthened self -infusion capacity**.

- **Engagements with regional health authorities in Francistown and Maun,** identifying opportunities for development of sustainable regional haemophilia treatment centres, leading to **strengthened care and diagnosis services in Francistown, reducing travel time by up to 10 hours for a round trip to the capital, Gaborone**
    - Strengthening care and awareness in Nyangabgwe Referral Hospital, Francistown:
        - **2 nurses, 1 medical officer and 1 laboratory technician** from the haemophilia treatment centre received a 1-week training in Gaborone, improving capacity for the haemophilia treatment centre to conduct intermediate haemophilia testing and provide basic and emergency care**.**
        - **30 healthcare professionals** including nurses, medical doctors, and pharmacists at Nyangabgwe Referral Hospital received a 1-day training, strengthening their capacity to spot haemophilia symptoms and manage emergency cases.
    - Exploring the possibility to establish a haemophilia treatment centre at the Letsholathebe II Memorial Hospital in Maun
        - Given Botswana's relatively small population (5 million), options for further decentralising diagnosis and care capacity for bleeding disorders were explored, including the feasibility of a placement model for necessary laboratory equipment. Building on lessons from a neighbouring country, a 2-day visit to the University of the Free State, South Africa, was organised for four representatives from the medical team, patient community, and Ministry of Health to assess whether such a model could offer a more sustainable solution for the Maun region. A solution has not yet been found and is part of a bigger strategic plan by the Ministry of Health. At the same time, the **dialogue with health authorities and the hospital management is ongoing to identify the most appropriate solution for the northern region.**
- **The diagnosis rate increased by 48%, rising from 24% to 34% (from 58 to 86 people with haemophilia),** bringing the diagnosis rate close to the ambitious target of 37%
    - **15 nurse haemophilia champions** from district-level hospitals were trained to raise haemophilia awareness, conduct family tree tracing, identify and refer suspected cases to haemophilia treatment centres. 17 new haemophilia cases were confirmed following the targeted family tree tracing conducted by nurse haemophilia champions.
- **Government commitment to haemophilia care improved, leading to procurement of 0.91 IU per capita of Factor VIII and 0.24 IU per capita of Factor IX**
    - The Botswana Inherited Bleeding Disorders Association (BIBDA) actively participated in targeted advocacy meetings with the Ministry of Health, contributing to government procurement of factor treatment. This has enabled access to prophylaxis for people with haemophilia and reduced

reliance on humanitarian aid compared to 2023. Drawing directly on learnings from targeted capacity-building initiatives, including an exchange visit and meeting the South African Haemophilia Foundation, BIBDA further strengthened its advocacy skills.

3.4. Burundi 1 Project

- Programme title **Building integrated care for haemophilia and sickle cell disease in Burundi**
- Phase Formalisation
- Partners
    - Centre Hospitalier de Kamenge represented by Dr Hélène Bukuru, paediatrician at CHU Kamenge
    - Solidarité Burundaise contre l'Hémophilie (SOBUH), represented by Mr Gilbert Niyonkuru,
    - Association des Personnes Drépanocytaires (APD), represented by Christine Ndayishimiye
    - Ministry of Public Health represented by Dr Leonidas Nzisabira
- Duration 2.5 years
- Activity start date Q3 2026
- ***This project is supported by a grant from Novo Nordisk Foundation***

Objectives

- Establish a multidisciplinary care team in the capital for both haemophilia and sickle cell disease, and initiate basic and emergency care services for both conditions in one region
- Increase the haemophilia diagnosis rate from 1% to 5%, develop a sustainable, referral pathway for diagnosis and ongoing care of people with haemophilia and sickle cell disease
- Empower the haemophilia and sickle cell patient organisations through improved organisational governance and leadership, and increased participation of patient communities
- Increase awareness and advocate for stronger government support for haemophilia and sickle cell disease, leveraging regional synergies and shared advocacy approaches within the East Africa coalition

Status

- The project was approved at the NNHF Council meeting in May 2026 and is currently working on the formalities to sign the project partnership agreement and soon commence activities.

3.5. Democratic Republic of Congo 2 Project

- Programme title **Hemodrepa 2 – An integrated initiative for better access to care for haemophilia and sickle cell disease communities**
- Phase Execution
- Partners Cliniques Universitaires de Kinshasa - Prof Jean Lambert Gini and Prof Léon Tshilolo from CEFA Monkole
- Duration 2 years
- Activity start date Q3 2024

Objectives

- Improve access to haemophilia and sickle cell disease diagnosis for people with these conditions living in Kinshasa, Mbuji Mayi, Kisangani and Lubumbashi
- Strengthen healthcare professional network nationwide and improve access to haemophilia and sickle cell disease care in Kinshasa, Mbuji Mayi, Kisangani and Lubumbashi
- Expand patient organisation reach and improve knowledge of haemophilia and sickle cell disease and their management amongst those affected and their family members
- Raise awareness and advocate for the inclusion of haemophilia and sickle cell disease in the Non-Communicable-Disease programme

Status

- **Haemophilia and sickle cell disease care and diagnosis decentralised in Kinshasa, Mbuji Mayi, Kisangani and Lubumbashi**
    - One nurse from Mbuji Mayi completed a 1-month training at the National Center Transfusion Sanguine in Dakar, Senegal. Upon return the nurse has already started to conduct trainings for other nurses and general doctors in Kinshasa at the IRB/CEFA-Monkole.
    - 2 physicians from Mbuji-Mayi received specialised training at IRB/CEFA-Monkole, in the capital city**.**
    - 15 healthcare professionals trained on the use of the health acarology, an electronic registry used in the capital city and across 4 regions.
    - Procurement of one ultra-low temperature (-80°C) freezer, supporting future fresh frozen plasma production.
    - 2 military camps in Kinshasa and Mbuji-Mayi incorporated into sickle cell disease screening and follow-up activities.
    - Procurement of 2 solar refrigerators for treatment storage in 2 basic referral centres in Kinshasa.

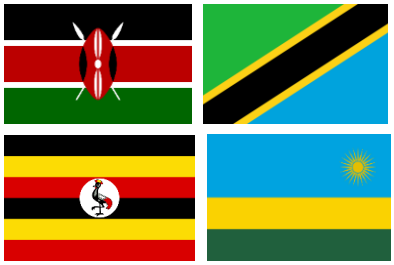
- **Raised awareness and advocate for the inclusion of haemophilia and sickle cell disease in the Non-Communicable-Disease programme through:**
    - Conducted a community survey in Mbuji-Mayi involving approximately 1,000 families. 5% of households were identified and reported prolonged bleeding following circumcision, indicating potential inherited bleeding disorders.
    - Pregnant women screened through targeted campaigns in Kingasani and Saint Jérôme health facilities.
    - World Haemophilia Day and World Sickle Cell Day were commemorated through a series of awareness-raising campaigns, diagnosis days and stakeholder engagement activities. These events brought together patients, families, healthcare professionals, community leaders, and policymakers to increase awareness of haemophilia and sickle cell disease and advocate for their inclusion within the national Non-Communicable Diseases programme and broader public health priorities.
    - As a result, 9 people with haemophilia were newly diagnosed, increasing the number of patients from 115 to 124.

World Sickle Cell Day celebration at the IRB1-Health with youths in Kinshasa in June 2026.

- **Increased government engagement and ownership for bleeding disorders and haemoglobinopathies:**
    - The participation of the Vice-Governor of Kasai Oriental in World Haemophilia Day celebrations in Mbuji-Mayi created an important opportunity to increase local government commitment to haemophilia and sickle cell disease advocacy.

    - In Kinshasa, discussions with the Provincial Ministry of Health's Directorate of Studies helped promote the involvement of Health Zone Chief Medical Officers, supporting future integration of haemophilia and sickle cell disease interventions within the health system.
- **Empowered 15 members of the haemophilia patient organisation:** A 2-day advocacy and communication training workshop was organised for 15 representatives of patient associations from the project's 4 implementation sites: Kinshasa, Kisangani, Lubumbashi, and Mbuji-Mayi. The training aimed to strengthen participants' advocacy, communication, and stakeholder engagement skills, enabling them to more effectively represent and promote the needs of people living with haemophilia and sickle cell disease.

3.6. East Africa 3 Project: Kenya, Tanzania, Uganda and Rwanda



- **Programme title:** An integrated approach to haemophilia and sickle cell disease care in East Africa
- **Phase** Execution
- **Partners**
    - **Kenya**
        - Kenya Haemophilia Association (KHA) – Dr Jeremiah Shem and James Kago
        - Sickle Cell Federation of Kenya – Dr Doreen Karimi and Dr Bernard Awuonda
    - **Tanzania**
        - Haemophilia Society of Tanzania (HST) – Dr Stella Rwezaula
        - Muhimbili National Hospital – Dr Faraja Chiwanga
        - Tanzania Sickle Cell Disease Alliance – Dr Elisha Osati, Chairperson and Dr Degratias Soka, Chief Executive Officer
        - Muhimbili University of Health and Allied Sciences – Dr Mwashungi Ally
    - **Uganda**
        - Haemophilia Foundation of Uganda (HFU) – Prof Grace Ndeezi and Agnes Kisakye
        - Raising Hope International Friends, Uganda – Isaac Okello
        - Mulago National Hospital – Dr Phillip Kasirye Gitta and Dr Deogratias Munube
    - **Rwanda**
        - Rwanda Federation of Hemophilia – Dr Evariste Ntaganda and James Ndahayo
- **Duration:** 2 years
- **Activity start date:** Q3 2025
- ***This project is supported by a grant from Novo Nordisk Foundation***

Objectives

- To raise awareness among the public, patients, and caregivers, we aim to achieve a 20% increase in the haemophilia diagnosis rate, resulting in the diagnosis of 700 new people with haemophilia and 3,600 infants with sickle cell disease
- Strengthen 15 joint treatment centres for haemophilia and sickle cell disease in Tanzania, Kenya, Uganda, and Rwanda to provide accessible and comprehensive care and evaluate the effectiveness of existing centres and the referral system to ensure optimal patient outcomes

- Data-driven advocacy to government and decision-makers for enhanced quality of care and access to treatment for people with haemophilia and sickle cell disease
- Strong patient organisations with clear governance structures including medical advisory committees, boards, and youth/parent technical working groups, and robust advocacy through capacity development, cross-learning, and experience sharing

Status

Kenya:

- 31 people with haemophilia newly diagnosed through clinic-based follow-up and family tracing, increasing the total number of registered people with haemophilia from 1,260 to 1,291 and raising the diagnosis rate from 22.9% to 23.5%.
- Enhanced quality of care across the national haemophilia treatment centres' network by conducting centre assessments and refresher training in 11 haemophilia treatment centres across Kakamega, Bungoma, Tana River, Kilifi, Kisumu, Meru, Taita Taveta, Mombasa, Kitui, and Nakuru, strengthening service delivery, clinical management, and adherence to standards of care.
- Expanded healthcare workforce capacity by training more than 300 healthcare providers in identification of haemophilia patients, diagnosis, management, and comprehensive care, strengthening facility readiness to deliver timely and appropriate haemophilia services.
- Advanced Regional Training Centre (RTC) development by securing institutional commitments from Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) to establish RTC and supported two specialists, Dr Carole Kilach and Dr Catherine Muendo, through the International Society for Thrombosis and Haemostasis (ISTH) Reach-the-World Fellowship applications which were awarded.
- Integrated oral health into haemophilia care by developing a national dentist training curriculum and oral health education materials, which were used to train 70 dental healthcare professionals from KNH, MTRH, the University of Nairobi, Moi University, and Coast General Teaching and Referral Hospital.
- Strengthened patient empowerment and engagement by providing education and self-management training to more than 180 people living with haemophilia and established a patient and parent welfare group to promote psychosocial support, peer learning, and ongoing engagement.
- Advanced policy advocacy and financing by supporting to secure parliamentary consideration of its haemophilia petition which led to a formal hearing before the Parliamentary Health Committee (*watch video here*), which committed to advocating for dedicated budget allocation for haemophilia treatment products, services, and care.

