Sydney, a boy with haemophilia in Luanda, Angola, with his mother and grandmother outside. their home.

NNHF Half-Year Report

1 July - 31 December 2025

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 second half of 2025, **from 1 July to 31 December.** 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 thalassemia. It also highlights ongoing challenges, 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 December 2025, NNHF has supported 260 projects, 74 fellowships, and 32 awards across 86 countries. This report offers NNHF partners and ambassadors a consolidated snapshot of progress achieved during the second 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 - scroll through the report to read the key highlights from each region and country. **Learn how Central American advocates are shaping national goals, how Mali's military health teams are bringing haemophilia care into conflict-affected communities, and how a parliamentary workshop in India has sparked work on national treatment guidelines and much more.** 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

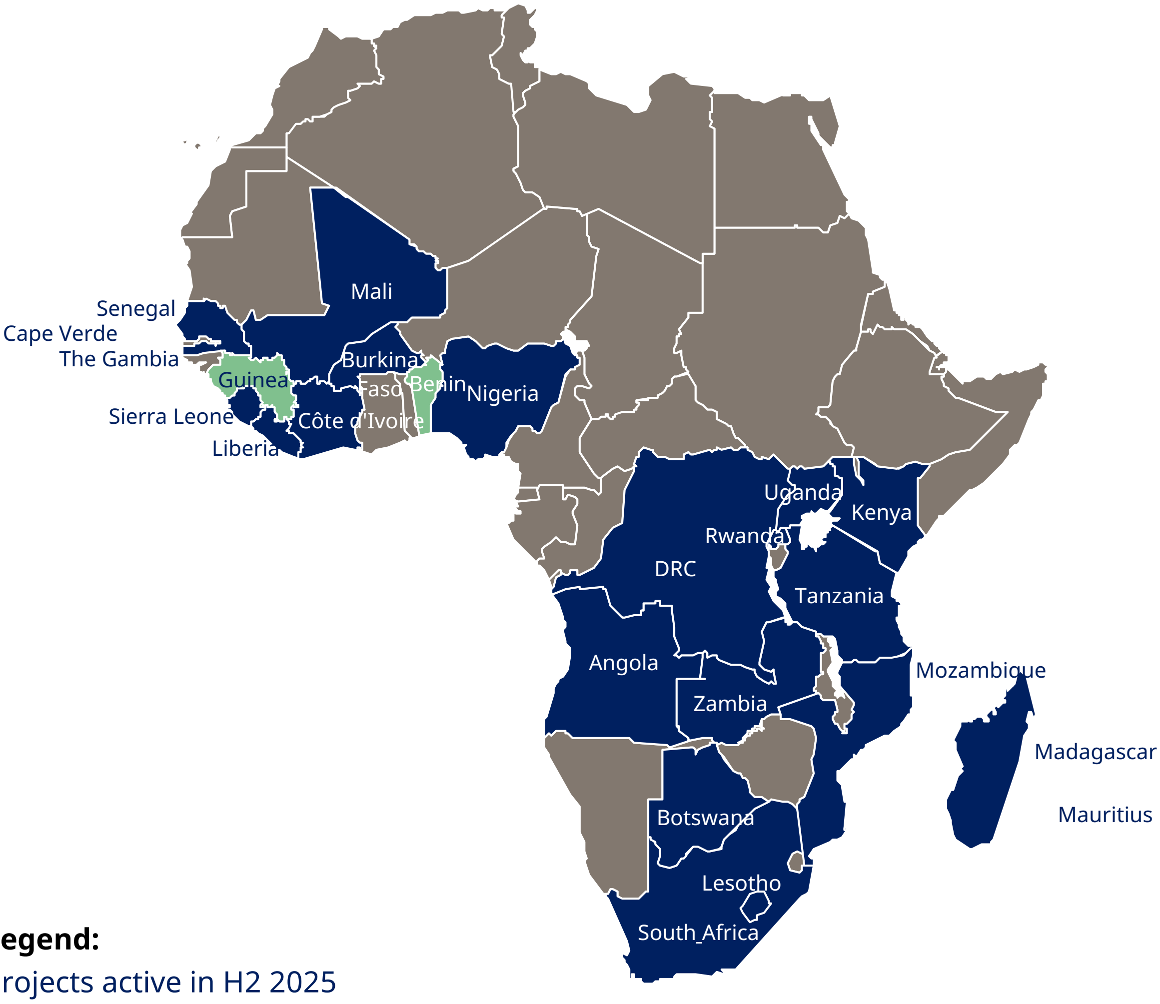
1 July – 31 December 2025

Programmes approved since 2005:

- 260 projects (2 new projects since H1 2025)
- 74 fellowships
- 32 awards

in 86 countries

3. Africa

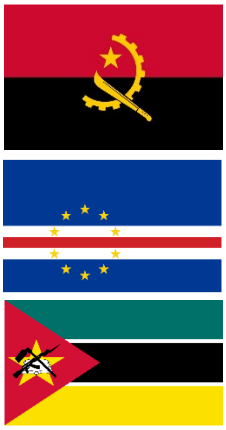


Legend:

Projects active in H2 2025

Projects completed in H2 2025

3.1. Angola, Cape Verde & Mozambique Project



- 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 3 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 SCD landscape, build strategic alliances and define strategy for Mozambique and Angola

Status

- A one-week specialised training on haemophilia was conducted at Dra Victoria Paediatric Institute of Espirito Santo, Luanda by a 5-member team from the University of Campinas (UNICAMP), Brazil. 3 haematologists, 3 paediatricians, 3 dentists, 7 laboratory technicians, 5 nurses, and 4 physiotherapists were trained.

    - During the one-week training, 40 people with haemophilia were retested for reclassification out of which 20 were found to have inhibitors.
- A one-day advocacy workshop comprising of representatives of the patient community and healthcare professionals from Angola, Cape Verde & Mozambique was conducted in Luanda, Angola in August 2025 thus strengthening the capacity for the partners to further advocate for sustainability of reagents supply from their respective local governments.
    - In furtherance of advocacy, Angola partner participated in a meeting with the 6th Committee of the National Assembly and the Ministry of Health to discuss the inclusion of haemophilia in the country's national strategic plan for the prevention and control of Non-Communicable Diseases focusing on strengthening early diagnosis.
- In Luanda, Angola, two healthcare talks on haemophilia were delivered by a haemophilia nurse at Nadia Neves School and Universidade de BELAS (UNIBELAS), reaching a total of 14 teachers and 70 students to promote awareness and understanding of haemophilia.
- In Cape Verde, family tree tracing and awareness raising has helped move the number of diagnosed people from 22 to 30 and the diagnosis rate from 36% to 49%.

Mozambique team engaging in a group discussion during a one-day advocacy workshop held in Luanda, Angola, in August 2025, alongside partners from Angola and Cape Verde.

