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Selected programme updates

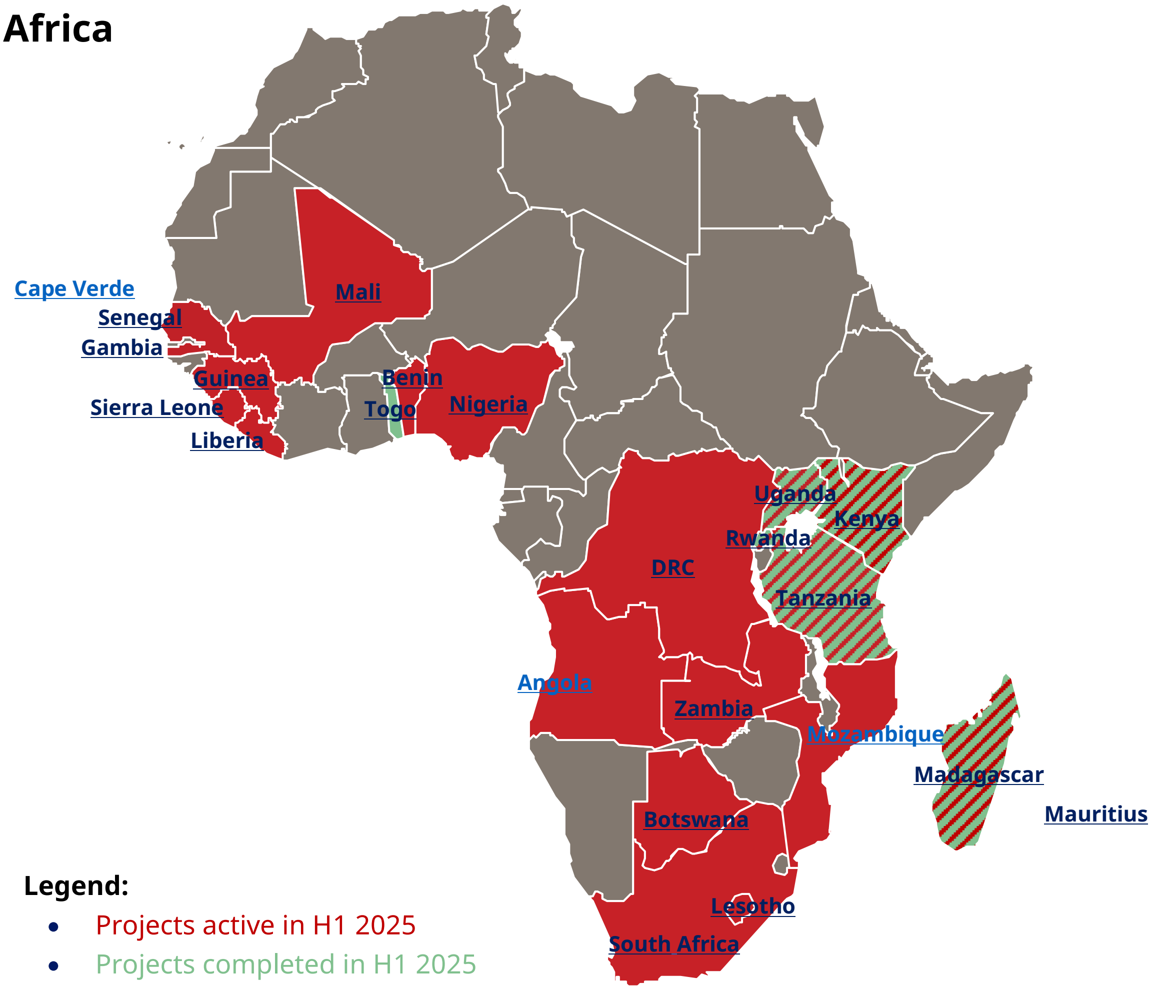
1 January – 30 June 2025

Programmes approved since 2005:

- 254 projects (6 new projects since H2 2024)
- 74 fellowships
- 30 awards

in 86 countries

Africa



Legend:

- Projects active in H1 2025
- Projects completed in H1 2025

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	Associacão Moçambicana de Hemofilia e Outras Coagulopatias Congénitas – Mr Nelson Damião, President and Maputo Central Hospital, represented by Dr Eldon Alafo and supported by Dr Patrícia Silva and Dr Nelia Manguele Liga dos Amigos dos Doentes Hematológicos de Angola (LADHA) – Mr Kaunda da Gama, President and Dra Victoria Pediatric Hematological Institute represented by Dr Francisco Antonio Domingos Associação Caboverdiana de Hemofilia e de Outras Coagulopatias Congénitas (ACHCC) – Dr Conceição Pinto and Dr Carla Lima from Hospital Agostinho Neto
NNHF contact	zagi@nnhf.org
Duration	3 years
Start date of activities	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

- Mozambique partners, Associação Moçambicana de Hemofilia (AMH), successfully raised awareness on bleeding disorders by commemorating World Haemophilia Day (17 April) and World Sickle Cell Day (19 June). These events attracted more than 100 participants including people with haemophilia and Sickle Cell, healthcare professionals, and government representatives through the National Directorate of Medical Assistance.
- In Mozambique, 16 healthcare professionals from Beira, Nampula and Quelimane Central Hospitals received basic training through workshops on haemophilia, thus

strengthening the respective centres. These trainings were conducted by Dr Jesús Serrano Mirabal and Dr Keiby Luís from Maputo Central Hospital.