- Access to financial protection and health coverage was improved through support provided to KNH and MTRH in developing and submitting haemophilia intervention proposals for consideration under SHIF, thereby advancing the inclusion of haemophilia care within a national health insurance, the Social Health Authority (SHA) framework.
- Governance and leadership within the Sickle Cell Federation of Kenya were strengthened through the operationalisation of key committees and the establishment of a new Advisory Board, enhancing oversight, accountability, patient representation, and stakeholder confidence.
- Advocacy resulted in the inclusion of apheresis and red blood cell exchange services in Kenya's Social Health Insurance Fund benefits package, improving access to specialised sickle cell disease care and reducing financial barriers.

Members of the Kenya Haemophilia Association and other partners engaging the Kenya Medical Supplies Agency on the procurement of haemophilia treatment products.

Tanzania

- 139 people with haemophilia newly diagnosed by reaching out to over 250 families through family tracing and screening, increasing the national tally from 538 to 677 people with haemophilia, which translates to a 10.2% diagnosis rate, up from 8.1%.
- 74 people with sickle cell disease were identified through screening and 584 individuals with sickle cell trait, with 100% of diagnosed cases successfully linked to care.
- Access to specialised care was expanded through the establishment of 5 integrated haemophilia and sickle cell disease treatment centres in Tarime DC, Tarime TC, Bunda, Rorya, and Musoma Municipal, as well as 3 haemophilia treatment centres in Singida, Geita, and Shinyanga Regional Referral Hospitals, resulting in stronger referral pathways and improved quality of care.

- Built workforce and community capacity by creating awareness among 730 people, including 114 healthcare providers, 62 community health workers, 276 traditional healers, 86 educators, and 192 people with haemophilia and caregivers, thereby improving awareness, referral pathways, and self-management.
- Advanced policy and advocacy efforts by securing parliamentary engagement and submitting recommendations for the inclusion of haemophilia and sickle cell disease priorities in the 2026/27 national budget and health financing mechanisms.
- World Haemophilia Day officially recognised as a national day to be led and spearheaded by the Ministry of Health.
- Strengthened local patient organisations by convening 13 board members, leaders, and representatives from the Tanzania Sickle Cell Disease Alliance (TSDA), Bone and Blood Foundation (BBF), and Sickle Cell Disease Patients Community of Tanzania (SCDPCT) for a governance workshop that enhanced leadership, accountability, financial management, donor compliance, and board oversight, resulting in action plans to improve governance, sustainability, resource mobilisation, and the delivery of high-quality sickle cell disease programmes.
- Influenced national policy and health systems by supporting the integration of sickle cell disease and haemophilia modules into the Government of Tanzania Health Operations Management Information System (GoT-HOMIS) and advocating for sustainable financing, treatment access, health insurance coverage, and expanded diagnostic services, securing parliamentary commitment to further engagement with the Ministry of Health on implementation.
- Strengthened national sickle cell disease care through the development of a newborn screening protocol, the launch of updated national sickle cell disease management guidelines, and the integration of sickle cell disease screening into the child health booklet, promoting standardised screening, early diagnosis, timely linkage to care, and evidence-based treatment.
- Signed sustainability agreements with local government authorities to ensure that people screened within the programme have access to care and that the interventions are sustained by government.

A coagulation machine donated to Morogoro Hospital with the support of NNHF.

Tanzania Sickle Cell Disease Alliance board members during a governance and leadership workshop.

Uganda

- 36 people with haemophilia newly diagnosed, improving patient identification and access to care through community outreach, family tracing and screening activities that increased the national number of diagnosed people with haemophilia from 485 to 521 and raised the diagnosis rate from 10% to 10.7%.
- 35 new persons with sickle cell disease were diagnosed while 392 individuals were identified to have sickle cell trait, with 100% of diagnosed cases transitioned to care, improving access to sickle cell disease services.
- Expanded diagnostic capacity by decentralising laboratory services and deploying specialised diagnostic equipment across 4 regions, improving access to haemophilia testing and reducing diagnostic delays.
- Enhanced treatment centre readiness by conducting assessments and delivering targeted training in 6 emerging treatment centres, strengthening regional capacity to diagnose and manage haemophilia, while expanding specialised joint-care services through the Point of Care Ultrasound (POCUS) programme.
- Strengthened sickle cell disease and haemophilia care in Iganga District by creating awareness among 102 healthcare providers from 28 health facilities and 114 newly graduated community health workers on diagnosis, referral, management, and community support through a capacity-building programme led by Ministry of Health and clinical experts.
- Increased public awareness and patient empowerment through community outreach, media campaigns, World Haemophilia Day activities, and youth education programmes, improving awareness, reducing stigma, and strengthening patient self-management.

- Advanced policy and institutional strengthening by collaborating with the Ministry of Health to establish the central public health laboratory as a national reference laboratory for haemophilia and sickle cell disease and securing commitments to strengthen diagnostic services.
- Supported the Ministry of Health's sickle cell technical working meeting in Kampala, bringing together key stakeholders to advance sickle cell disease programming through the harmonisation of data collection tools, integration of sickle cell disease data into national digital health systems and a national sickle cell registry, review of District Health Information Software 2 (DHIS2) indicators, and standardisation of Ministry-approved health education materials.
- Established a national sickle cell disease advocacy platform through the formation of the Sickle Cell Alliance of Uganda (SCAU), which united 18 local organisations and strengthened advocacy, coordination, and stakeholder engagement.
- Advanced national advocacy and policy influence through efforts that contributed to Uganda's first Parliamentary Motion on sickle cell disease, recognising it as a national public health priority and supporting progress towards a national sickle cell disease registry and stronger health information systems.

The signing of an MoU between the Haemophilia Federation of Uganda and the National Council for Persons with Disabilities for continued support for persons living with bleeding disorders.

Sickle cell organisations in Uganda coming together to form a national alliance, as a national umbrella body to continue supporting advocacy initiatives.

Rwanda

- 7 new people with haemophilia A were identified, improving diagnosis and linkage to care through family tracing and screening activities, increasing the national number of persons with haemophilia from 134 to 141 patients and raising the diagnosis rate from 9.6% to 10.1%.
- Strengthened haemophilia care capacity by training 676 healthcare providers (42 doctors, 575 nurses, 13 laboratory technologists, 2 physiotherapists, and 44 medical interns) from 10 district hospitals through multidisciplinary programmes delivered by RFH and the Rwanda Biomedical Centre, improving diagnosis, treatment, referral pathways, and integration of haemophilia care into routine practice.
- Strengthened community-based haemophilia care by conducting awareness sessions for 100 community health workers from 5 health centres in the Southern and Western Provinces, alongside NCD nurses and health centre leaders, to improve awareness, early identification of suspected cases, patient support, follow-up, and continuity of care for newly diagnosed patients.
- Integrated haemophilia into national health programmes through collaboration with the Rwanda Biomedical Centre, resulting in the inclusion of haemophilia in national NCD training and sensitising 238 healthcare providers on haemophilia.
- Developed a 5-year strategic plan for the Rwanda Fraternity against Hemophilia to enhance organisational capacity, strengthening governance, advocacy, and long-term sustainability.
- Expanded awareness and future workforce capacity by sensitising 118 final-year medical students and using World Haemophilia Day activities and media campaigns to increase public awareness and patient education.
- Strengthened community-based detection and support by sensitising 100 Community Health Workers, improving awareness, early case identification, patient follow-up, and referral systems.
- Advanced national advocacy efforts through engagement with the Ministry of Health on haemophilia treatment procurement and service delivery, strengthening government commitment to sustainable access to care.

Healthcare providers under the leadership of Rwanda Fraternity against Hemophilia creating awareness on haemophilia among the Community Health Workers in Hanika.

3.7. Lesotho 2 Project

- Programme title **Enhancing haemophilia care services in the capital of Lesotho and in the regions**
- Phase Execution
- Partner Haemophilia Association of Lesotho – Moeketsi Mootisa, Chairperson and Dr Benjamin Nwako, paediatrician at Queen Elisabeth II Hospital
- Duration 2 years
- Activity start date Q3 2024

Objectives

- Improve haemophilia care and diagnosis in Maseru
- Establish basic care in Northern and Southern Lesotho
- Reach a diagnosis rate of 19% through awareness raising
- Set up WFH WBDR registry
- Advocate for a bleeding disorders policy that will enable increased factor procurement for the newly diagnosed patients

Status

- The diagnosis rate has increased from 8% to 10%, with confirmed haemophilia cases rising from 18 to 23 registered individuals. Additionally, 2 new confirmed cases of Von Willebrand Disease (vWD) have been identified.
- **Improve diagnosis rate and enhance haemophilia awareness across regions**
    - A one-day awareness-raising workshop was successfully conducted, reaching 267 kindergarten and primary school teachers across three regions of Lesotho. Organised in collaboration with the Ministry of Education, the workshop improved educators' awareness of haemophilia, equipping them with the knowledge to identify potential cases early.
    - The association launched a screening and diagnosis campaign across digital platforms, including Facebook and a revamped website. The updated website now provides comprehensive information on haemophilia and available support services, making critical resources more accessible to the public.
    - Leveraging the Self-Administered Bleeding Assessment Tool (Self-BAT), volunteers from the Haemophilia Association of Lesotho conducted targeted family tree tracing, identifying 8 suspected cases. Of these, 3 were confirmed as haemophilia cases and 2 were confirmed as Von Willebrand Disease (vWD), demonstrating the effectiveness of community-based screening approaches.

- Through continued advocacy efforts, the association successfully influenced the National Drug Service Organization (NDSO) to procure safer clotting factor concentrates, ensuring improved and safer treatment options for people living with haemophilia in Lesotho.

3.8. Liberia 1 Project

- Programme title **Establish basic care in Liberia**
- Phase Execution
- Partner Liberia Hemophilia Program (LHP) – Prince Kwenah and Dr Tabehde Murray
- Duration 4 years
- Activity start date Q1 2023

Objectives

- Establish haemostasis laboratory at Redemption Hospital in Monrovia
- Capacity building for healthcare professionals from Monrovia abroad and outreach training in 3 counties
- Increase awareness of haemophilia through local media and strengthen Liberian patient organisation

Status

- In February 2026, two volunteers from Kenya, Dr Carole Kilach from Moi Teaching and Referral Hospital (MTRH) and Mr Hannington Okoth from Kenyatta National Hospital (KNH) visited Liberia to support capacity strengthening in haemophilia diagnosis and laboratory services at John F. Kennedy Medical Centre. During the three-day programme, 5 laboratory technologists received specialised training in haemophilia diagnosis, while 40 healthcare professionals including paediatricians, general surgeons, and nurses were trained on the identification and management of haemophilia and sickle cell disease.
- **Increase awareness of haemophilia in the capital and the regions**
    - Dr Ye-Jeung Coleman-Nekar and Dr Carole Kilach co-facilitated a haemophilia awareness webinar in February 2026, bringing together more than 50 healthcare professionals and Ministry of Health representatives. The webinar strengthened awareness of haemophilia diagnosis, management, and referral among key healthcare professionals.
    - World Haemophilia Day was commemorated across three regions of Liberia, with eight health facilities participating in activities held from 13–24 April 2026. Outpatient health talks and the distribution of haemophilia information flyers were conducted across all the participating facilities. These awareness raising activities led to the identification of three suspected haemophilia cases, with one subsequently confirmed, increasing the number of diagnosed cases in Liberia from 4 to 5.