3.2. Benin 1 Project

Programme title	**Fostering change for people with haemophilia in Benin**
Phase	Closing
Partner	Association Béninoise des Hémophilies - Mrs Chimene Vignon and Prof Dorothée Kinde
Duration	3 years, Q2 2022-Q3 2025

Objectives

- Create a network of haemophilia across Benin with more than 150 primary healthcare professionals trained
- Increase haemophilia diagnosis rate from 6% to 12% by 2024
- Decrease risks associated with circumcision for children with haemophilia
- Expand national patient organisation’s reach and activities
- Raise awareness and interest of health authorities on bleeding disorders

Achievements

- This project has directly benefitted **165 people with haemophilia.**
- Multidisciplinary care improved in the national referral centre and six basic haemophilia centres strengthened/established in the regions, **reducing travel time to receive basic and emergency care by up to 18 hours** (roundtrip from Tanguieta to the capital Cotonou)
    - To strengthen the haemophilia core team in Cotonou, two nurses and two lab technicians received specialised training at the Centre de Transfusion National (CNTS) in Dakar, Senegal. Upon their return, they conducted awareness-raising sessions for healthcare professionals in their departments and across the 6 regions.
    - Six basic haemophilia treatment centres were strengthened/established, each equipped with refrigerators to initiate decentralisation of treatment availability. To strengthen haemophilia care, 14 healthcare professionals from each centre including lab technicians, general doctors, nurses, and midwives were trained in haemophilia management and basic haemostasis tests (PT, APTT), led by Dr Bienvenu Houssou and the trained team of nurses and lab technicians from Dakar.
- **Community-based awareness raising and an increase of the haemophilia national diagnosis rate by 109%.** This was achieved through:
    - 278 healthcare professionals have been trained nationwide to recognise the clinical signs of haemophilia, refer suspected cases to the reference centre, and manage emergencies. These efforts combined with screening days led to a doubling of the national diagnosis rate from **6%**

  to 12% (from 79 to 165 people with haemophilia now diagnosed and registered).
- In collaboration with local authorities and healthcare professionals, the Association Béninoise des Hémophiles (ABH) raised awareness of haemophilia symptoms among 500 traditional practitioners across six regions of Benin. The initiative aimed to reduce non-medically supervised circumcisions and prevent haemorrhagic complications in undiagnosed boys. Following the training,

  Dr Bienvenu Houssou and Mrs Chimene Vignon, from the patient organisation, received over eight referrals of suspected cases, leading to the diagnosis of two haemophilia cases.

Project team from left to right: Dr Baglo Tatiana, Dr Houssou Bienvenu, Vignon Chimene and Tossou Anicet, during the advocacy and strategy workshop in Dakar, Senegal, April 2025.

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
● Activity start date	Q3 2023

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%

Status

- The partners, Botswana Baylor Children’s Centre of Excellence and Botswana Inherited Bleeding Disorders Association (BIBDA), conducted family tree tracing in two districts in the southern part of the country resulting in the identification of 13 suspected cases of haemophilia. Following the screening, 4 cases were confirmed moving the confirmed number of haemophilia cases in the country from 82 to 86 and the diagnosis rate now stands at 37%.
- One-day laboratory training conducted at Princess Marina Hospital in Gaborone. 2 laboratory technicians performed diagnosis for the suspected cases picked during the family tree tracing.

3.4. 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
Partner	Cliniques Universitaires de Kinshasa - Prof Jean Lambert Gini and Prof Léon Tshilolo from CEFA Monkole
Duration	2 years
Activity start date	Q3 2024

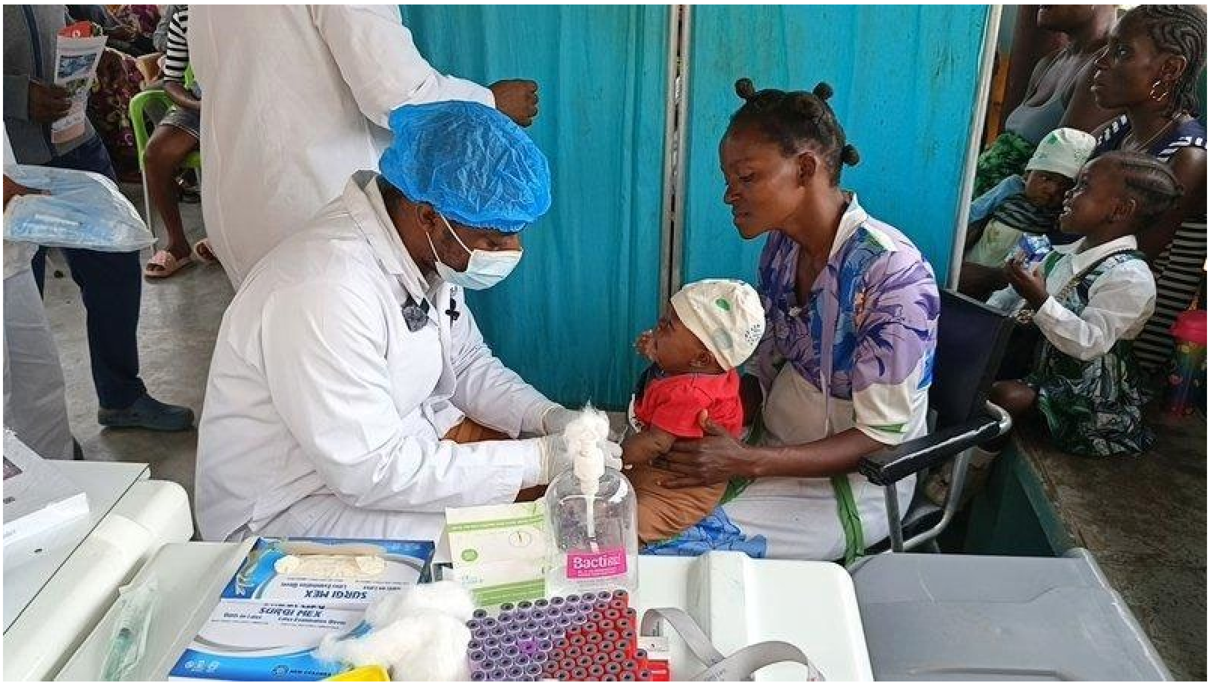
Objectives

- Improve access to haemophilia and SCD 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 SCD care in Kinshasa, Mbuji Mayi, Kisangani and Lubumbashi
- Expand patient organisation reach and improve knowledge of haemophilia and SCD and their management amongst those affected and their family members
- Raise awareness and advocate for the inclusion of haemophilia and SCD in the Non-Communicable-Disease (NCD) programme

Status

- Raised awareness and advocate for the inclusion of haemophilia and SCD in the Non-Communicable-Disease (NCD) programme through:
    - Dissemination of haemophilia awareness video clips in four local languages led to the identification and registration of 4 new individuals with haemophilia.
    - Deployment of the mobile laboratory in two hard-to-reach regions enabled the diagnosis of 115 new individuals with Sickle Cell Disease, moving the diagnosis numbers from 1,262 to 1,377 people with SCD diagnosed.
    - Hold meetings with the Programme National de Lutte contre la Drépanocytose (PNLCD) to discuss the inclusion of haemophilia into the SCD national programme and the Centre National de Transfusion Sanguine (CNTS) to discuss the procurement of treatment products such as the establishment of cryoprecipitate.
    - Advocacy initiatives were pursued to secure a local supplier capable of providing hydroxyurea at an affordable price. These efforts have contributed to a significant reduction in the market cost of hydroxyurea, with the price of a 20-capsule box decreasing from USD 10–15 to USD 6, improving accessibility for people with SCD.

- Improved access to haemophilia and SCD care in the capital city through:
    - Training of 47 healthcare professionals, including lab technicians, general doctors, gynaecologists, nurses and paediatricians, in the capital city and 3 regions on the diagnosis and care for haemophilia and SCD.
    - 3 peripheral centres in Kinshasa were equipped with solar refrigerators for the proper storage of blood products, improving the availability of factors and safe blood for peripheral health facilities for people with haemophilia and sickle cell disease.
- Improved joint health: crutches and wheelchairs were distributed across four regions, complemented by therapeutic patient education sessions benefitting 102 people with haemophilia and their families.



SCD diagnosis day using the mobile lab in the peripheral areas of Kinshasa in DRC.