- Through continued advocacy initiatives in Mozambique, the Ministry of Health, through the National Directorate of Medical Assistance, has begun procuring treatment for people with haemophilia and is committed to continuing the purchase of these medicines to improve the health and well-being of people with haemophilia.
- In Angola, the partner organisation, Associação Liga dos Amigos de Doentes Hematológicos de Angola (LADHA), facilitated a health talk at the Faculty of Medicine, Universidade de BELAS (UNIBELAS). A haematologist from the Institute of Paediatric Haematology delivered a lecture on the clinical approach to haemophilia in hospital settings, targeting medical students and reinforcing early professional engagement in bleeding disorders care.

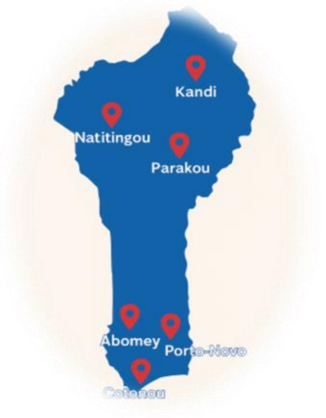
Benin 1 project

Programme title	**Fostering change for people with haemophilia in Benin**
Phase	Execution
Partner	Association Béninoise des Hémophilies - Mrs Chimene Vignon and Prof Dorothée Kinde
NNHF contact	cgtz@nnhf.org
Duration	3 years
Start date of activities	Q4 2022

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

Status



- On top of the 3 basic referral centres established and strengthened since the beginning of the project, in the capital city Porto-Novo and 2 regions in the South, three more haemophilia centres in the northern, western and central east of Benin have been established and launched, reducing travel time by up to 10 hours (round trip) for people with haemophilia to access basic care. The launch of the 3 centres were followed by a training of 14 lab technicians, general doctors, nurses and mid-wives from each region on haemophilia management and basic haemostasis tests, such as PT and APTT. These trainings were conducted by Dr Bienvenu Houssou and his team.
- The Association Béninoise des Hémophiles (ABH), in close collaboration with the local counties' authorities and healthcare professionals, raised awareness about haemophilia symptoms and signs among 500 traditional practitioners across six regions in northern, western, southern, and central-eastern Benin. The initiative aimed to reduce the incidence of non-medically supervised circumcisions and mitigate the risk of haemorrhagic complications in undiagnosed boys with haemophilia. Following the training, Dr Bienvenu Houssou, a haematologist at the national referral hospital in Cotonou, and Mrs Chimene Vignon, President of ABH, received over eight referrals of suspected haemophilia cases, which were subsequently tested.
- On World Haemophilia Day the Centre National Hospitalier Universitaire Hubert Koutoukou Maga (Cnhu-Hkm), ABH and its partners organised a one-day scientific and community engagement conference. The event included consultations and free screening, which led to an increased diagnosis rate from 6% to 11% (from 79 to 165 people with haemophilia).

Botswana 2 project

Programme title	**Decentralisation of care and diagnosis in two regions of Botswana**
Phase	Execution
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
NNHF contact	zagi@nnhf.org
Duration	2 years
Start date of activities	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), have managed to conduct awareness raising and family tree tracing in six regions and identified 30 suspected cases of haemophilia. These suspected cases will be tested in August 2025.
- The partners identified eight new people with haemophilia in the Northern province who previously lacked regular care. They are now enrolled with the patient organisation, strengthening ties with Nyangabgwe Referral Hospital. As a result, registered cases increased from 60 to 82 people with haemophilia.
- With the aim to build a sustainable laboratory infrastructure for coagulation testing, a technical working group visited the Department of Haematology at the University of the Free State (UFS), Bloemfontein in South Africa for a benchmarking exercise on placement model. The partners have shared the recommendations and learnings with the Ministry of Health, following the visit in a bid to explore the placement model as a pathway to enhance haemophilia diagnosis in the country.
- BIBDA, in partnership with Nyangabgwe Referral Hospital and Botswana Baylor Clinic, commemorated World Haemophilia Day in Francistown, drawing over 200 participants including people with haemophilia and healthcare professionals. The Assistant Minister of Health and Wellness attended as guest of honour. BIBDA advocated for the inclusion of bleeding disorders in the national disability support schemes and called for consistent access to medication.
- The partners conducted basic awareness raising through a workshop on basic haemophilia care where 63 healthcare professionals from Nyangabgwe Referral Hospital and Masunga Hospital were trained, thus improving access to basic haemophilia care in the regional areas.