3.9. Madagascar 3 Project

- Programme title **Expanding access to blood disorders care in Madagascar and initiate a regional collaboration with the Indian Ocean Islands**
- Phase Execution
- Partner Antananarivo Faculty of Medicine– Dr Mino Fitahiana Danielle and Prof Aimée Olivat Rakoto Alson
- Duration 3 years
- Activity start date Q3 2025

Objectives

- Enable comprehensive care in Antananarivo and build a joint clinic for haemophilia and sickle cell disease
- Strengthen the referral system in Madagascar, decentralising haemophilia and sickle cell care to 6 regions
- Initiate a network between Indian Ocean Islands, exploring opportunities and defining a strategy for regional collaboration
- Strengthen bleeding disorder's community knowledge on the condition and increase advocacy for improved care options
- Raise awareness on haemophilia and increase the diagnosis rate from 7% to 15%

Status

- This project has **benefitted 227 people with haemophilia.**
- Awareness and screening activities during World Haemophilia Day resulted in the screening of more than 200 people being tested in Antananarivo, the capital city. Of these, 12 people were diagnosed with haemophilia, increasing the number of people with haemophilia from 215 to 227.
- **Care and diagnostic capacity were strengthened and decentralised, reducing the travel time by 25 hours (round trip) for people with haemophilia to receive care.**
    - Strengthened laboratory diagnostic capacity through intermediate training for 11 laboratory technicians from six regions in the capital city.
    - Expanded access to professional education through a hybrid training programme, reaching 94 healthcare professionals and stakeholders on haemophilia, from Antananarivo and the regions during World Haemophilia Day activities.
- **Initiated the regional collaboration with the Indian Ocean Islands to advocate and improve care for haemophilia and sickle cell disease**
    - A national symposium on haemophilia and rare bleeding disorders was held on 27 June 2026 in Mauritius, bringing together more than 50

healthcare professionals. The symposium featured a panel discussion on strengthening haemophilia care and regional collaboration in the Indian Ocean. This was followed by a strategic workshop reuniting Madagascar, Mauritius, Comoros, and Seychelles on 28th June to explore a roadmap that will reinforce regional collaboration.

- **Strengthened advocacy, policy development and government engagement through:**
    - Initiated the development of a national haemophilia policy in collaboration with the Ministry of Public Health.
    - Convened a national workshop on sickle cell disease, bringing together healthcare professionals, Ministry of Public Health representatives, and patient organisations to identify priority actions for improving care for both haemophilia and sickle disease in terms of treatment and decentralisation.
    - Developed a national neonatal screening protocol for newborns at risk of sickle cell disease, establishing a foundation for earlier diagnosis and intervention.
- **Strengthened collaboration on sickle cell disease care** through a national stakeholder workshop that brought together healthcare providers, patient organisations, and Ministry of Public Health representatives to define priority actions for the improvement of sickle cell disease management.

Pictures taken during World Haemophilia Day, 17 April 2026, in Madagascar.

3.10. Malawi 3 Project

- Programme title **Strengthening haemophilia and sickle cell disease care in the capital and regions of Malawi**
- Phase Formalisation
- Partner Kamuzu Central Hospital (KCH), The Society of Haemophilia and Allied Disorders (SHAD) and Etienne Nkwanda Sickle Cell Foundation (ENSICEF) - represented by Dr Yohannie Mlombe, haematologist, Kamuzu Central Hospital and Chairperson SHAD, Ms Chimwemwe Chande, CEO SHAD and Mr Peter Nkwanda, Director ENSICEF
- Duration 3 years
- Activity start date Q4 2026

Objectives

- Establish advanced multidisciplinary care for haemophilia and sickle cell disease in the capital, strengthen services in the Southern region, and establish care in the North, thereby creating effective referral pathways across all three regions
- Strengthen the haemophilia and sickle cell disease patient organisations, and establish an umbrella organisation for sickle cell disease to provide a unified platform for advocacy, awareness, and patient support
- Improve community awareness of haemophilia and sickle cell disease and increase the haemophilia diagnosis rate from 4.5% to 7% while strengthening sickle cell disease screening and diagnostic capacity
- Advocate for increased allocation of resources towards improved diagnosis and treatment of haemophilia and sickle cell disease

Status

- The project was approved at the NNHF Council meeting in May 2026 and is currently working on the formalities to sign the project partnership agreement and soon commence activities.

3.11. Mali 3 Project

- Programme title **Decentralise haemophilia diagnosis and strengthen multidisciplinary care in Mali**
- Phase Execution
- Partner Association Malienne de Lutte contre l'Hémophilie (AMALHEC) - Prof Yacouba Diallo
- Duration 3 years
- Activity start date Q4 2023

Objectives

- Improve haemophilia diagnosis and epidemiological data in Mali
- Establish basic and emergency care for people with haemophilia living in conflict-affected regions
- Strengthen multidisciplinary care team in Bamako and initiate decentralisation in Segou and Sikasso regions
- Improve quality of life of people with haemophilia living with joint disabilities through physiotherapy
- Increase awareness and knowledge of general public and authorities on haemophilia

Status

- This project has **benefited 286 people with haemophilia**.
- **Strengthened treatment and diagnostic systems through government engagement**:
    - The national treatment guidelines were endorsed and will be used in hospitals across the country.
    - A blood sample transfer protocol between district hospitals and diagnostic centres was developed by the Hôpital du Mali and is under Ministry of Health validation.
    - On 11 June 2026, a national validation workshop chaired by the Secretary General of the Ministry of Health and Social Development of Mali brought together healthcare professionals and representatives of the Ministry's decentralised structures to validate key documents for the management of bleeding disorders. These included the national guidelines for the management of haemorrhagic emergencies, as well as standard operating procedures for haemostasis testing and sample referral across different levels of the health system.

Validation workshop chaired by the Secretary General of the Ministry of Health, 11th June 2026, Bamako, Mali.

3.12. Mauritius 3 Project

- Programme title **Achieving optimal and holistic haemophilia and blood disorders care**
- Phase Execution
- Partner Haemophilia Association of Mauritius – Mohsena Olath Carramtally, Operations Manager, and Dr Janaki Sonoo, Victoria Hospital
- Duration 3 years
- Activity start date Q3 2024

Objectives

- Complete advanced diagnostic capabilities in Mauritius
- Standardise treatment protocols for bleeding disorders across all five regional hospitals to enhance equitable access to multidisciplinary care, treatment and effective management
- Improve online registry to include MSK data, and implement joint care and management programme to prevent and reduce joint issues in 80% of patients
- Provide holistic care to 70% of people with haemophilia and caregivers by supporting their psychosocial needs

Status

- The Haemophilia Association of Mauritius commemorated World Haemophilia Day at the Municipal Council of Curepipe, bringing together approximately 80 people with haemophilia and their caregivers, 10 healthcare professionals, and the Director General of the Ministry of Health and Wellness. The event featured education sessions on haemophilia, self-care, and the importance of early diagnosis and treatment adherence. A peer-to-peer meeting also provided participants with the opportunity to share experiences, challenges, and coping strategies, strengthening emotional support within the community.
- A Medical and Scientific Advisory Council (MASAC) meeting was held on 26 June 2026 at Subramanian Bharati Eye Hospital, focused on the establishment of a Medical Advisory Council for Haemophilia Association of Mauritius and their role in supporting the haemophilia patient community. Dr Yasmin Goga from the South African Haemophilia Foundation (SAHF) shared valuable insights on building a strong MASAC borrowing from the MASAC in South Africa. The meeting was attended by 50 healthcare professionals from five haemophilia treatment centres and marked a significant step towards the formalisation of a Medical Advisory Council for the Haemophilia Association of Mauritius, strengthening its capacity as a patient organisation.
- A national symposium on haemophilia and rare bleeding disorders was held on 27 June 2026, bringing together more than 50 healthcare professionals. The

symposium featured a panel discussion on strengthening haemophilia care and regional collaboration in the Indian Ocean, with experts sharing insights on establishing a comprehensive haemophilia care centre in Mauritius.

- To foster regional collaboration, 10 representatives including healthcare professionals and patient organisation representatives from the Vanilla Islands including Madagascar, Comoros, and Seychelles participated in the symposium. Their participation marked an important step towards enhanced collaboration and knowledge sharing among countries in the Indian Ocean region.
- One physiotherapist completed a one-month training programme in India on physiotherapy management and musculoskeletal (MSK) care for people with haemophilia. The training led to the introduction of MSK joint scoring at Victoria Hospital, where 9 people with haemophilia have been assessed, improving the monitoring of joint health and enabling timely interventions to prevent long-term disability.
- A photo language tool was introduced to strengthen emotional and psychosocial support for people with haemophilia and their families. The tool is used during counselling sessions, support groups, and therapeutic activities to help participants express their feelings, explore emotions, and develop coping strategies. This has contributed to improved emotional well-being and stronger peer support among the haemophilia community.

Healthcare professionals and Ministry of Health representatives from Madagascar, Comoros and Seychelles during a visit to Victoria Hospital in June 2026, as part of strengthening collaboration and knowledge sharing among countries in the Indian Ocean region.

3.13. Nigeria 4 Project

- Programme title **Strengthening comprehensive care in 7 haemophilia treatment centres across Nigeria**
- Phase Execution
- Partner University of Benin Teaching Hospital – Prof Omolade Awodu
- Duration 3 years
- Activity start date Q3 2023

Objectives

- Improve diagnostic capacity in 7 comprehensive haemophilia treatment centres in Nigeria
- Develop and strengthen comprehensive care in the management of haemophilia in Nigeria
- Improve treatment regimens at the 7 comprehensive haemophilia treatment centres
- Raise awareness about haemophilia and ensure strategic advocacy efforts

Status

- **31 people with haemophilia were newly diagnosed**, increasing the total number of identified people living with haemophilia from **880 to 911** and raising the diagnosis rate from **3.8% to 3.9%**. This progress was driven by increased awareness, family-tree tracing, and enhanced screening and testing across the seven strengthened centres.
- Strengthened implementation, monitoring, referral pathways, documentation, patient follow-up, and alignment with project objectives across the seven centres linked to **an improved coordination between haemophilia treatment centres** coordinators and project officers.
- **Strengthened national advocacy and state-level ownership** through the Inherited Blood Disorders Leadership Forum, held in Abuja on 11–12 February 2026, which convened 74 stakeholders from government, healthcare institutions, patient groups, professional bodies, faith-based organisations, and development partners. The Forum **expanded haemophilia advocacy beyond the health sector**, created a **coordinated platform for integrating haemophilia and other inherited blood disorder services**, and led to the establishment of a **technical working group for sickle cell disease, haemophilia, and other inherited blood disorders** to guide follow-up action and sustain agreed advocacy milestones.
- **Renewed Federal Government commitment to haemophilia care** advanced through continued engagement with the Federal Ministry of Health, supporting

the **inclusion of inherited bleeding disorders in national health planning and budgetary processes**, the establishment of a **technical working group**, and ongoing advocacy toward a **national bleeding disorders registry**.

- **Increased awareness and strengthened community case finding** across Abuja, Benin City, Enugu, Kano, Lagos, and Ibadan through mainstream and social media activities, particularly during World Haemophilia Day. In partnership with the Haemophilia Foundation of Nigeria (HFN), the "Road to Clot" initiative established a practical mechanism to support **diagnosis, referral, patient enrolment, emergency response, and registry development**.
- **Initiated engagement with the National Health Insurance Authority** to advocate for the **inclusion of clotting factor concentrates, treatment products, and specialised laboratory investigations** in the national health insurance benefit package, with the aim of **reducing out-of-pocket costs for people living with haemophilia**. These advocacy efforts are ongoing.