3.5. Guinea 1 Project

Programme title	**Increase haemophilia awareness and diagnosis in Guinea**
Phase	Closing
Partner	Association Guinéenne pour la lutte contre l’hémophilie et autres maladies hémorragiques (AGUILHAMH) – Dr Mamady Diakité and Mr Abdoulaye Camara
Duration	2 years, Q1 2023 – Q2 2025

Objectives

- Increase haemophilia diagnosis rate from 3% to 9% by the end of 2024
- Strengthen healthcare professionals' network nationwide for better access to haemophilia care
- Improve people with haemophilia and their families' knowledge about the condition
- Strengthen haemophilia and sickle cell disease awareness in Guinea
- Advocate for integrated data of haemophilia and sickle cell disease to improve efficiency in providing care for rare blood disorders

Achievements

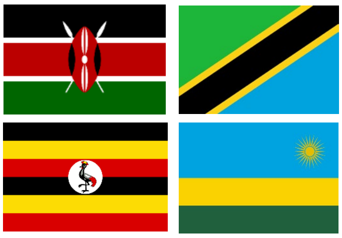
- This project has directly benefitted **120 people with haemophilia and 1,200 people with sickle cell disease**.
- **Four haemophilia and SCD treatment centres established/strengthened in the regions**, **reducing the travel time to receive emergency and basic care by up to 96 hours** (per round trip from N’zérekoré to the capital Conakry) for people with haemophilia and SCD.
    - A national cold chain protocol for treatment and diagnosis was developed by haematologists, lab technicians, and pharmacists and validated by the Ministry of Health. After the donation of five portable refrigerated units, the new protocol was implemented nationwide, improving the transport and distribution of donated treatment factors.
    - Due to low national awareness of both haemophilia and SCD, training sessions were conducted for **211 healthcare professionals and 104 traditional circumcisers**. Led by Prof Mamady Diakité and his team from the capital Conakry, the training sessions covered diagnosis and basic treatment of haemophilia and SCD for general practitioners, lab technicians, nurses, emergency doctors, pharmacists, and paediatricians.
- The haemophilia **diagnosis rate increased by 38%** (from 87 to 120 people with haemophilia diagnosed and registered), **reaching the target of a 9% diagnosis rate**.
    - A national TV and radio campaign raised awareness among the general public and the authorities and helped mobilise over 3 million Guinean

Francs (CHF 350) for the haemophilia patient organisation to host their annual general meeting.
    Following the media campaign and the awareness raising amongst healthcare professionals, 5 targeted awareness caravans and screening days were held in the capital and four regions, leading to the identification of 33 newly diagnosed people with haemophilia.

- **Synergies between haemophilia and SCD and advocacy progress**
    - Advocacy led to a verbal agreement recognising haemophilia and SCD as non-communicable diseases, with official confirmation pending.
    - A partnership between the patient organisation Association Guinéenne pour la lutte contre l'hémophilie et autres maladies hémorragiques (AGUILHAMH) and the Ministry of Health was signed, initiating a dialogue on financial support.
    - The patient organisation, AGUILHAMH, supported the SCD communities, leading to the creation of a patient organisation for SCD, la Fédération Guinéenne des Personnes Atteintes de la Drépanocytose (FEGUIPAD), launched on World Sickle Cell Day 2025. Both organisations will collaborate to raise awareness, improve care access, and influence policies for integrated care.

The project team during the strategic and advocacy training in Dakar, 2024.

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



- Programme title **An integrated approach to haemophilia and sickle cell disease care in East Africa**
- Phase Execution
- Partner
  - **Kenya**
    - Kenya Haemophilia Association (KHA) – Dr Kibet Shikuku and James Kago
  - **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 1 years
- Activity start date Q3 2025
- *This project is supported by a grant from Novo Nordisk Foundation*

Objectives

- To raise awareness among the general 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:**
    - 41 people were newly diagnosed with haemophilia, increasing the total number of people living with haemophilia from 1,218 to 1,259 bringing the diagnosis rate from 22.1% to 22.9%.
    - Celebrating World Sickle Cell Day, an integrated approach to haemophilia and sickle cell disease care programme was launched in East Africa alongside the Ministry of Health, County Government of Kilifi and other key stakeholders.
    - Advocated for the procurement of treatment in Kenya through various engagements including a meeting at the East Africa Legislative Assembly and a separate meeting with the leader, the Chair of the National Assembly Health Committee and the Majority Leader in Kenya Parliament.
    - Engaged the Ministry of Health on review of haemophilia treatment guidelines, purchase of treatment products, inclusion of haemophilia care services in the national healthcare insurance scheme, Social Health Authority (SHA), and representation of haemophilia and SCD in Technical Working Group of the Ministry of Health.
    - Developed standardised assessment tools for basic and comprehensive haemophilia treatment centres, tailored to different levels of care.
    - The Coast General Teaching and Referral Hospital, Kenyatta National Hospital, and the Moi Teaching and Referral Hospital (MTRH), renewed their commitment to purchase reagents for screening.
    - The first cohort of students to the haemophilia and sickle cell disease training programme at the Kenya Medical Training College were enrolled, 3 graduating from the course at the end of 2026.
    - The first knee replacement surgery for a person with haemophilia in Kenya was completed at Nairobi Spinal Injury Referral Hospital.

- **Tanzania**
    - Government Buy-In from project inception: Sustained engagement with the Ministry of Health and the Regional Administration and Local Government at both national and regional levels in Dodoma and Mara achieved strong government support and commitment to sustainability for this programme. This recognition enabled smooth coordination and effective implementation of integrated haemophilia and sickle cell disease interventions, fully aligned with national health priorities.

  - Established a national coordination platform on sickle cell disease, bringing together 36 partners from patient organisations, healthcare professionals, Ministry of Health officials, and other key stakeholders to standardise newborn screening and long-term policy alignment for sickle cell disease in Tanzania.
  - Screened 22 youths (17 AS, 1 SS, 4 AA) during World Sickle Cell Awareness Month and collected 56 units of blood through a blood drive in Dar es Salaam, reaching 30 people with sickle cell disease for counselling and awareness raising.
  - Increased awareness in the community and the general public through engagement with mainstream media, including radio, television, print, and social media.
  - Initiated a behavioural change campaign dubbed "Vunja Mduara, Pima, Jua Hali Yako Ya Sikoseli" ("Break the SCD Cycle, Know Your Status"), which highlighted the importance of early testing and personal responsibility, successfully expanding awareness within the wider community.

- **Rwanda**
  - Through consistent family tree tracing and dedicated screening days held at Kigali University Teaching Hospital (CHUK), 18 new individuals were diagnosed with haemophilia increasing the diagnosis rate from 8.2% to 9.6%, bringing the total number of people with haemophilia from 116 to 134.
  - 36 healthcare professionals (doctors, physiotherapists, and nurses) were trained in the management of haemophilia.
  - Basic training and awareness raising sessions were provided to 83 community health workers.
  - Haemophilia treatment guidelines were reviewed and a standardised protocol, including a haemophilia clinical algorithm, was developed to guide healthcare professionals across different levels of health facilities.
  - Leadership and governance training was conducted for all leaders of the Rwanda Fraternity Against Haemophilia to enhance leadership, governance and accountability.
  - Discussions were initiated with local legislators (Members of Parliament) to advocate for the procurement of treatment products and raise awareness of haemophilia among parliamentarians.
  - With the support of Rwanda Biomedical Centre, the Department of Non-Communicable Diseases has requested the Ministry, through the National Transfusion Centre, to advocate for sustainable access to haemophilia products. They are currently exploring partnerships with

pharmaceutical companies to exchange plasma for haemophilia products.