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
NNHF contact	cgtz@nnhf.org
Duration	2 years
Start date of activities	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

- Prof Thsilolo Leon, Dr Gueth Kundabi and the team conducted an awareness raising training where 31 healthcare professionals, including haematologists, general practitioners, nurses, laboratory technicians, emergency staff, surgeons, and gynaecologists from Kinshasa were trained, thus improving access to basic haemophilia and Sickle Cell Disease care in Kinshasa and peripheral areas.
- In partnership with the Bill & Melinda Gates Foundation, the procurement of a mobile laboratory for screening and monitoring of people with sickle cell disease and other bleeding disorders in rural and remote areas has been completed. The team started collecting samples in Kasai and Mbuji Mayi, with 730 tests conducted to date and 103 confirmed cases of sickle cell disease identified.
- The treatment unit at Dipumba Hospital, within the paediatrics department of the Official University of Mbuji Mayi, was rehabilitated and equipped with clinic day furniture and a solar-powered refrigerator. These upgrades have provided the hospital with a suitable environment to deliver care to people with haemophilia and sickle cell disease in the region.
- The development of an online registry for sickle cell disease and haemophilia, along with training of eight healthcare professionals including nurses, lab technicians and general doctors from Mbuji Mayi and Kinshasa, has enhanced decentralised diagnosis and improved data integration.
- As advocacy is at the heart of this project, this year's World Sickle Cell Day commemoration contributed meaningfully to awareness and policy efforts. The event was attended by a national Member of Parliament who introduced a bill in support of people living with sickle cell disease, alongside the Mayor of the Commune and the Chief Medical Officer of the Health Zone, reinforcing local and national commitment to improved care and recognition.

The Gambia 2 project

Programme title	**Strengthen haemophilia in the capital and expand capacity and awareness in the rural areas of the Gambia**
Phase	Closing
Partner	Safe Motherhood and Hemophilia Foundation The Gambia - Mr Vandy Jayah and Dr Salifi Gaye
NNHF contact	zagi@nnhf.org
Duration	2 years
Start date of activities	Q2 2023

Objectives

- Strengthen the capacity of the haemophilia patient organisation in rural areas
- Raise awareness amongst healthcare professionals in 6 regions of the Gambia
- Improve quality of diagnosis in the capital and increase diagnosis rate from 7% to 15%

Status

- Through family tree tracing and community awareness raising in rural areas, more suspect cases have been identified and tested, bringing the confirmed cases of haemophilia from 32 in 2024 to a total of 38 for the first half of 2025. This brought the diagnosis rate up from 13% to 16%.
- 2 lab technicians and 2 doctors from Sierra Leone and Liberia joined the Gambia for laboratory training conducted by Dr Samuel Ntambi from Uganda. This training is to prepare the partners to establish sustainable laboratory infrastructure for diagnosis of haemophilia.
- To support the Ministry of Health's strategy to decentralise basic diagnosis,10 lab technicians from 4 regional labs attended a three-day basic diagnosis training in Banjul. The training was led by Dr Salifi Gaye and the multidisciplinary care team from Edward Francis Small Teaching Hospital (EFSTH).
- A safe circumcision awareness session for children with haemophilia was conducted by a multidisciplinary team from Edward Francis Small Teaching Hospital (EFSTH), resulting in safe circumcision of two paediatric haemophilia patients.
- World Haemophilia Day was commemorated with key attendees drawn from healthcare professionals and people with haemophilia. The Ministry of Health was represented by Director of Health Services, with keynote speeches advocating for improved care from the government for people with haemophilia.

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
NNHF contact	cgtz@nnhf.org
Duration	2 years
Start date of activities	Q1 2023

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.

Status

- This project has **benefitted 120 people with haemophilia.**
- The **diagnosis rate increased from 3% to 9%,** showing an increase from 87 people with haemophilia since the beginning of the project in 2023 to now approximately 120 people with haemophilia diagnosed and registered.
    - This was supported through awareness raising activities. A telethon was organised on Guinea's national television channel RTG to raise public awareness about the signs and symptoms of haemophilia, mobilise funds, and issue an urgent call to action to the government for improved care and treatment supply for haemophilia. As a result of this broadcast, new cases of haemophilia were identified in Conakry and within 4 regions.
- **Increased engagement from authorities and hospitals management, securing an infrastructure for integrated care for haemophilia and Sickle Cell Disease for a more improved referral system in the capital city.**
    - This year World Haemophilia Day was commemorated with a week full of awareness and advocacy activities for integrated care for haemophilia and sickle cell disease. A basic training session was held in Conakry on integrated care of haemophilia and sickle cell disease for 25 healthcare professionals. Participants included general doctors, emergency physicians, laboratory technicians, and nurses from the two referral hospitals, Ignace Deen Hospital and Donka Hospital. The training was facilitated by Prof Mamady Diakité and his team over two days. The training will help identify and diagnose new cases of both haemophilia and sickle cell disease and provide quality care.
    - This was followed by a one-day advocacy conference in Conakry, which brought together healthcare professionals from Conakry and 4 regions, the Deputy Director of the Ministry of Health and Public Hygiene in Guinea, other Ministry of Health representatives, the Non-Communicable Diseases Programme Coordinator, and a WHO representative. During the conference, a policy brief

    was presented, outlining current haemophilia data and recommended actions for integrated care for haemophilia and sickle cell disease.

- A series of meetings were held by Association Guinéenne pour la lutte contre l’hémophilie et autres maladies hémorragiques (AGUILHAMH) represented by Prof Mamady Diakité and sickle cell disease stakeholders to coordinate joint activities, and to develop joint strategies. The meetings resulted in the establishment of a national Sickle Cell Disease patient organisation “la Fédération Guinéenne des Personnes Atteintes de la Drépanocytose (FEGUIPAD)” and was officially launched during World Sickle Cell Day. FEGUIPAD and AGUILHAMH will work in close collaboration to raise awareness, advocate for improved access to care, and influence policy for people living with haemophilia and sickle cell disease in Guinea.