Participants at the Inherited Blood Disorders Leadership Forum, held on 11–12 February 2026 in Abuja, including government officials, healthcare professionals, patients, caregivers, and representatives from academia, pose for a picture.

3.14. Senegal 2 Project

- Programme title **Expand haemophilia comprehensive care in Senegal and regional care networks in West Africa**
- Phase Closing
- Partner Association Sénégalaise des Hémophiles - Mr Abdoulaye Loum and Centre National de Transfusion Sanguine - Prof Saliou Diop
- Duration 2 years, Q1 2024 – Q1 2026

Objectives

- Strengthen the haemophilia treatment centre in Dakar as a regional training hub and initiate a network in francophone West Africa, advocating for improved and standardised care
- Establish multidisciplinary care teams and strengthen the coordination among healthcare professionals in Saint Louis, Kaolack and Ziguinchor regions for an optimal referral system
- Strengthen the diagnostic system in Senegal, developing protocols and increasing haemophilia diagnosis rate from 17% to 23% by 2025
- Strengthen the patient organisation's chapters in Saint Louis, Kaolack and Ziguinchor to participate in the orientation of suspected cases in their region
- Empower haemophilia community of Dakar, Saint Louis, Kaolack and Ziguinchor regions through educational sessions to better manage the condition and engage regularly with care providers

Achievements

- This project has directly benefitted **510 people with haemophilia**
- In Dakar, the Centre National de Transfusion Sanguine (CNTS) was renovated and equipped to improve the quality of care and treatment for people with haemophilia
- **Multidisciplinary care has been decentralised into 3 regions reducing up to 15 hours travel time** (round trip from Ziguinchor to Dakar) for people with haemophilia **to receive basic and emergency care.**
    - Training to healthcare professionals from CNTS during the Senegal 1 project was cascaded to 137 local healthcare professionals across Kaolack, Ziguinchor, and Saint-Louis, strengthening local care capacity.
    - **2 paediatricians, 2 physiotherapists and 2 dentists received in-depth training for 3 weeks at the CNTS in Dakar.**
    - 99 healthcare professionals, including lab technicians, general practitioners, nurses, emergency physicians, gynaecologists, orthopaedic surgeons, and social workers in all three regions were trained over two days on basic haemophilia care and emergency response, fostering a multidisciplinary approach.

    - 32 midwives received basic training to support the early diagnosis of people with haemophilia, focusing on women with bleeding disorders and carriers
- **The haemophilia diagnosis rate increased from 17%** at the beginning of the project **to now 25%, representing an 8 percentage point increase,** (from 304 to 510 people with haemophilia diagnosed and registered), **exceeding the target of 23% diagnosis rate**.
    - The referral of new patients followed the targeted training sessions for healthcare professionals in Kaolack, Ziguinchor, and Saint-Louis.
    - In addition, 100 community health workers from 10 departments in the capital and the three regions were mobilised and trained to recognise the signs and symptoms of haemophilia.
    - Furthermore, family-tree tracing was conducted for 50 families.

Youth group of the Senegalese Hemophilia Association (ASH) during an awareness raising training in Saint-Louis.

Successful engagements with health authorities

- An advocacy committee of 10 patient organisation members and 5 healthcare professionals was trained by NNHF, enabling them to define national advocacy priorities. Since then, several important advocacy uptakes have materialised:
    - **Haemophilia was integrated into the national NCDs strategic plan** (achieved in 2024).
    - **Factor concentrates were included in the essential medicines list**, realised in July 2025 following an advocacy symposium led by CNTS and the patient organisation ASH with key health authorities.
    - **In collaboration with the Ministry of Health, national treatment guidelines for haemophilia were developed** and are now being implemented across the country.
    - An online, **nationwide patient registry was developed and endorsed by the Ministry of Health.** The registry provides clinicians with real-time data to support follow-up and treatment decisions, while also informing advocacy and planning. Access is available to the CNTS and regional haemophilia treatment centres.

Patient education and strengthening the community

- **The patient organisation Association Senegalaise des Hemophiles is strengthened, improving the reach and the leadership of the community**
    - **Three regional chapters established** (Saint-Louis, Kaolack and Ziguinchor) to play an active role in identifying and directing suspected cases to appropriate care within their regions.
    - **A youth group established and empowered**: 34 members empowered through peer support, awareness raising, and leadership development, contributing to the sustainability of patient advocacy efforts.
    - 450 families from Dakar, Saint Louis, Kaolack and Ziguinchor regions were empowered through educational sessions to better manage the condition and engage regularly with care providers.

Building a coalition

- **A francophone West Africa network was built to promote improved and harmonised care across the region**, resulting in a strong and ambitious coalition application from **Senegal Mali Benin Guinea and Côte d'Ivoire**, approved in October 2025 with the support of NNF
    - During a three-day strategic planning and advocacy workshop in Dakar a regional network was established and opportunities for collaboration explored. The workshop brought together healthcare professionals and patient organisation members from the five countries. The key coalition components are centred on strengthening integrated care for haemophilia and sickle cell disease through united, decentralised service delivery in the regions, advancing regional advocacy for better treatment and care, and promoting joint training initiatives for healthcare professionals across the region.

3.15. Sierra Leone 2 Project

- Programme title **Enhancing diagnosis and expanding haemophilia care from Freetown to the regions**
- Phase Execution
- Partner Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) – Harry Mayeah Koroma and Dr Mavolo Toure
- Duration 2 years
- Activity start date Q3 2025

Objectives

- Establish multidisciplinary care in the capital city and initiate basic and emergency care in three regions
- Improve diagnosis rate from 3.5% to 7.5%
- Strengthen the capacity of the patient organisation to pursue higher government support
- Explore sickle cell disease landscape, build strategic alliances and define a strategy for Sierra Leone

Status

- The **diagnosis rate increased from 3.5% to 5.5%** with the total number of confirmed haemophilia cases moving up from 32 to 50 people with haemophilia.
    - This was thanks to the family tree tracing activities in the rural communities in Western Sierra Leone. Amongst others this led to the identification of 6 suspected cases of which two were confirmed with haemophilia.
- **Enhanced haemophilia awareness across regions**
    - To mark World Haemophilia Day, Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) organised an awareness event attended by 70 participants, including people with haemophilia, their families, healthcare professionals, and Ministry of Health representatives. Through educational sessions, patient testimonies, and media engagement, the event increased awareness of haemophilia and strengthened advocacy dialogue with the Ministry of Health, helping to advance support for improved diagnosis, treatment, and care services for haemophilia.
    - A one-day awareness workshop on safe circumcision was conducted for 40 participants including nurses, community leaders, and traditional healers from six districts, with support from a paediatrician and nurse from FHBDSL. The workshop strengthened knowledge of safe circumcision practices and fostered collaboration between healthcare and community stakeholders, helping reduce the risk of severe bleeding complications in people with haemophilia.

3.16. South Africa 6 Project

- Programme title **Achieving self-sufficiency for bleeding disorders in South Africa and building a Southern Africa Regional Coalition**
- Phase Execution
- Partner South Africa Haemophilia Foundation (SAHF) – Prof Jaco Joubert, Chair Elect (Medical and Scientific Advisory Council MASAC), Dr Yasmin Goga, Chairperson (MASAC), Clerment Sefojane, Chairperson SAHF and Bradley Rayner, Programme Manager SAHF
- Duration 3 years
- Activity start date Q1 2026

Objectives

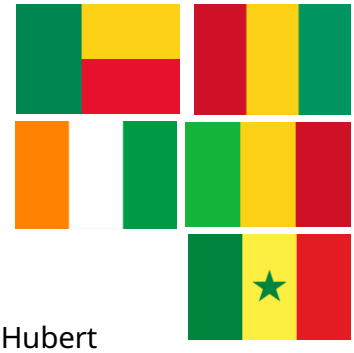
- Standardise haemophilia care and improve diagnostic capacity in 6 provinces (KwaZulu-Natal, Eastern Cape, Northern Cape, Limpopo, Mpumalanga and North West) by strengthening the referral system and laboratory infrastructure
- Promote equitable access to haemophilia treatment across all provinces by supporting national and regional advocacy efforts for policy influence and increased country ownership
- Strengthen collaboration between local haemophilia treatment centres and the patient community through self-infusion training
- Strengthen regional collaboration in bleeding disorders care across Southern Africa focused on mentorship, joint capacity-building and advocacy

Status

- To strengthen musculoskeletal care for people with haemophilia, the South Africa Haemophilia Foundation (SAHF) procured six point-of-care ultrasound (POCUS) devices for six haemophilia treatment centres. This strengthens the capacity of treatment centres to detect and monitor joint bleeding, enabling earlier intervention, reducing long-term joint damage, and ultimately improving the quality of life for people with haemophilia.
- The University of the Free State procured a fully automated haemostasis analyser to strengthen the referral system and laboratory infrastructure for von Willebrand disease (VWD) diagnosis. This has expanded the country's diagnostic capacity, increasing the number of centres able to diagnose VWD and establishing the university as a reference centre for VWD testing across the Southern Africa region.

- A national accreditation committee, comprising representatives from the patient community and multidisciplinary care teams, has been established and a terms of reference framework developed to guide the standardisation of care across haemophilia treatment centres and haemophilia comprehensive care centres. This provides a structured approach to delivering consistent, high-quality haemophilia care, strengthening referral pathways and improving coordination across treatment centres.
- World Haemophilia Day was commemorated across 14 haemophilia treatment centres nationwide, engaging over 300 people with haemophilia, healthcare professionals, and provincial Department of Health representatives. Educational sessions covering diagnosis, treatment, genetics, oral health, and joint health equipped participants with critical knowledge to better manage their condition. A radio talk show in the Eastern Cape province further amplified the reach of haemophilia awareness to a wider public audience and fostered greater community understanding of the condition.

3.17. West Africa 1 Project



- Programme title **An integrated approach to haemophilia and sickle cell disease care in West Africa**
- Phase Execution
- Partner
    - **Benin**
        - Centre National Hospitalier Universitaire Hubert Koutougou Maga (CNHU-HKM) – Prof Tatiana Baglo and Dr Houssou Bienvenu
        - L'Association Beninoise des Hémophiles ABH – Mrs Chimene Vignon
    - **Côte d'Ivoire**
        - Centre Hospitalier Universitaire de Youpougon – Dr Adjambri Eusebe
        - Internationale Hemophilie Et Autres Maladies Du Sang – Mr N'dri Koffi
    - **Guinea**
        - Centre Hospitalier Universitaire Ignace Deen – Prof Mamady Diakité
        - Association Guineene pour la Lutte contre les maladies Hemoragiques (AGUILHAMH) – Mr Abdoulaye Camara
        - Fédération Guinéenne des Personnes Atteintes de la Drépanocytose (FEGUIPAD) – Mrs Saidatou Ly and Prof Mamady Diakité
    - **Senegal**
        - Centre National de Transfusion Sanguine- Dakar – Prof Saliou Diop
        - L'Association Sénégalaise des Hémophiles ASH – Mr Abdoulaye Loum
        - L'Association Senegalaise de Lutte contre la drépanocytose – Mr Maguèye Ndiaye
    - **Mali**
        - Hôpital du Mali – Prof Diallo Yacouba
        - Association Malienne de Lutte contre l'Hémophilie et les autres Coagulopathies – Mr Daouda Malle
        - Centre de Recherche et de Lutte contre la Drépanocytose (CRLD) – Prof Guindo Aldiouma
- Duration 1 year
- Activity start date Q1 2026
- ***This project is supported by a grant from Novo Nordisk Foundation***