Haemophilia family tree tracing at the University Teaching Hospital of Butare in western Rwanda including care givers and parents.

- **Uganda**
    - 34 people were newly diagnosed with haemophilia, increasing the total number of people living with haemophilia from 451 to 485 bringing the diagnosis rate from 9.3% to 10%.
    - 6 laboratory personnel from Mityana General Hospital completed an intensive training at Mulago National Referral Hospital, enhancing their expertise in haemophilia diagnostics.
    - Engagements with Ministry of Health, Department of Laboratory Services, are underway to establish a centre of excellence for haemophilia and sickle cell disease screening and diagnosis at the Central Public Health Laboratories.
    - East African nations are collaborating to facilitate the bulk procurement of haemophilia treatment products. A proposal to incorporate these products into a regional pooled procurement mechanism is currently awaiting deliberation by the East African Legislative Assembly. This matter was addressed during a meeting held in Arusha, Tanzania, which was attended by representatives from Uganda, Kenya, Tanzania, Rwanda, and the East African Legislative Assembly.
    - Increased awareness through the media, where a radio talk show hosted a representative of the Medical Advisory Board and the parents' representative.
    - A Memorandum of Understanding was established with the National Council for Persons with Disabilities, which operates under the Secretariat of Special Interest Groups. This agreement enables individuals with haemophilia to be formally recognised as a special group, thereby granting them access to specialised support and services.

- School-based awareness campaigns successfully reached over 2,000 children, providing basic education on haemophilia and distributing informative materials.
- Trained 57 nurses from Mulago National Referral Hospital on haemophilia management through a continuous medical education session and the point of care ultrasound diagnostics.
- Held a meeting with the Ministry of Health to evaluate the possibility of establishing additional treatment and care centres for haemophilia and other bleeding disorders.

NNHF partners in East Africa met with members of the East African Legislative Assembly Health Committee to advocate for pooled procurement of haemophilia treatment products across the region.

3.7. Lesotho 2 Project

Programme title	**Enhancing haemophilia care services in the capital of Lesotho and in the regions**
Phase	Closing
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 2023

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

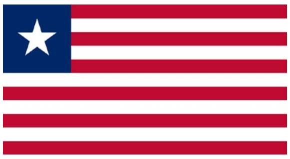
Status

- The diagnosis rate has increased from 8% to 9% with confirmed haemophilia cases moving up from 18 to 20 registered people with haemophilia.
- Improve the level of care in the capital of Maseru and enhance haemophilia awareness in the regions.
    - A two and half day's workshop on haemophilia was conducted in December 2025 targeting healthcare professionals from six regional hospitals. The workshop strengthened the healthcare professionals' clinical understanding of haemophilia care thus enabling them to improve the care provided to people with haemophilia.
    - Two volunteers with the Haemophilia Association of Lesotho (HAL) conducted an awareness raising talk at Queen Mamohato Memorial Hospital (QMMH) following their training in South Africa. This talks enhanced awareness and knowledge on haemophilia for healthcare professionals working in the hospital.
    - Dental and oral care has been incorporated as a routine check-up every six months for people with haemophilia. Thanks to the training of a dentist from Maseru District Hospital in Cape Town, they were able to pick one case of haemophilia after the patient presented with prolonged tooth bleeding following dental extraction.
- The partner has joined the Non-Communicable Disease & Injury (NCDI) committee, providing them with an opportunity to advocate with the Ministry of Health to address issues facing the community of people with haemophilia

including procurement of a coagulation machine as well as procurement of safe medications for people with haemophilia who have developed inhibitors.

A two and half day's haemophilia workshop held in December 2025 brought together healthcare professionals (doctors, dentists, lab technicians, nurses and physiotherapists) from six regional hospitals.

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	3 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

- Built a core project team for haemophilia diagnosis led by a paediatrician from John F. Kennedy Medical Center (JFKMC) in Monrovia. The core team includes a paediatrician, who is leading the care of sickle cell disease in the hospital. They currently manage 4 cases of people with haemophilia diagnosed in Ghana.
- Strengthened the diagnosis of haemophilia at John F. Kennedy Medical Center (JFKMC) with the partner signing a Memorandum of Understanding to sustain the coagulation machine through regular supply of reagents and servicing. This marks a significant move towards improving diagnosis of haemophilia in the country.

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 Medecine– 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

- Within the first three months of the third NNHF-supported project in Madagascar, the project team successfully trained eleven laboratory technicians from seven regions in the pathophysiology, biological diagnosis, and screening of haemophilia and sickle cell disease, enabling them to perform haemostasis tests, accurately diagnose patients, and share this expertise within their laboratories and communities to strengthen early detection and patient follow-up.

Picture taken during a physiotherapy training session in Madagascar, August 2025.

3.10. 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

Over the 6 months reporting period, the project team achieved substantial progress in strengthening haemophilia care systems, improving patient outcomes, and building national capacity through training and infrastructure support.

- Strengthened treatment and diagnostic systems, this was achieved through:
    - 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.
    - Hôpital du Mali is now procuring reagents and consumables to support improved diagnostic and treatment readiness.
    - Through the support of Mali 3 project, Hôpital du Mali in collaboration with the patient organisation AMALHEC renovated and inaugurated a day clinic: the Haemophilia Research and Treatment Centre in December 2025, marking a milestone in service delivery capacity for the patient's community in Mali.

- To strengthen the bleeding disorders communities across the country, the patient organisation successfully conducted three self-infusion and auto-physiotherapy training sessions in Sikasso, Segou, and Mopti benefiting a total of 96 people with haemophilia and their families. Building on this, the patient organisation plans to expand these trainings in more regions in the future as these were appreciated by the communities.
- Expanded Healthcare Workforce Capacity, through:
    - 2 training sessions conducted for 102 healthcare professionals from the health department of the National Police and the Central Direction of Army Health- Forces Armées du Mali (FAMA) in Bamako. These successful trainings were including haematologists, lab technicians, general doctors and nurses.

Training of the medical department of the Malian Armed Forces (FAMA) in the basic diagnosis and management of haemophilia across Mali, including in conflict zones and areas inaccessible to civilian healthcare professionals.

3.11. 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

- Haemophilia Association of Mauritius through awareness raising initiatives has managed to diagnose 12 new cases of haemophilia, moving the cases registered from 94 to 106 and the diagnosis rate from 72% to 81%.
- In December 2025, targeted screening for Von Willebrand Disorder (VWD) involving 25 individuals, including 17 carriers of Factor VIII deficiency, 7 Male, and 1 female with clinical features suggestive of Von Willebrand Disorder, was conducted at Victoria Hospital.
- A two-day training programme was conducted at the New Cancer Hospital. The programme aimed to strengthen their capacity in the accurate diagnosis, immediate management, and referral of patients with haemophilia and other inherited bleeding disorders.
- A two-day training on emergency care for people with haemophilia was held at the New Cancer Hospital targeting healthcare professionals working in Accident and Emergency Departments. A total of 20 healthcare professionals (HCPs), including 9 nursing officers, 5 medical officers, 3 physicians, 2 surgeon, 1 haematologist from the 5 regional hospitals participated in the training, thus strengthening their capacity to manage cases of haemophilia in the emergency departments.
- Two physiotherapists from Jeetoo Hospital (JH) and Sir Seewoosagur National Hospital (SSNH), have conducted joint assessment and scoring for 12 people

with haemophilia at the five regional hospitals. This marks an important step toward strengthening physiotherapy care for people with haemophilia and with this preventing long-term joint complications.