Kenya, Tanzania, Uganda and Rwanda joint project: East Africa 2

- Programme title **Expanding access to blood disorders care in Eastern Africa**
- Phase Closing
- Partners
    - 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
    - Uganda
        - Haemophilia Foundation of Uganda (HFU) - Prof Grace Ndeezi and Agnes Kisakye
    - Rwanda

        Rwanda Federation of Hemophilia – Dr Evariste Ntaganda and James Ndahayo
- NNHF contact lymw@nnhf.org
- Duration 2 years, Q3 2023 – Q2 2025
- *This project is supported by a grant from Novo Nordisk Foundation.*

Objectives

- Leverage on the learnings and experiences from all four countries
- Improve access to blood disorders care infrastructure in all four countries by establishing/strengthening 7 centres in 3rd and 2nd level hospitals in Uganda and Rwanda and making basic care available in more than 30 primary care facilities across Kenya and Tanzania
- Increase diagnosis rate by equipping the centres and through awareness raising and screening activities (diagnosing 700 new persons with haemophilia)
- Create or upgrade national blood disorders registries in Uganda and Rwanda
- Empower the national patient organisations
- Build strategic alliances and advocate for improved care

Achievements

Over the implementation period, this project has significantly advanced access to care, advocacy, partnerships and grown the coalition in East Africa. In all four countries, the Ministry of Health has been actively involved in the project activities and inspired more healthcare professionals to engage with haemophilia, sickle cell disease, and allied disorders. Most importantly, all countries have secured governmental commitments, for example, Uganda has committed to purchasing reagents, while Rwanda and Tanzania have officially endorsed treatment guidelines and standard operating procedures, respectively. In Kenya, the project has developed a training curriculum on haemophilia and sickle cell disease at the Kenya Medical Training College (KMTC), the country's largest healthcare training institution, which trains over 84,000 healthcare workers. The enhanced training capacity established by this project increases access to opportunities for healthcare professionals to receive training within Africa, reducing dependence on South Africa. Click here to access the final report and read about the full project achievements.

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 Formalisation
- 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
- NNHF contact lymw@nnhf.org
- Duration 1 years
- Start date of activities 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

- The project was approved during the NNHF Council meeting in May 2025.

Kenya Sickle Cell 1 project

Programme title	**Strengthening capacity and networks in the Sickle Cell Disease community**
Phase	Closing
Partner	Sickle Cell Federation Kenya (SFK) –Ms Emily Gumba, CEO and Prof Constance Tenge, Deputy Chairperson
NNHF contact	lymw@nnhf.org
Duration	1 year, Q2 2024 – Q2 2025

Objectives

- Align Sickle Cell Disease (SCD) patient organisations of Kenya and Tanzania around a common vision and build their governance structures and organisational capacity
- Increase knowledge on care and the referral system among patients, caregivers, and HCPs by 30% in disease-burdened areas of Kenya and Tanzania, as outlined in the respective treatment guidelines.
- Build strategic alliances and advocate for improved affordability and accessibility of SCD treatment

Achievements

- The project has directly **benefitted at least 1,060 people with sickle cell disease**.
- **Aligned SCD patient organisations of Kenya around a common vision and built their governance structures and organisational capacity**
  - Strengthened the national umbrella organisation through capacity development, board and leaders training, and the creation of essential organisational policies (finance, procurement, human resources) to guide the day-to-day operations of the Sickle Cell Federation of Kenya. This has resulted in a stronger patient organisation.
  - Established a federation website and social media presence to enhance visibility.
- **Increased knowledge on care and the referral system among people with sickle cell disease, caregivers, and healthcare professionals in disease-burdened areas of Kenya**, as outlined in the respective treatment guidelines.
  - **Trained 136 healthcare professionals** in Kisii and Busia counties, increasing the level of knowledge and SCD management at the primary care level: 42 nurses, lab technicians, pharmacists, clinical officers and medical officers. 44 Community Health Assistants/Community Health Extension Workers, and 50 Community Health Promoters trained to serve as primary points of contact for patients in their homes and communities.
  - **Developed and implemented data collection tools and protocols** for sickle cell disease, currently distributed at 15 treatment centres nationwide to collect data on those diagnosed with *Hb SS (with sickle cell disease)* and *Hb AS (carriers)* providing a structure in data collection for sickle cell disease in Kenya.
- **Built strategic alliances and advocated for improved affordability and accessibility of SCD treatment**
  - Established relationships with the county governments and other relevant government institutions and departments in the target regions (Kisii, Busia, and

Kilifi counties), facilitating smooth project implementation, raising awareness, and providing education to government officials and hospital representatives.

- **Contributed to sickle cell disease being recognised by the National Social Health Authority/Social Health Insurance Fund**, enabling people with sickle cell disease to access essential medicines and treatments including laboratory tests and pharmacy services. Additionally, an allocation of KES 70,000 (USD 530) has been designated for red cell exchange, covering one session and up to four sessions per year. Although this policy is a positive initial step, it has yet to be fully implemented.
- In collaboration with other NNHF partners in haemophilia from East Africa, the Sickle Cell Federation of Kenya co-organised the first **East Africa Blood Disorders Leadership Forum** which served as learning towards an integrated approach to haemophilia and sickle cell disease. It also provided a platform for people with sickle cell disease, caregivers, healthcare professionals, Ministry of Health, policy makers and other stakeholders to advocate for improved care and to learn from other countries in the region.