Objectives

- Standardise treatment guidelines and strengthen comprehensive haemophilia and sickle cell disease care in the capital cities of Côte d'Ivoire, Benin, Mali, Senegal, Guinea, and Burkina Faso
- Decentralise haemophilia and sickle cell disease care in at least 3 regions in each country and increase the diagnosis rate, reaching 800 new people with haemophilia and 7,000 new people with sickle cell disease
- Strengthen capacities of 6 national haemophilia and sickle cell disease patient organisations to build strong governance and expand their reach
- Raise awareness among the public on recognising sickle cell disease and bleeding disorder symptoms to refer for diagnosis
- Build strategic alliances and advocate for improved haemophilia and sickle cell disease care in all 6 countries

Status

Benin

- **Increased awareness and community engagement**
  - 16 new people with haemophilia were newly diagnosed, increasing the total number of identified people living with haemophilia from 165 to 181 and raising the diagnosis rate from 12% to 13%.
  - 96 people with sickle cell disease were also newly screened and confirmed. This progress was made through awareness-raising activities, community outreach, screening initiatives, and family pedigree tracing and systematic diagnosis at 7 strengthened centres.
  - Distributed 60 haemophilia identification cards, supporting patient recognition and access to appropriate care.
- **Strengthened healthcare capacity and quality of care by improving diagnosis and access to care**
  - Developed and disseminated haemophilia treatment guidelines across all 9 haemophilia treatment centres in Benin, contributing to more consistent and decentralised care.
  - Trained 7 healthcare professionals including surgeons, paediatricians, urologists, rheumatologists, and internal medicine physicians on the diagnosis and management of haemophilia and sickle cell disease.
- **Strengthened patient organisation capacity**
  - Trained 17 Association Béninoise des Hémophiles representatives and focal points on family pedigree tracing in haemophilia.
  - Enhanced the operational capacity of the Benin Haemophilia Association (ABH) through the provision of two laptops to support data management, administration, and coordination of activities.
  - Jointly celebrated World Haemophilia Day and World Sickle Cell Day through awareness campaigns, digital outreach, and community engagement activities,

highlighting the strong partnership and integrated approach of both patient organisations.

Côte d'Ivoire

- **Capacity building of healthcare professionals**
    - A total of 32 healthcare professionals were trained, including physicians, nurses, midwives, and laboratory technicians from health facilities in Man. The training focused on the recognition, diagnosis, referral, and management of patients with sickle cell disease and bleeding disorders. The activity strengthened the capacity of frontline healthcare workers to identify suspected cases and ensure timely referral for diagnosis and specialised care.
- **Development of awareness and educational materials**
    - Educational and awareness-raising materials on haemophilia and sickle cell disease were developed to support community sensitisation and health education activities.
    - These materials provided information on disease symptoms, early warning signs, diagnosis, and available care services.
- **World Haemophilia Day and World Sickle Cell Day celebrations**
    - Awareness activities were organised in connection with World Haemophilia Day (17 April) and World Sickle Cell Day (18 June). These events brought together healthcare professionals, patients, families, community members, and stakeholders to improve public understanding of both conditions. The celebrations served as key advocacy and awareness platforms, promoting early diagnosis and encouraging affected individuals to seek appropriate care.

Guinea

- **This project has benefitted 128 people with haemophilia and 1,500 people with sickle cell disease**
    - Awareness raising increased through successfully implemented awareness campaigns on haemophilia and sickle cell disease in Conakry and Kindia, increasing visibility and public understanding of both conditions.
    - A national situational analysis of sickle cell disease was conducted, providing critical evidence on the burden of disease and key gaps in care to inform future advocacy and programme planning.
    - Mobilised patients, families, healthcare workers, policymakers, and communities through public awareness and engagement activities, contributing to greater recognition of haemophilia and sickle cell disease at national level.
- **Strengthened Advocacy and government engagement**
    - Successfully advocated for the inclusion of the National Centre for haemophilia and sickle cell disease treatment and research project in the

Ministry of Health's Finance Law, laying the foundation for long-term investment in specialised care.
    - Participated in the technical validation process of the Africa Centres for Disease Control and Prevention (Africa CDC) Continental Strategic Plan for sickle cell disease, haemophilia, and other rare blood disorders, strengthening Guinea's contribution to regional health policy discussions.
- **Advanced integrated care and multi-stakeholder collaboration**
    - Officially launched the integrated regional approach for haemophilia and sickle cell disease, promoting coordinated planning and implementation across both disease areas.
    - Strengthened collaboration and synergies between the haemophilia and sickle cell patient organisations, enhancing collective advocacy and service delivery efforts.
    - Secured agreements with regional hospital leadership to support the decentralisation of care project, facilitating improved access to services outside Conakry.
- **Expanded diagnosis, capacity building and patient support**
    - Supported the diagnosis of numerous new patients through screening, awareness campaigns, and case-finding activities, increasing access to treatment and follow-up care.
    - Strengthened healthcare services through the training of healthcare professionals and community actors on haemophilia and sickle cell disease.
    - Empowered patients and families through education and awareness activities, improving disease knowledge, self-management, and engagement in care.

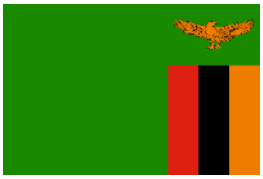
Senegal

- Successful completion and closure of the Senegal 2 project, including final reporting and transition planning.
- Launch and implementation of Senegal activities under the West Africa 1 Coalition Project, with activities scheduled to continue throughout the second half of 2026 to strengthen diagnostic and care for both haemophilia and sickle cell disease.

Mali

- Mali 3 project closing in Q3 2026.
- Development of a new Mali application under the West Africa 1 Coalition Project to ensure continuity of support and expansion of haemophilia and sickle cell disease activities at national level.

3.18. Zambia 3 Project



- Programme title **Strengthen awareness and care of haemophilia and sickle cell disease in Zambia**
- Phase Execution
- Partner Haemophilia Foundation of Zambia - Mr Chilufya Pikiti
- Duration 3 years
- Activity start date Q3 2023

Objectives

- Increase access to diagnosis and care for haemophilia and sickle cell disease in Zambia
- Increase awareness of haemophilia and sickle cell disease amongst healthcare professionals and the general public
- Advocate with government representatives at local, regional and national level to improve care for haemophilia and sickle cell disease

Status

- Diagnosis increased, with 36 people newly diagnosed with haemophilia, raising the diagnosis rate from 18.9% to 20.6%, and increasing the total number of people with haemophilia from 397 to 433. In addition, 1 person was newly diagnosed with von Willebrand disease, and 1,538 people were newly diagnosed with sickle cell disease.
- Strengthened clinical capacity in Western Province by training 35 nurses and doctors, alongside 2 caregivers and 2 patients, drawn from 16 district, mini and mission hospitals, in haemophilia and sickle cell disease management, genetic counselling, factor infusion procedures and physiotherapy.
- Expanded timely sickle cell disease diagnosis in Muchinga Province by providing the province's first gazelle Hb electrophoresis machine to Chinsali General Hospital, reducing reliance on external facilities and enabling the confirmation of 40 new cases, while training 5 laboratory technicians.
- Expanded stroke-risk screening capacity for children with sickle cell disease in Copperbelt Province by providing a transcranial doppler machine to Arthur Davison Children's Hospital in Ndola and training 8 healthcare workers, including 3 doctors, 3 nurses and 2 radiologists, to conduct screening and identify children at risk of stroke early.
- Delivered early clinical impact through a free transcranial doppler screening programme for children under 15 years of age, during which 45 children were screened, and 5 high-risk patients were identified and referred for further management and care.

- Strengthened continuity of care and patient follow-up in Luapula Province through ongoing mentorship at Mansa General Hospital, contributing to the gradual development of a sickle cell disease database for patients seen across district hospitals in the province.

Healthcare professionals participate in practical transcranial doppler ultrasound training and screening at Arthur Davison Children's Hospital in Ndola.

4. Americas

Legend:
Projects active in H1 2026
Projects completed in H1 2026

4.1. Bolivia 2 Project

- Programme title **Developing multidisciplinary care in Bolivia**
- Phase Closing
- Partner Asociación Cochabambina de Hemofilia - Mr José Luis Quino and Dr Suzana Loayza
- Duration 3.5 years, Q2 2022 – Q4 2025

Objectives

- Strengthen laboratory in the Valle region and develop diagnosis access across the country
- Increase awareness about haemophilia amongst the general public and foster support from authorities
- Improve haemophilia knowledge and referral system for first-contact healthcare professionals in rural regions of the country
- Develop haemophilia multidisciplinary care team in Cochabamba
- Empower 100 people with haemophilia and family members on self-infusion
- Empower patient organisations from Bolivia, Peru, Paraguay and Ecuador

Achievements

- This project has directly **benefitted 52 people with haemophilia**.
- **The regional diagnosis rate in the Cochabamba metropolitan region has increased from 29% (38 PwH) to 40% (52 PwH) marking a 38% increase.**
    - This increase has been driven by targeted awareness campaigns reaching the general public and healthcare professionals in the 2nd and 1st level hospitals of the region.
- **Improved access to comprehensive care in the region Cochabamba through the establishment of an advanced multidisciplinary team at Hospital Ascencio Villarroel.** Roundtrip **travel time** for people with haemophilia has **decreased by 17 hours**, removing the need to travel to La Paz or Santa Cruz for diagnosis and advanced care. This has expanded access to high quality local services and reduced out-of-pocket transportation costs by approximately CHF 100 per trip.
    - **In-depth trainings** were organised through **mobilised expertise from across Latin America** with trainers from 5 countries: Venezuela, Panama, Chile, Argentina and Mexico.
        - **The hospital laboratory was strengthened** after the new director allocated a larger space; it was equipped with laboratory equipment and 3 laboratory technicians received training in

coagulation assays and inhibitor testing under the supervision of Marión Echenagucia, a laboratory expert from Venezuela.
    - **30 nurses** from Cochabamba completed training led by Luz Villalaz (Panama), strengthening nursing capacity for haemophilia care.
    - **Musculoskeletal (MSK) services were reinforced** when 2 physiotherapists underwent a training **in Santiago de Chile** and the hospital acquired a point of care ultrasound device, enhancing MSK care and overall health outcome for people with haemophilia
    - **An odontologist** from Cochabamba also trained in Salta, Argentina, improving dental care for haemophilia patients.
    - **Surgical capacity** increased after 6 orthopaedic surgeons completed training delivered by Dr Johnathan González, an expert from Mexico, expanding availability of specialised surgical procedures for people with haemophilia in the region.
- Development of a manual on haemophilia management following successful collaboration and organisation of care among trained healthcare professionals in Cochabamba, bringing together clinical, laboratory, nursing, physiotherapy, dental, and surgical expertise. The manual covers clinical protocols, laboratory procedures, MSK rehabilitation, dental precautions, and psychosocial support, and is designed for both people with haemophilia and caregivers to standardise care and improve outcomes across haemophilia treatment centres in the region.
- **Empowerment of patient community through increased capacity to self-infuse, allowing people with severe haemophilia to be on early on-demand treatment, ensuring that bleeds are treated faster**
    - Through the virtual follow-up support of Luz Villalaz from Panama, the trained nurses have reached 80% of the diagnosed people with haemophilia in Cochabamba – 42 out of 52. These 42 individuals have been empowered through self-infusion training. Prior to the trainings, only around 10 patients were able to self-infuse.

Laboratory training in Cochabamba with Marión Echenagucía.

Training of physiotherapists in Chile with the team of Dr Lamas.