- The partner strengthened the psychological well-being of the haemophilia community by delivering psychosocial support sessions. A total of 20 people with haemophilia and 45 caregivers were visited in their home and benefited from emotional support, education, and guidance to help them cope with the challenges associated with living with haemophilia.

3.12. 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

- 46 people with haemophilia were newly diagnosed, increasing the total number of people living with haemophilia from 834 to 880, and bringing the diagnosis rate from 3.6% to 3.8%. This is mainly attributed to increased awareness, family tree tracing, and enhanced screening and testing at the seven strengthened centres.
- Capacity building workshop on haemophilia care and management for community health extension workers (CHEWs) was held at the University of Benin Teaching Hospital (Benin City), targeting 11 CHEWs. The sessions were didactic, interactive, and case-based, helping the CHEWs understand family tree tracing and enhancing their skills in identifying people with haemophilia. This training is expected to increase diagnosis rates by an estimated 10% within the project period.
- The “Haemophilia Diagnosis: A Laboratory Guide” was officially launched at the 2025 Nigerian Society for Haematology and Blood Transfusion Annual Scientific Meeting. Manuals were distributed to the seven participating institutions to strengthen laboratory capacity.
- Ongoing advocacy work is being directed at the government and stakeholders to secure procurement commitments for clotting factor concentrates.

- Planning for the Nigeria Inherited Blood Disorders Forum began in October 2025, with the development of a programme and agenda, speakers list and securing a venue.

Community Health Extension Workers from across Nigeria pose with their certificates at the end of a training session held in Abuja.

3.13. Senegal 2 Project

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

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

Status

- Awareness raising activities increased the number of people with haemophilia diagnosed from 319 at the beginning of the project in 2024 to currently 413 people with haemophilia, showing an increased diagnosis rate from 17% to 22%.
    - A two-day symposium was organised during the week of World Haemophilia Day, bringing together over 200 people with haemophilia and family members, healthcare providers, representatives from the World Federation of Hemophilia (WFH), and officials from the Ministry of Health.
    - 62 healthcare professionals, including general practitioners, nurses, emergency physicians, gynaecologists, orthopaedic surgeons, and social workers from Dakar, Saint-Louis, Kaolack, and Ziguinchor were trained over two days in each region on basic haemophilia care and emergency response, fostering a multidisciplinary approach to treatment and care.

- 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 (haematologists and laboratory technicians) and patient organisation members from Mali, Benin, Guinea, and Côte d'Ivoire.
- The Association Sénégalaise des Hémophiles (ASH) developed an online patient registry to track the medical records of people with haemophilia in Dakar, Saint-Louis, Kaolack, and Ziguinchor. This registry is accessible to healthcare professionals for patient follow-up and provides real-time statistics.
- In collaboration with the Ministry of health, the National Blood Transfusion Centre developed emergency treatment guidelines for the treatment of haemophilia and is being implemented across Senegal.

Patient organisations and healthcare professionals from Mali, Benin, Guinea, Côte d'Ivoire and Senegal at the National Bood Transfusion Centre in Dakar, Senegal.

3.14. 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 SCD landscape, build strategic alliances and define a strategy for Sierra Leone

Status

- The diagnosis rate increased from 3.5% to 5% with the total number of confirmed haemophilia cases moving up from 32 to 47 people with haemophilia.
    - This was realised through the efforts of the association, Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL), where targeted family-tree tracing was conducted in four families in the Bo District in Southern Sierra Leone and 15 new cases of haemophilia were identified.
    - A one-day haemophilia awareness raising workshop was conducted in Bo district targeting 2 nurses, 1 laboratory technician and 26 members of the community comprising people with haemophilia and their caregivers. This session strengthened awareness and knowledge on basic haemophilia care within the Southern region.
- Strengthening regional hospital diagnostic capacity and reinforcing the referral system to reduce the need for people suspected to have haemophilia to travel to the capital.
    - To strengthen regional capacity, three regional hospitals; Kono Government Hospital (East), Bo Government Hospital (South), and Makeni Government Hospital (North) received refrigerators for

    haemophilia medication storage. This investment brings life-saving treatment closer to patients, reducing travel burdens and ensuring access to medication in the regional areas.
    - To further improve diagnostic capabilities in the regional hospitals, the partner donated three cooler boxes to support safe transportation of blood samples from the regional hospitals to Connaught Hospital in Freetown. This initiative reduces the need for suspected people with haemophilia to travel to the capital for testing.
- In an important advocacy achievement, the partner successfully secured a waiver from the Ministry of Health for allocation of a dedicated space at Connaught Hospital once ongoing renovations are completed. This space will support services for both haemophilia and sickle cell disease, advancing the adoption of an integrated care model for bleeding disorders and haemoglobinopathies.

3.15. South Africa 5 Project

Programme title	**Raising the standard of care and promoting specialities in haemophilia care**
Phase	Closing
Partner	South Africa Haemophila Foundation (SAHF) - Mr Bradley Rayner
Duration	3 years, Q2 2022 – Q3 2025

Objectives

- Improve data collection and diagnosis
- Promote utilisation of ultrasound for better patient assessment and management
- Disseminate updated treatment guidelines to support standardisation of care across all provinces
- Increase awareness on haemophilia through community outreach
- Continue strengthening SAHF
- Global South Footwear for South Africa

Achievements

- This project has directly benefitted **2,475 people with haemophilia**.
- Outreach workshops in five provinces engaged more than 150 healthcare professionals, leading to the diagnosis of an additional 121 people with haemophilia up from 2,354 in 2022 to now 2,475 people with haemophilia. **Increasing the diagnosis rate from 39% to 41%.**
- **Improved standardisation of haemophilia care, enhancing musculoskeletal assessment, joint management, and national training capacity.**
  - **9 doctors and 3 physiotherapists received specialised training in the Joint Activity and Damage Exam (JADE) ultrasound protocol**, conducted by specialists from the Haemophilia & Thrombosis Treatment Center, University of California San Diego School of Medicine. This enhanced their ability to assess joint health and manage haemophilia-related complications. This training has also helped the partner to develop **a strong team of in-country trainers for musculoskeletal care; meaning they no longer rely on experts from abroad** for such training.
  - An ultrasound working group led **the decentralisation of Point of Care Ultrasound training across four haemophilia treatment centres** in the Western Cape, Gauteng, KwaZulu-Natal, and Free State provinces, **implementing a train-the-trainer model to expand reach and sustainability**. Three centres were also strengthened with the procurement of Point of Care Ultrasound machines.

    - 12 nurses drawn from the haemophilia treatment centres across South Africa enhanced their capacity to care for people with haemophilia after completing a one-day training. The session equipped them with essential skills in bleed recognition, infusion techniques, and patient support, strengthening their role in delivering quality haemophilia care.
    - The Medical and Scientific Advisory Council (MASAC) **updated and disseminated the national treatment guidelines and developed a Standard of Care document, fostering consistent haemophilia care nationwide**. The treatment guidelines included prophylaxis as the standard of care while the Essential Medicines List (EML) was updated to include new therapy options. Inclusion of new therapies has been achieved through advocacy meetings with Department of Health.
- **The national patient organisation has been strengthened, enhancing its leadership, governance, and strategic direction to better serve people living with bleeding disorders in South Africa.**
    - **Governance structures were enhanced** through the election of a new executive team, including a president and a MASAC chair. A **core project team was established** to enhance operational efficiency, financial management, governance, and compliance. **Succession planning** was initiated, with the newly elected chairperson, Mr Clerment Sefojane, representing youth leadership and signalling the organisation's commitment to transitioning leadership. These developments culminated in **a national strategic planning workshop in February 2025, which resulted in a five-year roadmap** focused on improving access to treatment, ensuring equity in care offered and strengthening advocacy across South Africa.
- **Haemophilia patient community empowered through expanded awareness and improved self-care capacity.**
    - Education and empowerment workshops for women bleeders, elder men, and youth were carried out during World Haemophilia Day commemorations involving over 100 people with haemophilia. Through these sessions, people with haemophilia and their caregivers received psychosocial counselling and training on self-care. Nurse-led home therapy training sessions enhanced confidence and self-infusion skills among people with haemophilia. **For Western Cape province, this meant raising home treatment uptake with 200%**, from 100 to 300 people with haemophilia on home treatment.