Stakeholders in Sickle Cell Disease from East Africa including patients, caregivers, NNHF, and partners from India and the Fondation Pierre Fabre, gather for a group photo after a successful workshop in Nairobi, October 2024.

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
NNHF contact	zagi@nnhf.org
Duration	2 years
Start date of activities	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 WBDR registry
- Advocate for a bleeding disorders policy that will enable increased factor procurement for the newly diagnosed patients

Status

- A pharmacist from Maseru District Hospital underwent a one-week basic training while a laboratory technician underwent a two-week refresher training at the University of the Free State (UFS), Bloemfontein in South Africa, under the lead of Prof Jaco Joubert.
- A social worker underwent a one-week training at the University of Cape Town and is envisioned to support people with haemophilia and their caregivers with psychosocial counselling.
- A dentist and a physiotherapist from Maseru District Hospital underwent a two-week training at the University of Cape Town. With better comprehension of handling people with haemophilia, the two trainees will ensure inclusion of physiotherapy and dental services as part of follow up pathway for people with haemophilia.
- In a bid to build a sustainable diagnostic infrastructure, the partner, including representatives from the National Reference Laboratory, Queen Mamohato Memorial Hospital (QMMH) and Maseru District Hospital, went for a two-day benchmarking exercise at the University of the Free State (UFS), Bloemfontein, South Africa to learn about placement model for coagulation. With learnings from this visit, the partner has advocated to government receiving a nod to pilot the placement model for one year. Approval has been granted by the Ministry of Health to procure four coagulation analysers where one will be placed at the National Reference Laboratory for advanced testing and three of them in the regional hospitals for basic testing.
- A two-day youth patient camp brought together 16 young individuals with haemophilia and healthcare practitioners. During the event, participants developed a strategic plan for the youth wing and established a dedicated committee for media and advocacy. The camp also played a key role in strengthening succession planning within the patient organisation.
- An annual patient camp was held in February with 41 attendees, both people with haemophilia and their caregivers. The camp focused on educating people with

haemophilia on the importance of medical adherence, first aid for emergency bleeds and adherence during clinic follow-ups.

- Through the ongoing awareness raising initiatives, the Lesotho Haemophilia Foundation managed to move the diagnosis rate up from 5.8% to 8% with confirmed haemophilia cases from 13 to now 18 registered people with haemophilia.

The youth wing of Haemophilia Association of Lesotho (HAL) during a 2-day youth patient camp.

Liberia 1 project

Programme title	**Establish basic care in Liberia**
Phase	Execution
Partner	Liberia Hemophilia Program (LHP) – Prince Kwenah and Dr Tabehde Murray
NNHF contact	zagi@nnhf.org
Duration	3 years
Start date of activities	Q1 2023

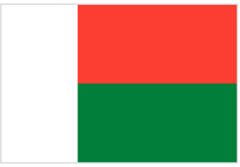
Objectives

- 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

- A one week follow up training for 8 laboratory technicians in Monrovia was conducted by Dr Dinesh Chandra from Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow, India. This training prepared the team to build a sustainable diagnostic setup across the country. Now travel time for diagnosis has reduced by 22 hours (round trip) as previously suspected cases had to travel to Accra, Ghana for diagnosis.
- 2 laboratory technicians and 1 doctor from Liberia joined a laboratory training conducted in Banjul, the Gambia with teams from Sierra Leone, and the Gambia. The training was facilitated by Dr Samuel Ntambi from Uganda to strengthen the team's ability to further build sustainable laboratory infrastructure.
- At the same time, a joint advocacy workshop was held to strengthen the capacity for the partners to further advocate for sustainability of reagent supply.

Madagascar 2 project



Programme title	**Improving access to care and treatment for people with haemophilia in Madagascar**
Phase	Closing
Partner	University Hospital Tambohobe Fianarantosa – Dr Mino Fitahiana Danielle and Prof Aimée Olivat Rakoto Alson
NNHF contact	cgtz@nnhf.org
Duration	2.5 years, Q4 2022 – Q1 2025

Objectives

- Strengthen multidisciplinary care in the capital city Antananarivo
- Bring basic care closer to people with bleeding disorders living outside the capital city
- Improve accessibility of treatment outside the capital city
- Obtain support from health authorities for diagnosis and treatment of bleeding disorders
- Strengthen bleeding disorder's community awareness and knowledge on the condition

Achievements

- This project has **directly benefitted 199 people with haemophilia**.
- **The number of people diagnosed increased by 31% (**from 152 to 199), marking a new diagnosis rate of 7%. This was achieved through:
    - Awareness raising among 317 community health workers in 5 regions of Madagascar about bleeding disorders symptoms. The community health workers were also trained on the importance of proper management during circumcision. This will contribute to the reduction of mortality.
- **Haemophilia care has been enhanced both in the capital Antananarivo and in 3 regions,** making it easier for people with bleeding disorders to access quality care and treatment, **reducing travel time by up to 12 hours** (based on a round trip from Mahajanga to Antananarivo)
    - A 3-day specialised training on point of care for 20 healthcare professionals including haematologists, nurses and physiotherapists from the main referral centre in Antananarivo. Healthcare professionals are now able to provide improved care and diagnosis to people with haemophilia. This training was conducted by the team from Necker Hospital in Paris, France.
    - Purchase of physiotherapy equipment for the referral centre in the capital city Antananarivo and the 3 regional haemophilia treatment centres: Mahajanga, Toamasina and Fianarantsoa, supporting the possibility to improve people with haemophilia's musculoskeletal care.
    - Trainings for 83 healthcare professionals including doctors, nurses, physiotherapists, laboratory technicians, emergency physicians and odontostomatologist from the capital and the regions on haemophilia management and diagnosis.
    - The establishment of treatment distribution and storage protocols, as well as the purchase of refrigerators have strengthened the distribution of donated factor concentrates to the 4 established haemophilia treatment centres in the