4.2. Dominican Republic 3 Project

- Programme title **Accelerating haemophilia and sickle cell disease care in the Dominican Republic**
- Phase Formalisation
- Partner
    - Dominican Foundation for Mothers & Infants (DOFMI), Represented by Dr Angélica Florén, President
    - Hospital Padre Billini, Represented by Dr Ana Nadal Ponce
    - Hospital Infantil Dr Robert Reid, Represented by Dra Krismely Moya
- Duration 3 years
- Activity start date Q3 2026

Objectives

- Improve management of haemophilia and sickle cell disease in the capital Santo Domingo and in Santiago, including establishment of sickle cell disease treatment guidelines
- Establish diagnosis in sickle cell disease in the country and improve haemophilia diagnosis in 3 centres
- Establish the first national sickle cell disease registry to capture comprehensive national data
- Advocate for removal of out-of-pocket costs and dedicated budget allocation for both disorders as well as the establishment of sickle cell disease diagnosis in the country

Status

- The project was approved at the NNHF Council meeting in May 2026 and is currently working on the formalities to sign the project partnership agreement and soon commence activities.

4.3. Ecuador 1 Project

- Programme title **Raise standard of haemophilia and sickle cell disease care in Quito and Guayaquil**
- Phase Formalisation
- Partner Sociedad Ecuatoriana de Hematología – Dr Jessyca Manner and Dr Sadys Rendón
- Duration 2.5 years
- Activity start date Q3 2026

Objectives

- Raise and standardise training capacity in haemophilia and sickle cell disease care in the capital Quito and in Guayaquil
- Improve the collection of epidemiological data on both diseases to better inform authorities and improve patient care.
- Strengthen network of leading haematologists and facilitate knowledge exchange ensuring synergies between haemophilia and sickle cell disease

Status

- The project partnership agreement has been signed, but activities have not yet begun due to a recent leadership change at the Sociedad Ecuatoriana de Hematología. The transition period is expected to be finalised in September 2026.

4.4. El Salvador 2 Project

- Programme title **Enhancing bleeding disorders and sickle cell disease care and advocating for decentralisation in El Salvador**
- Phase Execution
- Partner Hospital Nacional de Niños Benjamín Bloom – Dr Armando Estrada, paediatric haematologist, and Hospital Nacional Rosales – Dr Donato Milla, haematologist
- Duration 2.5 years
- Activity start date Q3 2025

Objectives

- Enhance multidisciplinary care teams at Hospital Nacional de Niños Benjamín Bloom and Hospital Nacional Rosales and establish a clinic for women with bleeding disorders at the paediatric hospital
- Improve diagnostic capabilities in San Salvador by providing access to advanced testing
- Improve sickle cell disease care in El Salvador and establish a data collection system through the initiation of a disease registry
- Advocate for higher budget allocations for haemophilia treatment and decentralisation of basic care to 1-2 regions
- Increase reach of patient community through patient education

Status

- Three healthcare professionals from Hospital Nacional de Niños Benjamín Bloom have completed specialised training abroad strengthening the multidisciplinary team:
    - A gynaecologist was trained in Panama City on bleeding disorders and sickle cell disease.
    - A radiologist was trained in Barcelona on the doppler technique for sickle cell disease management.
    - A physiotherapist was trained in Campinas, Brazil on the management of haemophilia and sickle cell disease.
- Building on the trainings completed in 2025 and 2026, preparatory work began on El Salvador's sickle cell disease registry with formal development planned for the second half of 2026.

Training of physiotherapist from San Salvador in haemophilia and sickle cell disease management in Campinas, Brazil.

4.5. Guatemala 2 Project

- Programme title **Establishing a national haemophilia registry and multidisciplinary care teams in Guatemala**
- Phase Execution
- Partner Hospital San Juan de Dios - Dr Pedro Alvarado and Dr Josué Bautista
- Duration 2.5 years
- Activity start date Q2 2024

Objectives

- Achieve consolidated national data on haemophilia and other bleeding disorders in Guatemala
- Improve quality of haemophilia care in Guatemala City with the strengthening of multidisciplinary care teams
- Increase national access to diagnosis and care through decentralisation to Quetzaltenango
- Advocate for the implementation of prophylaxis for children under the public healthcare system
- Increase quality of life of people with haemophilia through awareness and empowerment

Status

- Two laboratory technicians from Hospital Roosevelt participated in an online coagulation training provided by Marion Echenagucia, as preparation for the upcoming decentralisation trainings.
- Coordination and preparation activities have been completed for the upcoming decentralisation trainings for laboratory technicians and physiotherapists in Quetzaltenango.
- Data has been continuously added to the newly developed national registry.

4.6. Jamaica 2 Project

- Programme title **Developing a country wide care network for bleeding disorders in Jamaica**
- Phase Execution
- Partner University Hospital of the West Indies (UHWI) – Dr Gilian Wharfe and Dr Magdalene Nwokocha
- Duration 4 years
- Activity start date Q1 2023

Objectives

- Improve quality assurance for diagnosis and care of people with bleeding disorders at the University Hospital of the West Indies in Kingston
- Enhance collaboration with and capacity of 5 peripheral hospitals for the referral and follow-up of haemophilia cases to UHWI
- Include bleeding disorders' diagnosis and treatment in a national healthcare programme by 2025
- Increase reach of the Haemophilia Society of Jamaica

Status

- General/emergency room trainings reached 76 healthcare professionals this semester. Sessions were delivered across three provinces (Kingston, Madeville, St. Ann's Bay), combining a previous academic evaluation with practical guidance for physicians, nurses and laboratory technologists on emergency management and sample collection.
- Physiotherapy equipment was donated to Mandeville, St. Ann's Bay and Montego Bay, expanding access to care for people with haemophilia islandwide.
- A visiting expert volunteer specialist nurse from Royal Free London NHS strengthened local capacity through training of 12 nurses in the clinical management of people with haemophilia.
- Under a new leadership, the patient association Hemophilia Society Jamaica (HSJ) organised activities on World Haemophilia Day to raise public awareness of the condition.

Nurse training delivered by Molly Ndebele from Royal Free London NHS in Kingston, Jamaica.

4.7. Panama 3 Project

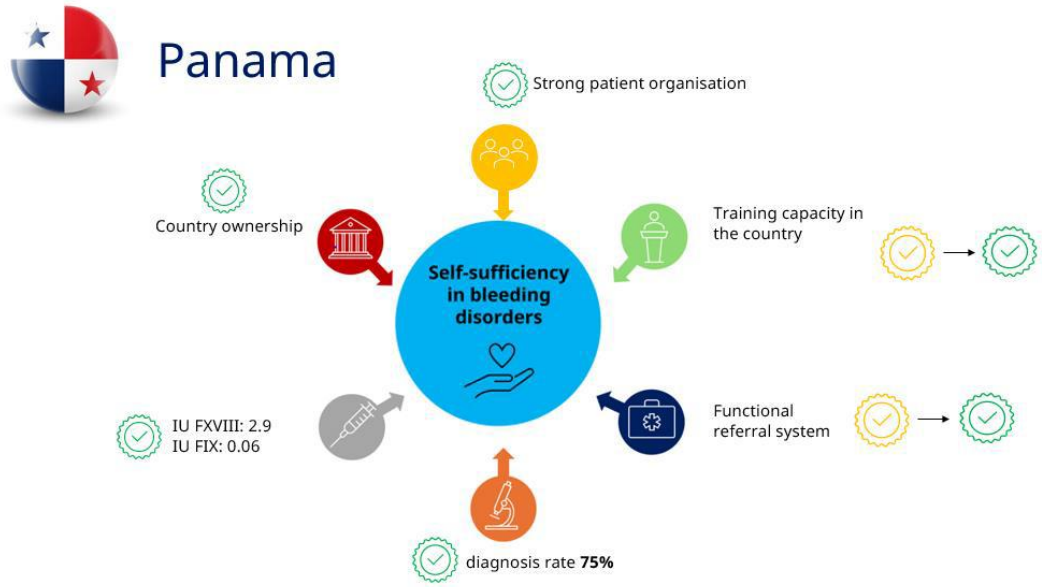
- Programme title **Strengthen multidisciplinary care teams and paediatric-adult care transition**
- Phase Closing
- Partner Fundación Panameña de Hemofilia - Ms Luz Villalaz and Ms Alaisa de Melgar
- Duration 3 years, Q1 2023 – Q1 2026

Objectives

- Develop haemophilia multidisciplinary care teams of 4 hospitals in David and Panama City to improve paediatric to adult transition and care
- Strengthen 20 haemophilia satellite clinics across Panama by 2025
- Increase outreach of people with haemophilia in 4 provinces and improve the diagnosis rate from 29% to 50% in Western Panama by the end of 2025
- Empower people with haemophilia and parents for better adherence and transition from paediatric to adult care

Achievements

- This project has **directly benefitted 1,025 people with bleeding disorders** and **109 people with sickle cell disease**
    - **Panama has achieved self-sufficiency in bleeding disorders,** meeting the remaining two indicators: **A functional referral system** in the capital for adults and children and regional coverage through the strengthened satellite centres.
    - **Local training capacity** has been strengthened through delivery of both international and domestic medical training programmes.



- **Adults with haemophilia have access to high quality, specialised care at Hospital Santo Tomás, improving significantly the transition from paediatric to adult care:**
    - The following members of the multidisciplinary care team received specialised training abroad:
        - **1 radiologist** trained in **Salta**, **Argentina**, in ultrasound and MRI protocols for haemophilia joint disease
        - **1 physiotherapist** trained in **Monterrey**, **Mexico**, in haemophilia-specific rehabilitation and bleed prevention
        - **1 physiatrist** trained in **Buenos Aires**, **Argentina**, in long-term musculoskeletal care, pain management, and multidisciplinary rehab planning
        - and **1 orthopaedic surgeon** trained in **Milan, Italy**, in advanced surgical procedures such as synovectomy, arthroscopy, joint replacement for people with haemophilia.
    - The Fundación Panameña de Hemofilia maintains a strong collaboration with trained healthcare professionals from Hospital Santo Tomás to ensure continuity of care for adult patients.

- **Functional referral system established with 20 satellite centres strengthened,** resulting in equity in care offered across the country and a **reduction in average patient travel times by 12 hours** (round-trip Panama-City to Chiriquí)
    - **6 seminars** (between 1-4 days) held in Panama City **addressed haematology, nursing, diagnosis, psychology, social work, pharmacy, and dentistry benefitting in total 170 healthcare professionals**. These trainings were led by local and trained experts, such as Guadelupe Vivero (laboratory), Luz Villalaz (nursing) and Dr Nadia Barsallo (haematologist) supported by international experts from the region: Marion Echenagucia (laboratory technician from Caracas, Venezuela), Dr Laura Forzani (odontologist from Salta, Argentina), Ezequiel Martinez (psychologist from Mexico City, Mexico) and Laura Páez (social worker from Monterrey, Mexico).
    - Ensuring standardised care offered across the 20 satellite centres **11 centres across** Panamá Province, Panamá Oeste, Colón, Comarca Ngöbe-Buglé, and Veraguas **were upgraded with essential equipment** such as e.g. refrigerators and voltage regulators to ensure proper storage of treatment.

- While the **national diagnosis rate has already reached an impressive 75%**, the **Western provinces have also demonstrated strong progress, achieving 52% increase, from 29% to 44%** (21 to 49 PwH) bringing the region close to the ambitious target of a 50% diagnosis rate.
    - Home visits were carried out in Chiriquí, Comarca Ngöbe-Buglé and Darién to identify patients, carriers and to refer patients to the nearest

satellite centre. Hospital Santo Tomás coordinated confirmatory testing for parents of patients with suspected von Willebrand disease.

- **PEP-model developed and piloted** with 15 families serving as mentors and trainers through Fundación Panameña de Hemofilia FUNP H) “Parents ducating Parents” programme:
    - The programme was led by psychologists, nurses and social workers. The programme covered parenting and disease management skills.
    - FUNPAH and the mentor families are **continuing to cascade their knowledge** to other families and **will support the national sickle cell disease patient organisation** in adapting and implementing this peer-mentoring model for its community.