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	Formalisation
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

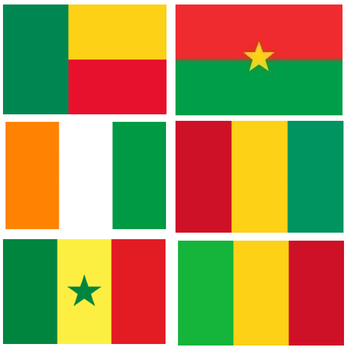
Objectives

- 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

- The project has been approved during the NNHF Council meeting in October 2025 and is currently working on the formalities to sign the project partnership agreement and commence activities in early 2026.

3.17. West Africa 1 Project



- Programme title **An integrated approach to haemophilia and sickle cell disease care in West Africa**
- Phase Formalisation
- 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
    - **Burkina Faso**
        - Groupe d'Intervention en Hématologie (GIH) – Prof Kafando and Dr Nebie Yacouba
    - **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 SCD 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 SCD
- Strengthen capacities of 6 national haemophilia and SCD patient organisations to build strong governance and expand their reach
- Raise awareness among the public on recognising SCD and bleeding disorder symptoms to refer for diagnosis
- Build strategic alliances and advocate for improved haemophilia and SCD care in all 6 countries

Status

- The project has been approved during the NNHF Council meeting in October 2025 and is currently working on the formalities to sign the project partnership agreement and commence activities in early 2026.

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

- 69 people were newly diagnosed with haemophilia, increasing the total number of people living with haemophilia from 328 to 397, and bringing the diagnosis rate from 15.4% to 18.6%.
- A total of 1,457 people with sickle cell disease were reached through screening, training, or activities to enhance care; of these, 777 were diagnosed in 2025.
- Awareness of haemophilia and sickle cell disease in Zambia increased, reaching over 500 people through a city marathon organised in Lusaka.
- Advocacy efforts continued, resulting in the successful passage of a bill in the national parliament supporting persons with disabilities and providing a foundation for further advocacy to include people with haemophilia and sickle cell disease.

4. Americas

Legend:
Projects active in H2 2025

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
Activity start date	Q2 2022

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

Status

- Diagnosis days were organised in Cochabamba, in total 4 people with haemophilia were identified.
- Meetings with authorities were organised to strengthen the commitment towards haemophilia.
- An ultrasound equipment was procured and installed at Hospital Manuel Ascencio Villarroel, thereby strengthening the MSK services for people with haemophilia.

4.2. 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 Libet Bosch
Duration	2.5 years
Activity start date	Q1 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 has been signed, but activities have not yet begun as NNHF is aligning with WFH to prevent overlapping efforts and ensure no duplication of work.

4.3. 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 SCD 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

- A maxillofacial surgeon from Hospital Nacional Rosales completed a two-week specialised training programme in haemophilia at Hospital de Niños José Renán Esquivel in Panama City.
- A regional advocacy workshop was held in Santo Domingo with representatives from El Salvador, the Dominican Republic, Guatemala, Honduras, and Panama; each country defined its national advocacy objectives.

A regional advocacy workshop in Santo Domingo convened representatives from El Salvador, Guatemala, Honduras, the Dominican Republic, and Panama. During the workshop in November 2025, each country group defined its advocacy objective.

4.4. 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

- A total of 33 physiotherapists and physiatrists from FUNDABIEM underwent training delivered by lead clinicians who were trained in Panama, thereby improving the MSK services for people with haemophilia in the regions.
- Haematologists from Hospital San Juan de Dios, Hospital Roosevelt, and IGSS and other project-trained healthcare professionals have started drafting treatment guidelines, which will be presented to the Ministry of Health in 2026.
- 84 people with haemophilia benefited from the fundraiser donation, receiving wheelchairs, crutches, and walkers.
- Three representatives from Guatemala from the patient organisation and medical team took part in a regional advocacy workshop in Santo Domingo to define their national objectives.

The lead physiotherapists from the capital are training Fundabiem physiotherapists nationwide. Fundabiem is a non-profit organisation that provides rehabilitation services for people with disabilities in Guatemala.

4.5. Jamaica 2 Project

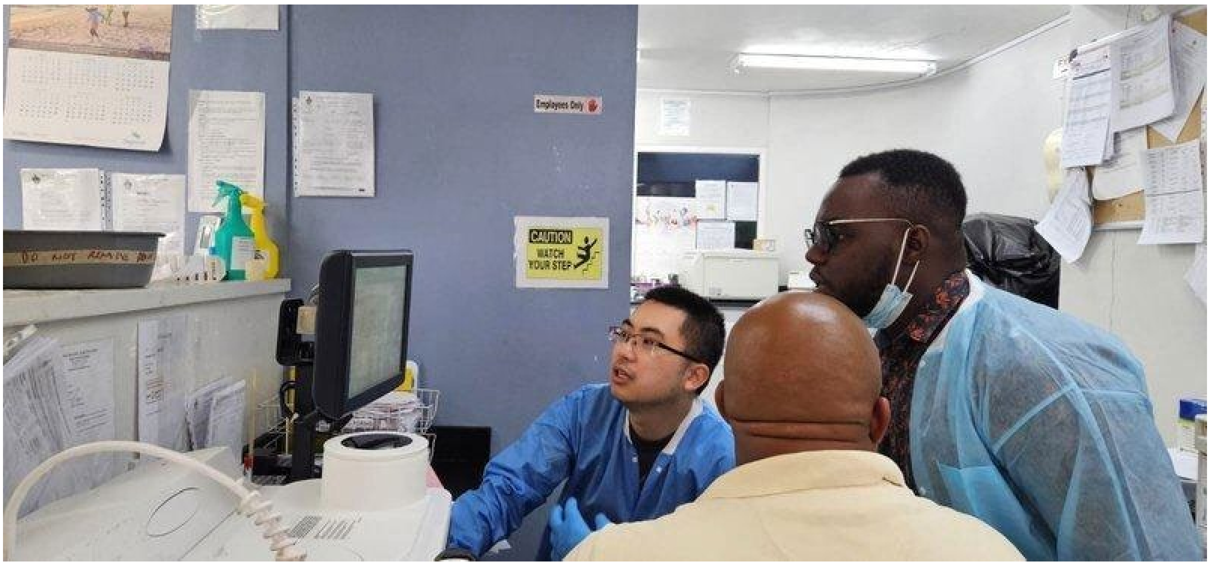
Programme title	**Developing a country wide care network for bleeding disorders in Jamaica**
Phase	Execution
Partner	University Hospital of the West Indies (UHWI) – Dr Gilian Wharfe and Dr Magdalene Nwokocha
Duration	4 years
Activity start date	Q1 2023

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

- A lab technologist from St. Michael’s Hospital, Toronto delivered a one-week specialised training on haemostasis testing in Kingston. Nine laboratory technicians were trained, and UHWI’s diagnostic capacity was strengthened with new assays implemented, including the chromogenic assay. An inter-laboratory sample exchange between St. Michael’s and the University of the West Indies (UHWI) will follow to assess assay concordance.
- The lead physiotherapist from UHWI, who was trained abroad early 2025, delivered a 3-day training to 33 physiotherapists across Kingston, St. Ann’s Bay, Mandeville and Cornwall Regional Hospitals, improving regional physiotherapy care.
- A patient camp reached 58 people with haemophilia in person and 20 online, providing dental care education, counselling, disease-management guidance and mental health support.
- Planned nursing and emergency-department outreach sessions were cancelled due to Hurricane Melissa.