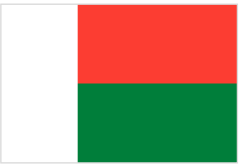
regions of Madagascar, the referral centre in the capital city Antananarivo and the 3 regional haemophilia treatment centres Mahajanga, Toamasina and Fianarantsoa.

- **Successful, regional advocacy uptakes achieved, discharging out-of-pocket payment for musculoskeletal and dental care for the bleeding disorders community**
    - Thanks to the partner's advocacy activities, the haemophilia treatment centre in Fianarantsoa (411km from the capital city) is now providing free musculoskeletal care including ultrasound and x-ray examinations. Free dental care was achieved for people with haemophilia living in Toamasina (347 Km from the capital city). Previously patients had to pay CHF 75 per ultrasound/X-ray examination respectively and up to CHF 20 for regular dental care.
    - Linked to the advocacy initiatives, hospitals in Antananarivo, Mahajanga, Toamasina, and Fianarantsoa equipped with semi-automatic coagulometers now allocate budget for procurement of reagents for haemophilia testing and other bleeding disorders.
    - Advocacy training conducted for an advocacy committee including the Association du Bien-être des Hémophiles en Madagascar and Centre de Traitement de l'Hémophilie Madagascar. National advocacy goals were set to reduce out-of-pocket payments for people with haemophilia and initiate procurement of treatment in Madagascar.
- **Empowered patient community.** This was achieved through educational sessions with 258 people with haemophilia and their families during haemophilia patient camps organised in Antananarivo and 3 regions outside the capital city: Mahajanga, Toamasina and Fianarantsoa. These educational sessions covered topics on therapeutic education, safe circumcision, self-infusion and physiotherapy exercises.

"We are thinking of sending Mario back to school because now we know what his condition is, and we know what we should do to prevent his bleeding and what to do if he does bleed or when his knees swell." Mario's grandmother, Mario, 7 years old, haemophilia B

"Haemophilia care without barriers" was our slogan for this second project. This has enabled us to overcome the barriers of dialect, road, social class and knowledge, so that we can share the care of all Malagasy patients." Andrindrantosoa Rasamoelina, nurse, Centre de Traitement de L'Hémophilie Madagascar

Madagascar 3 project



Programme title	**Expanding access to blood disorders care in Madagascar and initiate a regional collaboration with the Indian Ocean Islands**
Phase	Formalisation
Partner	Antananarivo Faculty of Medecine– Dr Mino Fitahiana Danielle and Prof Aimée Olivat Rakoto Alson
NNHF contact	cgtz@nnhf.org
Duration	3 years
Start date of activities	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

- The project was approved during the NNHF Council meeting in May 2025.

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
NNHF contact	cgtz@nnhf.org
Duration	3 years
Start date of activities	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 decentralization 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

- A multidisciplinary team from Hôpital du Mali developed a blood sample transferring protocol between health district hospitals and diagnosis centres to facilitate timely and secure transport of blood samples, improve diagnostic and enhance access to care for people with haemophilia.
- Advancement of decentralisation of haemophilia care through capacity building of healthcare professionals and hospitals management and equipment support in the region of Segou:
  - A semi-automated coagulometer was donated to the Segou hospital, enabling basic diagnosis closer to people with haemophilia in Segou, Sikasso Bla, and San.
  - The donation of the coagulometer was followed by a two-day training session for 6 lab technicians from Segou, Sikasso Bla and San hospitals in Segou held by Prof Yacouba Diallo and his team, ensuring quality diagnosis for haemophilia and other bleeding disorders through basic haemostasis testing, reducing mortality, identifying and registering at-risk patients and their families, and ensuring early treatment of disease and treatment-related complications.
- A one-day mid-term review meeting was held by the partners in Bamako to monitor and evaluate haemophilia care activities nationwide with the head physician, the haemophilia focal point and the laboratory manager from the 20 regions. This review resulted in an elaboration of a policy brief which was presented to the Non-Communicable Diseases programme and the health committee of the parliament on World Haemophilia Day on 17th April 2025.
- This year's World Haemophilia Day featured a roundtable discussion where the Association Malienne de Lutte contre l'Hémophilie (AMALHEC), represented by President Daouda Mallé and Prof Yacouba Diallo, advocated for improved haemophilia care with the Ministry of Health. The Secretary General and other prominent health sector figures

attended. A press conference followed at the Hospital of Mali, with local media and healthcare professionals present.
- Physiotherapy equipment was procured for the regional hospitals of Mopti and Sikasso.

Prof Diallo Yacouba demonstrating the use of physiotherapy equipment, April 2025.