- **A national sickle cell disease strategy roadmap for Panama was developed leading to alignment among stakeholders and the formation of a national sickle cell disease coalition**
    - Following a thorough landscape review, stakeholder mapping and engagement, a national strategy workshop at the end of 2025 brought together key haematologists from across the country and representatives of two patient organisations and representatives from the haemophilia patient organisation. The workshop produced a national sickle cell disease strategy roadmap resulting in a comprehensive project application led by Asociación Panameña para la Prevención de la Anemia Falciforme (APPAF).
    - Initial pilot activities to raise sickle cell disease awareness were organised in collaboration with Fundación Infantil Anemia Falciforme (FIAF). These included seminars attended by 73 nurses, 24 other healthcare professionals, 11 teachers and 109 people with sickle cell disease.

Laura Páez providing training to social workers from across the country in 2025.

Training of orthopaedic surgeons from Panama and Guatemala in Italy in 2025.

4.8. Panama 4 Project

- Programme title **Strengthening sickle cell disease care in Panama: Leveraging lessons from haemophilia**
- Phase Formalisation
- Partner
    - Asociación Panameña para la Prevención de la Anemia Falciforme (APPAF) – Ms Mirna Allen, president and haematologist Dr Kenia Miller, Hospital del Niño Dr. José Renán Esquivel
    - Fundación Panameña de Hemofilia (FUNPAH) Represented by Luz Villalaz, treasurer and Alaisa Arauz de Melgar, executive director
- Duration 3 years
- Activity start date Q3 2026

Objectives

- Strengthen multidisciplinary teams for sickle cell disease in Panama City
- Establish a referral network across 14 regional centres and integrate haemophilia and sickle cell services into three regional hubs. In parallel, strengthen 17 regional haemophilia centres and disseminate treatment guidelines.
- Improve sickle cell disease diagnosis in the capital and in Veraguas
- Establish a national registry for haemophilia and sickle cell disease to secure sustained resource allocation for haemophilia and to strengthen advocacy and funding for expanded sickle cell disease services
- Advocate for integrated haemophilia and sickle cell services and reduced out of pocket costs
- Raise awareness to reduce stigma and promote better disease management in the sickle cell disease community

Status

- The project was approved at the NNHF Council meeting in May 2026 and is currently working on the formalities to sign the project partnership agreement and soon commence activities.

4.9. Paraguay 2 Project

- Programme title **Strengthen haemophilia care structures and network in Paraguay**
- Phase Execution
- Partner National Blood Programme (Ministry of Health)
  - Dr Carolina Molas and Mr Alejandro Cardozo, President of Asohemo
- Duration 3 years
- Activity start date Q1 2024

Objectives

- Strengthen haemophilia care in Asunción and develop basic care across the country for better geographical access
- Create a rehabilitation network and improve joint health of people with bleeding disorders
- Increase haemophilia diagnosis rate nationwide from 42% to 48% by 2026
- Strengthen the haemophilia community and empower people with haemophilia and families for an improved daily management of the condition
- Through advocacy, reach centralised haemophilia data as well as sustainable diagnosis and treatment

Status

- As part of the effort to expand rehabilitation services nationally, installation of modular physical rehabilitation containers began in June 2026.
- Multidisciplinary joint-evaluation sessions reached 36 people with haemophilia transported from rural areas (Caacupé, Pedro Juan Caballero, Coronel Ovideo and Ciudad del Este).
- The first family tree study of a person with haemophilia was completed, an initial step toward more systematic case-finding nationwide, leading to 4 newly diagnosed people with haemophilia.
- Facing budget constraints in the national health sector, the patient organisation ASOHEMO adjusted its focus toward ensuring continuity of treatment and care, while continuing to engage authorities and fellow patient organisations to advocate for restored funding. Two meetings were held in the Ministry of Health to strengthen government engagement and support the national haemophilia programme and to negotiate for continuous access to treatment.

4.10. Peru 4 Project

- Programme title **Leaders for institutional progress**
- Phase Closing
- Partner Asociación Peruana de la Hemofilia (ASPEH) - Mr Guillermo Pareja and Dr Gloria Chumpitaz
- Duration 4 years, Q4 2021 – Q4 2025

Objectives

- Identify and integrate new active leaders into ASPEH patient organisation
- Develop and strengthen organisational committee
- Strengthen the relationship between healthcare professionals and ASPEH organisation
- Increase ASPEH visibility and involvement from people with haemophilia and familie

Achievements

- This project has **directly benefitted 1,165 people with haemophilia**
    - A **130% increase in procurement of factor VIII** was achieved, with **IU rising from 0.547 to 1.26.** This increase has enabled people with severe haemophilia to be on prophylaxis, marking a **significant step towards self-sufficiency.**
        - In 2023, a strategic planning and leadership training was provided by NNHF to 20 board and key members of the national patient organisation ASPEH and healthcare professionals. This resulted in the formation of 5 sub-committees (mothers, youth, political, institutional and communications). Each committee was tasked with coordinating activities and reporting progress to the main committee. Together they designed outreach plans, identified priority actions such as regular follow-up with authorities. **Continuous efforts and contributions over the years by the political sub-committee and healthcare professionals secured the increased government commitment**
- A **national three-year strategy for haemophilia** (2025-2028) with a medical focus, developed by key haematologists including Dr Nancy Loayza, formed the basis for the **NNHF Peru 5 project which was approved in May 2025**.
    - In 2025, the NNHF collaborated with the Sociedad Peruana de Hematología to organise a strategic workshop in Lima. The workshop brought together 25 healthcare professionals and 9 community representatives across the country to define a joint vision for the future and establishing a national, medical consortium.

Strategy workshop in Lima – Haematologists Dr Bustinza, Dr Tokumura and laboratory expert Rosario Ticona brainstorming ideas.

- Empowering 144 people with haemophilia and **allowing implementation of prophylaxis: self-infusion skills and confidence rose by nearly 50% after training**
    - In collaboration with healthcare professionals, the patient organisation delivered ten self-infusion trainings across Arequipa, Cajamarca, Chiclayo, Piura, Trujillo and Lima for 144 people with severe haemophilia. Post-training evaluations averaged 16.11 out of a possible 20 points, an almost 50% increase in combined knowledge and confidence versus pre-training.

Self-infusion workshop in Cusco and Lima.

4.11. Peru 5 Project

- Programme title **Standardise haemophilia care and diagnosis across the regions of Peru**
- Phase Execution
- Partner Sociedad Peruana de Hematologia – Dr Adriana Bustinza and Dr Enrique Argumanis
- Duration 3 years
- Activity start date Q4 2025

Objectives

- Improve access and raise the quality of haemophilia care across the country
- Increase the diagnosis rate from 34.9% to 40%
- Define a clear epidemiological picture of haemophilia in Peru to optimise its management and treatment
- Achieve prophylaxis in 100% of adults and children and gain a dedicated budget for bleeding disorders

Status

- Completed and analysed a nationwide situation diagnosis survey across all planned haemophilia treating centres, covering the quality of service capacity, diagnostics and multidisciplinary care.
    - The survey results were presented to the Peruvian Haemophilia Society and treating centres, both in-person and virtual sessions, giving stakeholders a shared national picture of haemophilia care.
    - Based on the surveys, three national reference centres were identified for training (Hospital Rebagliati, Hospital Dos de Mayo and Instituto Nacional de Salud del Niño - Breña) and healthcare professionals were selected for international training.
- Coordination meetings were held with the patient registry technical group to define software improvements for haemophilia data collection.
- The project was presented to the Ministry of Health authorities and their support was secured for joint site visits, updated treatment guidelines and workshops with the entities responsible for access to treatment decisions.

4.12. Venezuela Donation

- Programme title **Enhancing musculoskeletal care and patient empowerment in the regions of Venezuela**
- Phase Execution
- Partner Fundación de Apoyo a la Asociación Venezolana para la Hemofilia (FAAVH) - Luis Enrique Rojas Marquez, President
- Duration 2 years
- Activity start date Q1 2025

Objectives

- Improve MSK care and physiatry in 12 states of the country and education for patients
- Procure wheelchairs and crutches for the haemophilia community

Status

- In total, 27 healthcare professionals from Mérida and Trujillo received training on joint treatment and musculoskeletal care for people with haemophilia: 9 physiatrists, 8 orthopaedic/trauma specialists, 8 haematologists, 1 general physician, and 1 physiotherapist.
- 28 people with haemophilia received training and education on medical and social topics; 10 people with haemophilia also underwent a joint evaluation.
- Due to the recent earthquakes in Venezuela trainings in 7 states were postponed. New timelines are being defined depending on the reopening of the airport in Caracas.

5. Asia

Legend:
Projects active in H1 2026
Projects completed in H1 2026

5.1. Cambodia 3 Project

- Programme title **Enhance haemophilia care in Phnom Penh and Siem Reap and improve basic care, service delivery and diagnosis across Cambodia**
- Phase Execution
- Partner Cambodia Hemophilia Association (CHA) and Dr Sing Heng from Angkor Hospital for Children
- Duration 2.5 years
- Activity start date Q2 2025

Objectives

- Improve organisation of care at paediatric hospitals in Phnom Penh and Siem Reap and establish adult care in Phnom Penh
- Improve haemophilia awareness amongst health authorities and decentralise basic care to the provinces
- Raise awareness, increase diagnosis rate from 18% to 24% and advocate for improved haemophilia care in the provinces
- Strengthen the national patient organisation and empower people with haemophilia to improve their joint health

Status

- The Cambodia 3 project has been on hold since January 2026, with no activities implemented. An update will be given in due course.

5.2. India 14 Project

- Programme title **Accelerate access to diagnosis and care in India**
- Phase Execution
- Partner Hemophilia Federation India (HFI) – Mr Prem Roop Alva, President and National Institute of Immunohaematology, Mumbai, represented by Dr Bipin Kulkarni
- Duration 3.5 years
- Activity start date Q4 2023
- ***This project is supported by a grant from Novo Nordisk Foundation***

Objectives

- Develop a state-level referral and training system and establish or strengthen comprehensive care in at least 9 state referral centres
- Make basic multidisciplinary care and diagnosis easily accessible, establishing or strengthening 36 district hospitals in 9 states
- Accelerate national improvements of diagnosis, care and treatment for people with haemophilia, advocating to state and central government
- Strengthen the national patient organisation, ensuring more collaboration with a broad medical network and increase awareness on haemophilia

Status

- Multidisciplinary comprehensive training conducted for 138 healthcare professionals including neurologists, orthopaedics, gastroenterologist and haemophilia treating doctors from 59 medical institutions.
- Successfully held a multi-stakeholder round table meeting in Dibrugarh, Assam with government doctors, NHM officials from Assam and Rajasthan, HFI, and Sickle Cell organisations. The discussion focused on assessing needs to establish centres of excellence for haemophilia and hemoglobinopathy and the implementation of haemophilia point of care in both the states.
- The haemophilia treatment centres at Assam Medical College and Hospital, Dibrugarh have been inaugurated.
- Hemophilia Federation India is part of the committee to formulate the national haemophilia treatment guidelines for the government of India.
- A cost-benefit analysis on prophylactic care and treatment was approved.

Multidisciplinary comprehensive training of healthcare professionals including neurologists, orthopaedics, gastroenterologist and haemophilia treating doctors.

Multi-stakeholder round table meeting in Dibrugarh, Assam with government doctors, NHM officials from Assam and Rajasthan, Hemophilia Federation India, and NASCO.