A lab technologist from St. Michael's Hospital, Toronto, ran a one-week haemostasis training in Kingston for nine technicians, strengthening University of West Indie's diagnostics with new assays.

4.6. 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
Activity start date	Q1 2023

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

Status

- A radiologist and a physiotherapist from Hospital Santo Tomás were trained in Salta, Argentina and Monterrey, Mexico, completing a functional multidisciplinary haemophilia team at the adult hospital.
- Visits to Chiriquí, Veraguas, Darién and Indigenous territories were organised and refrigerators were donated to four remote health centres (based on needs assessments) to ensure proper treatment storage. Existing and newly identified patients and their families received disease-awareness and management training, reaching 230 patients in total.
- A Parents Educating Parents programme was organised with support from psychologists, doctors and nurses; 25 parents have joined the programme.
- Fundación Infantil de Anemia Falciforme (FIAF) conducted home visits in Colón and Panamá Oeste to assess patient needs.
- A seminar was organised for 59 adult patients on sickle cell disease management.
- A national strategy workshop with key doctors and two sickle cell disease patient organisations produced a national strategy for sickle cell disease that will form the basis of a project application to be submitted in May 2026.

4.7. 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

- Joint evaluations for 150 people with haemophilia were conducted in Asunción by the lead physiotherapists trained in Salta, Argentina.
- The Ministry of Health approved the country's first national haemophilia treatment guidelines in August 2025.
- Two diagnosis days were organised in Asunción and Itauguá, leading to the identification of 11 new people with bleeding disorders.
- A patient camp attended by 93 people with haemophilia focused on disease management and self-infusion training.
- A proposal developed with the National Blood Programme to establish a national haemophilia registry is underway; the registry software is currently in the testing phase.
- The Ministry of Health appointed two additional haematologists to Hospital General de Barrio Obrero, with this expanding services to adult people with haemophilia (previously limited to paediatric care only). Haematology services were also introduced in the rural area of Coronel Oviedo through the appointment of one haematologist, improving access to care for people with haemophilia in that region.

4.8. 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
Activity start date	Q4 2021

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

Status

- The patient organisation delivered two self-infusion trainings — one in Lima and one in Cajamarca — training a total of 37 people with haemophilia.

4.9. 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

- The first in-person meeting brought together 18 healthcare professionals from Lima and the provinces to coordinate activities and agree on roles and responsibilities for this project.
- The centre assessment survey provided by NNHF has been adapted to local needs to begin a situational analysis of all HTCs nationwide, which will be instrumental for the nomination of reference centres and the planning of upcoming trainings and equipment requirements.

4.10. 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

- The lead physiatrist from Caracas, Dr Laura Aponte, led two-day trainings to 5 orthopaedic surgeons, 2 physiatrist and 1 anaestheologist, who will perform post-evaluation assessments for people with haemophilia in their state.
- Musculoskeletal evaluations were conducted for 26 people with haemophilia.
- Additionally, 53 people with haemophilia received training on the importance of physiotherapy and exercise.
- As part of the fundraising initiative, 5 wheelchairs, 7 crutches and 3 walkers were acquired for the states of Barinas and Monagas, which will be available for loan to individuals with haemophilia in need.

5. Asia

Legend:

Projects active in H2 2025

Projects completed in H2 2025

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)– Sithan Kong 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

- A specialised healthcare training for one physiotherapist from the Calmette adult hospital took place in the UK at the Royal Free Hospital in London, under the supervision of Dr Thynn Thynn Yee and her team.
- In September 2025, CHA took part in an advocacy workshop led by Advocacy and Policy Institute (API). The training covered key advocacy principles; the advocacy cycle, targeting, lobbying, coalition-building, and Cambodia's power dynamics and legislative process. CHA has developed several action plans that still need to be integrated into a single advocacy strategy; once finalized, they will approach the Ministry of Health.
- Further activities are currently on hold. 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

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 dentist training at KEM Mumbai – 21 dentists from 21 haemophilia treatment centres across India trained.
- Laboratory and physiotherapy equipment installed at Assam Medical College & Hospital, Dibrugarh, physiotherapy equipment received at King George Medical University, Lucknow and lab equipment for JNMC, AMU-Aligarh.
- Eastern and Southern regional youth workshops trained 66 second-line leaders (future HFI chapter leadership).
- Haemophilia sensitisation event for Members of Parliament (MP) – 70 MPs were engaged beforehand; 33 MPs and 4 ministers attended and pledged support. A needs file for relevant ministries was prepared in English and Hindi.

A parliamentary sensitisation workshop was held in August 2025. Key issues raised were employment rights, inclusion in disability schemes, timely access to medications, and development of national treatment guidelines. The programme's main objective was to raise awareness and influence policy decisions at the highest level across political parties. The government is now working on developing treatment guidelines.

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
Activity start date	Q3 2023

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

Status

- In August, a national focus group meeting was held, bringing together key healthcare professionals from 25 provinces across Indonesia along with representatives from Ministry of Health and the national health insurance. The discussions focused on the implementation of national treatment guidelines and the use of prophylaxis for people with severe haemophilia.
- Last outreach visit to Papua, executing awareness raising training on haemophilia for 64 healthcare professionals including paediatricians, internists, general practitioners, dentists, clinical pathologists, lab technicians, physiatrists, physiotherapists and nurses. Awareness and educational materials were distributed and lab technicians trained. Following the training two new people with haemophilia were diagnosed.
- Patient organisation chapters in West Sumatera and West Kalimantan were strengthened and involved in advocacy meetings with regional health authorities to encourage home treatment.
- In November, a two-day training programme was conducted in Jakarta for 20 physical medicine and rehabilitation specialists from across Indonesia. The physiotherapist training featured practical, hands-on sessions with people with haemophilia and was built upon the foundation established through previous project initiatives.

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

- To advance comprehensive haemophilia care in East Java, Airlangga University Hospital in Surabaya and Dr Saiful Anwar Hospital in Malang implemented several important measures. Multidisciplinary teams, including haematologists, paediatricians, nurses, laboratory technicians, pharmacists, physiotherapists, and emergency doctors, were formed in both hospitals to ensure integrated and timely patient care through well-defined roles and responsibilities. A structured referral system was established both within and between the hospitals, facilitating organised patient referrals for diagnosis and care.
- To address the objective to raise awareness and increase haemophilia diagnosis advocacy meetings were held at Airlangga University Hospital to facilitate better access to haemophilia diagnosis. Simultaneously, educational and awareness materials were developed and disseminated throughout hospitals and during outreach events across East Java, with support from the patient organisation chapters.
- Training sessions were conducted for patient organisation chapters in Surabaya and Malang to enhance their leadership, advocacy, and communication skills. Through these sessions, patient leaders acquired a better understanding of the healthcare system, patient rights, and effective methods to engage with hospitals, health insurance providers, and local government authorities.

- In Surabaya and Malang, educational sessions were held for people living with haemophilia and thalassaemia, as well as their families. These sessions included topics such as disease awareness, treatment options, emergency management, the significance of regular medical follow-up, and self-care practices. Attendees were encouraged to take an active role in managing their health and to contribute to ongoing advocacy efforts.