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
NNHF contact	zagi@nnhf.org
Duration	3 years
Start date of activities	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

- A haemophilia physiotherapy workshop session was held in June 2025 with a multidisciplinary team including 1 clinical haematologist, 1 director of laboratory services, 6 physiotherapists and 5 nursing officers from the five regional hospitals to strengthen collaboration in musculoskeletal health for people with haemophilia. The key outcomes included agreement on standardising joint assessments using scoring tools and integrating physiotherapy into routine care. A clinical haematologist provided valuable insights into the current challenges and opportunities in haemophilia management with a focus on musculoskeletal health.
- This year’s World Haemophilia Day was marked by the commissioning of a coagulometer machine to support the diagnosis of von Willebrand Disease (vWD), with a particular emphasis on identifying women and girls with bleeding disorders. During the event, the government pledged to ensure a sustainable supply of reagents, thereby securing continuity in diagnostic services. The event was attended by 60 participants including healthcare professionals, government officials, and 15 women and girls with bleeding disorders.
- A 1-day educational workshop was held in June 2025 at the Victoria Hospital, bringing together a multidisciplinary team from five regional hospitals, people with haemophilia, parents and caregivers. Participants included 4 physicians, 3 paediatricians, 6 nursing officers, 4 physiotherapists, 1 director of laboratory services, and 1 nutritionist, alongside 15 people with haemophilia and their caregivers. The workshop strengthened enhanced clinical understanding of haemophilia care and fostered direct engagement between healthcare providers and affected families, reinforcing patient-centred approaches and improving alignment on care pathways.

A 1-day educational workshop held in June 2025 at the Victoria Hospital, bringing together a multidisciplinary team from five regional hospitals, people with haemophilia, and caregivers.

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
NNHF contact	lymw@nnhf.org
Duration	3 years
Start date of activities	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

- Upgraded coagulation and haemostasis laboratories in 5 major teaching hospitals, University of Benin Teaching Hospital (UBTH), University of Nigeria Teaching Hospital (UNTH), Ituku-Ozalla, Enugu State, University College Hospital (UCH), Ibadan, Federal Teaching Hospital, Gombe, and the National Hospital, Abuja, significantly enhancing diagnostic capabilities, elevating standards of care and reducing travel time by an average of 5 hours (round trip) for people with haemophilia.
- 14 laboratory technicians and medical personnel from 7 centres (University of Benin Teaching Hospital (UBTH), University of Nigeria Teaching Hospital (UNTH), Ituku-Ozalla, Enugu State, University College Hospital (UCH), Ibadan, Federal Teaching Hospital, Gombe, Lagos University Teaching Hospital, Kano State University Teaching Hospital, National Hospital, Abuja) received advanced training.
- National awareness campaigns conducted during World Haemophilia Day at the 7 national haemophilia training centres led to the identification of 47 new people with haemophilia.
- 5 targeted health talks on bleeding disorders were delivered in antenatal clinics, resulting in increased awareness and enhanced early detection among mothers and care providers.
- Ongoing training for healthcare professionals and people with haemophilia on prophylactic treatment, self-infusion, and home-based therapy, empowering people with haemophilia to manage their disease independently and more confidently.
- Completed cryoprecipitate production training at Lagos University Teaching Hospital (LUTH) and Kano State University Teaching Hospital (AKTH), with five additional centres scheduled for training next semester, increasing the capacity for access to blood products at the hospital level.
- Established multidisciplinary teams in all participating hospitals, enhancing collaborative and coordinated care, though some teams remain incomplete due to healthcare provider turnover.

- Instituted regular multidisciplinary team meetings, resulting in improved communication and better management of care for people with haemophilia.
- Delivered comprehensive training of trainers' workshops for key multidisciplinary team members across all seven treatment centres, ensuring the sustainability of high-quality care.

Group photo of physiotherapists and other healthcare professionals taken at the conclusion of a training session on physiotherapy in Abuja, Nigeria.

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
NNHF contact	cgtz@nnhf.org
Duration	2 years
Start date of activities	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, firefighters, 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.

Group photo of NNHF partners patient organisations and healthcare professionals from Mali, Benin, Guinea, Côte d'Ivoire and Senegal at the National Bood Transfusion Centre in Dakar, Senegal.

Sierra Leone 2 project

Programme title	**Enhancing diagnosis and expanding haemophilia care from Freetown to regions**
Phase	Formalisation
Partner	Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) – Harry Mayeah Koroma and Dr Mavolo Toure
NNHF contact	zagi@nnhf.org
Duration	2 years
Start date of activities	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 strategy for Sierra Leone

Status

- The project was approved during the NNHF Council meeting in May 2025.

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
NNHF contact	zagi@nnhf.org
Duration	3 years
Start date of activities	Q2 2022

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

Status

- The partner continued with training on the utilisation of point-of-care ultrasound (POCUS) for patient joint assessment aiming to improve the overall musculoskeletal health for people with haemophilia. The awareness was conducted in three regional hospitals where fifteen physiotherapists were trained.
- The Medical and Scientific Advisory Council (MASAC) team finalised updating the treatment guidelines as well as the Standard of Care Document and begun disseminating them to the various provinces to ensure standardised care for people with haemophilia.
- The patient organisation conducted a targeted awareness raising outreach, reaching over 30 women and girls with bleeding disorders. Through the outreach, the women and girl were educated on self-care to enhance their overall health and quality of life.
- To continue strengthening the partner, a strategic planning meeting was held in February 2025 culminating to develop a strategic plan guiding their activities for the next five years.
- The partner engaged four nurses who conducted regular monitoring of haemophilia services in the provinces, organised regular outreaches for family tree tracing and nurse trainings.
- The diagnosis rate increased from 41% to 57%, showing an increase from 2,354 since the beginning of the project in 2022 to now approximately 3,200 people with haemophilia diagnosed and registered.