5.3. Indonesia 3 Project

- Programme title **Decentralise basic haemophilia care and diagnosis to 4 regions in Indonesia**
- Phase Closing
- Partner Indonesian Society of Hematology and Blood Transfusion – Dr Novie Amelia Chozie
- Duration 2 years, Q3 2023 – Q4 2025

Objectives

- Strengthen basic haemophilia care and raise haemophilia awareness amongst primary healthcare providers in East Nusa Tenggara, West Kalimantan, West Sumatra and Papua
- Decentralise diagnosis and raise haemophilia awareness to increase the diagnosis rate in the 4 regions by 55%
- Empower the patient community to self-manage their disease and strengthen the national patient organisation and its chapters in the regions

Achievements

- This project has directly **benefitted 180 people with haemophilia.**
- Basic haemophilia care is now available in East Nusa Tenggara, West Kalimantan, West Sumatra and Papua, **eliminating the need for patients to travel up to 3,700 km to Jakarta for essential care and treatment** (13 hours flight from Papua to Jakarta and back)
    - A paediatrician from each of the four provinces received a 2-week specialised training at Ramathibodi Hospital, Bangkok Thailand led by Prof Nongnuch Sirachainan and her team.
    - 117 healthcare professionals across the four provinces received basic haemophilia training delivered by Dr Novie Chozie and her team from Jakarta. This included self-infusion training for 5 nurses, basic and intermediate diagnostic training for 42 laboratory technicians, and musculoskeletal care and physical examination training for 24 physiotherapists.

In-depth training of four paediatricians at Ramathibodi Hospital in Bangkok, Thailand in February 2025.

- **Successful advocacy initiatives strengthened regional haemophilia care in 3 of the regions:**
    - In Kupang, **East Nusa Tenggara**, a dedicated budget has been secured for the procurement of reagents and factor treatment.
    - In **West Sumatra**, the **regional hospital now procures reagents for diagnosis** and can perform basic testing and factor VIII and IX assays.
    - In **West Kalimantan**, the haemophilia satellite **centre has allocated a budget for diagnostic testing**. For advanced tests not yet available locally, the hospital now **covers the cost of sending blood samples to Jakarta**. As a result, patients no longer need to travel themselves for diagnosis, saving significant out-of-pocket expenses and avoiding travel times of up to 96 hours for a round trip from West Kalimantan to Jakarta.

- **36 (vs 60 planned) new people with haemophilia have been diagnosed** from the 4 regions. Representing an increase in the diagnosis rate by 25% (vs an ambitious target of 40%). Overall, the **diagnosis rate increased from 6.8% to 8.6%**, representing 180 people with haemophilia in total.
    - Looking ahead, the continued support from provincial health authorities and the ongoing use of established local referral networks provide a strong foundation for further increasing the haemophilia diagnosis rate.

- People with haemophilia in the four regions have **strengthened their ability to self-manage their condition, enabling them to exercise their legal right in Indonesia to receive home treatment once they are able to safely self-infuse**
    - 159 people with haemophilia and their family members received educational training, getting a better understanding about their disease. Under the supervision of the newly trained nurses, people with haemophilia also learned how to self-infuse.

- **A national strategy for Indonesia was outlined, defining a roadmap for bleeding disorders from the health authorities** to expand access to quality, standardised diagnosis, care, and treatment across the country's more than 17,000 islands.
    - A 2.5-day national meeting was held in Jakarta convened healthcare professionals from across all regions of Indonesia, Ministry of Health representatives, and the national health insurance agency.
    - Building on the approved national guidelines for the diagnosis and management of people with haemophilia, the roadmap highlighted: establishing regional, multidisciplinary care teams, ensure hospitals submit factor purchase plans to regional health insurance representatives, and improve the regular availability of diagnostic reagents.

Key healthcare professionals from across Indonesia during the strategy meeting in Jakarta in August 2025.

5.4. Indonesia 4 Project

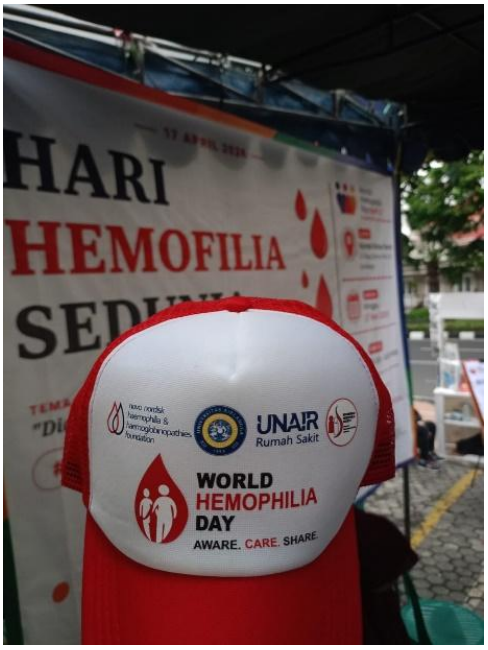
- Programme title **Establish a regional referral centre in Surabaya and sustainable diagnosis and treatment in East Java, Indonesia**
- Phase Execution
- Partner Airlangga University Hospital - Dr Pradana Zaky Romadhon and Dr Aditea Etnawati Putri
- Duration 2.5 years
- Activity start date Q4 2024

Objectives

- Establish advanced haemophilia and thalassaemia care in Surabaya, becoming a regional referral hub for East Java
- Raise awareness and increase haemophilia diagnosis rate in East Java from 7.5% to 16.5%
- Advocate for sustainable diagnosis and standardised care for haemophilia in East Java
- Empower patient organisation chapters to play an active role in advocating for improved care in East Java

Status

- Internal governance and project oversight were strengthened through the establishment of an internal audit team and the completion of audit and review processes, helping improve accountability, documentation, and programme quality.
- Factor VIII carrier testing was conducted at Airlangga University Hospital, improving access to haemophilia diagnostic services, supporting early carrier detection, and strengthening local diagnostic capacity.
- World Haemophilia Day and World Thalassaemia Day were successfully implemented under the theme "Campaign and Caring", increasing awareness among healthcare professionals, patients, families, and the wider community on the importance of early diagnosis and comprehensive care.
- Overall, the project has contributed to stronger programme governance, improved diagnostic capacity, and enhanced collaboration between hospitals, healthcare professionals, and patient organisations.



World Haemophilia Day awareness activities organised by HMHI East Java during a community Car Free Day event. Through educational booths, free health checks, and a public canvas of support, the event engaged patients, families, healthcare professionals, and the wider community, helping to raise awareness of the importance of early diagnosis and comprehensive haemophilia care.

5.5. Mongolia 1 Project

- Programme title **Improve organisation of care and diagnosis in Ulaanbaatar and decentralise basic care to the regions**
- Phase Execution
- Partner Mongolian National University of Medical Sciences, Mongolia – Japan Hospital – Prof Odgerel Tsogabadrakh, Head of the Haemophilia Centre
- Duration 2.5 years
- Activity start date Q2 2025

Objectives

- Strengthen the organisation of haemophilia care and diagnosis in Ulaanbaatar
- Establish a national registry, capturing the haemophilia landscape of Mongolia for advocacy initiatives
- Improve MSK care and empower people with haemophilia to self-manage their disease
- Decentralise basic and emergency haemophilia care to three regions outside Ulaanbaatar
- Strengthen the capacity of the patient organisation and empower its members

Status

- Two orthopaedic doctors trained through the project successfully treated and operated on a patient with severe haemophilia who sustained significant injuries following an accident, demonstrating improved local clinical capacity.
- The first round of Ministry of Health technical discussions on the national haemophilia guidelines was completed, with revisions now being incorporated based on expert feedback.
- Preparatory work for the haemophilia burden study has been completed, including establishment of the research team, obtaining permissions for key questionnaires, and reviewing the study tools for clarity and suitability.
- An awareness video on haemophilia was developed and disseminated through the hospital website and social media platforms to increase public awareness and education.
- World Haemophilia Day was jointly celebrated by the National Centre for Maternal and Child Health and the haemophilia centre of the Mongolia-Japan Hospital. The event included patient education and awareness sessions, as well as training for nurses on haemophilia care. These activities helped increase awareness of modern haemophilia treatment, management, and care, while strengthening collaboration among stakeholders. The nurse training aimed to

improve knowledge and understanding of haemophilia, enhance the quality and accessibility of nursing care, and strengthen practical skills in the management of people with haemophilia.

Orthopaedic surgeon training at Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milan, Italy. Through the project, two orthopaedic surgeons enhanced their expertise in haemophilia-related orthopaedic care and subsequently successfully treated a patient with severe haemophilia following a serious accident, demonstrating strengthened local clinical capacity.

5.6. Sri Lanka 3 Project

- Programme title **Decentralise haemophilia care across Sri Lanka and increase support from health authorities**
- Phase Execution
- Partner Hemophilia Association of Sri Lanka (HASL) – Shantha Karunarathne and Sri Lanka College of Haematologists – Dr Visaka Ratnamalala
- Duration 3 years
- Activity start date Q4 2025

Objectives

- Establish comprehensive haemophilia care in Colombo
- Strengthen three regional haemophilia treatment centres and improve the referral system across Sri Lanka
- Consolidate the national medical network, foster partnerships and advocate for improved care with health authorities
- Strengthen the patient organisation and empower people with haemophilia for better self-management

Status

- Completed the first phase of the “Beyond the Bleed” (general awareness) training programme for the healthcare professionals at the National Hospital of Sri Lanka (NHSL), improving knowledge on diagnosis, treatment, complication prevention, and emergency management.
- Conducted patient awareness activities in Embilipitiya, reaching patients and caregivers from Uva, Sabaragamuwa, and Southern Provinces.
- Established a regional patient welfare group to strengthen peer support and community engagement.
- Completed assessments of selected haemophilia treatment centres and submitted equipment requirements to the Ministry of Health for approval and procurement.
- Made progress towards establishing the Embilipitiya haemophilia treatment centre, including advocacy for a dedicated haemophilia care facility and treatment product storage.
- Initiated advocacy discussions with the MoH to strengthen haemophilia care services and government support.
- Selected healthcare professionals for advanced haemophilia training in India with visa and travel preparations underway.

Healthcare professionals participate in the first phase of the "Beyond the Bleed" training programme at NHSL. The session, attended by 74 participants, focused on haemophilia and comprehensive care, led by consultant haematologists with support from the HASL project team.

5.7. Uzbekistan 6 Fundraiser Project

- Programme title **Integrated health: Empowering communities for better inclusion in society**
- Phase Execution
- Partner Association of Hematologists and Transfusiologists of Uzbekistan – Dr Aziza Makhmudova
- Duration 1.5 years
- Activity start date Q1 2026

Objectives

- Decentralisation of haemophilia care at the primary healthcare level
- Educational patient camps – empowering people with haemophilia to self-manage their condition and providing psychological support
- Improving the performance of laboratory services in the region

Status

- Activities have started to ensure the decentralisation of haemophilia care at primary healthcare level. Training sessions were held for physicians from regional health institutions, and a new referral system was introduced to help ensure that people with haemophilia can access care at the nearest available centre.
- A refrigerator was purchased for the storage of reagents in preparation for the laboratory training. The laboratory training as well as the educational patient camps are planned for the second half of 2026.

6. Global Programmes

Legend:
Projects active in H1 2026

*The advocacy project is led out of Switzerland to improve the life of people with haemophilia and haemoglobinopathies in low- and middle-income countries.

6.1. Global 6: Advocacy Programme

- Programme title **Fostering advocacy to influence haemophilia care provision: Phase 3**
- Phase Execution
- Partner International and national advocacy experts
- Duration 5 years
- Activity start date Q4 2021

Objectives

- Support NNHF partner countries to create and implement advocacy strategies that create tangible systemic change
- Partner with national advocacy experts to widen advocacy knowledge pool and to enable provision of hands-on technical support as needed
- Expansion of programme delivery into Latin America and French-speaking Africa

Status

- Data-driven advocacy pilots running in East Africa, India, Indonesia and Malaysia.