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

- To strengthen the organisation of haemophilia care in Ulaanbaatar, a multidisciplinary team has been formed and specialists identified for international training. Specifically, two orthopaedic surgeons are scheduled to participate in advanced training in Italy in April 2026. Additionally, discussions are ongoing to facilitate training for other healthcare professionals in Uzbekistan.
- National treatment guidelines were established and reviewed. These guidelines were submitted to the Ministry of Health for approval. Upon receiving approval, implementation will proceed in coordination with the planned decentralisation of basic and emergency care to three regions outside of Ulaanbaatar.
- The registration process for people with haemophilia and other blood disorders has been initiated at the Mongolia-Japan Hospital. This activity aims to capture the haemophilia landscape of Mongolia to support targeted advocacy initiatives.
- In collaboration with the National Center for Maternal and Child Health, First State Central Hospital, and the National Blood Transfusion Center, a proposal has been submitted to the Health Development Center to establish remote patient monitoring, a unified national registry and integrate haemophilia care into the national health electronic information system.

- To improve MSK care joint assessments were conducted for people with haemophilia and first quotations for ultrasound equipment received.

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

- The patient organisation, Hemophilia Association of Sri Lanka, had a successful advocacy meeting with the Ministry of Health, strengthening its relationship with the new government leadership. The team successfully advocated for budget allocation for haemophilia treatment, leading to the start of treatment product procurement end of 2025 after no procurement in 2024.
- As part of strengthening three regional haemophilia treatment centres, the project team convened a productive meeting with the hospital management and regional health authorities in Ambilipitiya. As a result, a dedicated ward for haemophilia and other bleeding disorders will be established at the hospital in Ambilipitiya. A refrigerator for the laboratory has already been acquired.
- 2 youth members of the patient organisation took part in a Youth Leadership training in Bangalore, India alongside Hemophilia Foundation India. As a follow-up, an awareness raising Zoom meeting was held with HASL’s youth group.

In July 2025, two youth members from HASL attended a regional youth workshop in India organized by HFI. They gained practical leadership and advocacy skills, improved public speaking confidence, and learned about patient rights and advocacy. After returning, they organized an online youth workshop for HASL members in Sri Lanka to share their learnings, with plans to conduct more development workshops both in-person and online.

5.7. Thailand 5 Project

Programme title	**Strengthen haemophilia awareness and care in Southern Thailand**
Phase	Closing
Partner	Songklanagarind Hospital, Prince of Songkla University - Dr Natsaruth Songthawee
Duration	4.5 years, Q1 2021 – Q3 2025

Objectives

- Strengthen the referral system and basic multidisciplinary care in 8 HTCs
- Raise awareness amongst healthcare professionals in district hospitals, enabling them to refer for diagnosis and provide emergency care
- Educate people with haemophilia and their family members on optimal management of haemophilia and musculoskeletal (MSK) care
- Continue the specialisation of the national MSK trainer team focusing on ultrasound in haemophilia care

Achievements

- This project has directly **benefitted 2,062 people with haemophilia.**
- Songklanagarind Hospital in Southern Thailand has been strengthened to serve as a **regional referral and training centre**. Alongside the centres in Chiang Mai (North Thailand) and Khon Kaen (Northeastern Thailand) this centre is recognised as a regional training hub under the WFH IHTC (International Haemophlia Treatment Centre) programme. This means that it will be one of the regional centres visited by trainees from other countries after they complete their core training at Ramathibodi Hospital in Bangkok.
- Emergency and basic care decentralised, strengthening 8 haemophilia treatment centres, **reducing travel time up to 12 hours** (based on a round trip from Phang Nga to Songkhla). In total **358 healthcare professionals from these 8 centres have been trained**, taking a collaborative approach with the involvement of Prof Nongnuch Sirachainan from Ramathibodi hospital in Bangkok and Dr Rungrote Natesirinilkul and his team from Chiang Mai delivering parts of the training.
- **On a national level, MSK care was further advanced**, focusing **on the implementation and expansion of the use of point-of-care ultrasound**. The point-of-care ultrasound (POCUS) trainings saw the participation of healthcare professionals from all four regions (Central, North, Northeast and South Thailand). In 2024,
  Prof Andrea Doria and her team from SickKids Canada delivered a 3-day POCUS training for 33 healthcare professionals (haematologists, physiotherapists and radiologists) at Ramathibodi Hospital in Bangkok.

- **In August 2025, a follow-up specialised POCUS training for 3 radiologists took place at the Indiana Haemophilia and Thrombosis Center (IHTC) in Indianapolis** under the lead of Dr Kyle Davis and Stacie Akins.
- Following this, the project team is working on **finalising their local POCUS assessment tool to be implemented across Thailand**.

Thank you, Dr Amy Shapiro, for enabling the POCUS training at your centre. Back at Songklanagarind Hospital the newly trained radiologist had their first case on haemophilia early arthropathy detection with the ultrasound (HEAD-US) to detect and quantify early signs of joint damage.

- People with haemophilia are **empowered to better self-manage their care, improving health outcomes for the community in Southern Thailand:**
    - At Songklanagarind Hospital, the **prophylaxis rate increased from ~15% to 80%,** where at the beginning of the project there were 4 out of 27 people with haemophilia on prophylaxis and at the end 22 people are now on prophylaxis and able to self-infuse.
    - **In total, 277 people with haemophilia and their family members attended educational training** sessions on the management of haemophilia, topics covered MSK care and self-infusion. The educational sessions were led by the medical team from Songklanagarind Hospital and supported by fellow people with haemophilia.

"Learning to self-infuse at 14 made me more independent and meant fewer hospital visits for treatment. Now I am inspired to help others living with haemophilia to gain confidence and achieve greater independence for themselves and their carers", Daniel, 18, person with moderate haemophilia A.

5.8. Uzbekistan 6 Fundraiser Project

Programme title	**Integrated health: Empowering communities for better inclusion in society**
Phase	Formalisation
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

- Project partnership agreement has been signed and activities to start in Q1 2026.

6. Global Programmes

Legend:

Projects active in H2 2025

*The advocacy and the leadership projects are led out of Switzerland to improve the life of people with haemophilia 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

- Advocacy programme kicked off for coalitions from Portuguese-speaking Africa (PALOP) and Latin America with virtual and onsite advocacy workshops, in partnership with national experts.
- Follow-up support needs are being identified for the French-speaking cohort, comprising Benin, Côte d'Ivoire, Guinea, Mali and Senegal, together with regional expert organisation.
- Tailored, structured advocacy support has been provided to India and Nigeria.
- Data-driven advocacy pilots started in East Africa and India.

6.2. Global 7 – Leadership Programme

Programme title	**Virtual leadership programme for haemophilia practitioners**
Phase	Execution
Partner	NSRF Consulting – Robert Lugo
Duration	4 years
Activity start date	Q1 2022

Objectives

- Conduct a range of consultation activities to identify the most important skills and competencies required to be developed through the programme
- Develop a high quality, well tested virtual training programme that covers each of the identified needs
- Based on the content developed through objective 2, develop learning pathways (with multiple options customisable by learner groups) and delivery models (e.g. fully remote versus blended learning) to optimise learning and experience for potential participants
- Develop monitoring, evaluation and learning tools and framework to track progress and guide changes to the programme in the long-run
- Launch virtual programme with participants form the NNHF partner network

Status

- The virtual training programme will be refreshed in Q2 2026 and integrated into projects as part of our capacity building offering to partners.