Mr Clerment Sefojane, Chairperson of the South African Haemophilia Foundation (SAHF), demonstrating how to do self-infusion to members of the patient community during a self-infusion workshop held in Cape Town, South Africa, in July 2025.

Tanzania Sickle Cell 1 project

- Programme title **Strengthening capacity and networks in the Sickle Cell Disease community**
- Phase Closing
- Partner Tanzania Sickle Cell Disease Alliance (TSDA) – Dr Elisha Osati, Chairman and Dr Deogratias Soka, CEO
- NNHF contact lymw@nnhf.org
- Duration 1 year
- Start date of activities Q2 2024

Objectives

- Align Sickle Cell Disease (SCD) patient organisations of Tanzania around a common vision and build their governance structures and organisational capacity.
- Increase knowledge on care and the referral system among patients, caregivers, and HCPs by 30% in disease-burdened areas of Tanzania, as outlined in the respective treatment guidelines.
- Build strategic alliances and advocate for improved affordability and accessibility of SCD treatment.

Achievements

- The project has directly **benefitted at least 1,232 people with sickle cell disease**.
- **Aligned SCD patient organisations of Tanzania around a common vision and built their governance structures and organisational capacity**
    - Unified various sickle cell disease patient networks, resulting in the establishment of the Network of Sickle Cell Warriors in Tanzania (NeSWO), complementing the Tanzania Sickle Cell Disease Alliance as a patient support group.
    - Developed and implemented organisational policies, including those for human resources, procurement, finances, and monitoring and evaluation, to enhance capacity and efficiency of the Tanzania Sickle Cell Disease Alliance to lead as the umbrella body for sickle cell disease in Tanzania.
- **Increased knowledge on care and the referral system among people with sickle cell, caregivers, and healthcare professionals in disease-burdened areas of Tanzania.**
    - Training of healthcare professionals has been done in a newly dedicated sickle cell disease clinic which was established for the purpose of piloting point-of-care screening in Kilosa District. Training has been completed for a multidisciplinary team including nurses, doctors, pharmacists, therapists, and laboratory technicians. The clinic actively serves both paediatric and adult sickle cell disease patients.
    - Conducted awareness and screening campaigns for sickle cell disease in Tabora and Dodoma, **reaching over 2,030 people with sickle cell disease** and care givers and **diagnosing 133 new sickle cell disease patients** out of 1,126 screened**.**
    - **Established a national network of healthcare professionals specialising in sickle cell disease care**. A team of haematologists from Muhimbili National Hospital, including Dr Mbonea Yonazi, Dr Elisha Osati and Dr Deogratius Soka, mentored over 100 healthcare professionals through an online mentorship

    programme. The mentorship sessions aimed to enhance the knowledge of healthcare professionals, covering aspects such as diagnosis, management, and referral procedures for people with sickle cell disease.
    - Developed a national training curriculum for in-service training on sickle cell disease. The curriculum has now been adopted by other stakeholders working in sickle cell disease and conducting training of healthcare professionals across Tanzania.
    - **300% increased clinic attendance** in Rorya District Hospital, **rising from 20% to 80% of registered patients** (from 150 to 600 people with sickle cell disease). This improvement has helped reduce the risk **of developing complications associated with irregular consultations.** Carried out educational sessions in Rorya District Hospital for people with sickle cell disease and care givers on importance of adherence to treatment and good management of sickle cell disease.
- **Built strategic alliances and advocated for improved affordability and accessibility of SCD treatment**
    - Secured endorsement from the Ministry of Health for youth sickle cell disease screening programmes in schools and universities where some of the subsequent awareness and screening activities by the Tanzania Sickle Cell Disease Alliance will take place.
    - Advocated for the inclusion of sickle cell disease screening kits in the budgets of the Medical Stores Department (MSD) through the Ministry of Health. Whilst the Tanzania Sickle Cell Disease Alliance has had audience with MSD, this request is yet to be implemented.
    - The Tanzania Sickle Cell Disease Alliance and other coalition members from Tanzania were equally involved in the East Africa Blood Disorders Leadership Forum.

Healthcare professionals at Kilosa District Hospital in Morogoro, Tanzania, pose for a picture at the end of a training session on sickle cell disease management.

Togo 1 project

Programme title	**Expanding haemophilia diagnosis in Togo**
Phase	Closing
Partner	Institut National d'Hygiene - Dr Yao Layibo
NNHF contact	cgtz@nnhf.org
Duration	3 years, Q3 2022 – Q3 2025

Objectives

- Improve haemophilia screening and diagnosis in Togo, reaching 9% by 2024
- Increase the capability of more than 100 healthcare professionals in the management of haemophilia
- Increase general awareness on the condition amongst people with haemophilia and families
- Advocate for better haemophilia care and treatment in Togo

Achievements

- This project has directly benefitted **49 people with haemophilia.**
- Awareness raising activities have **increased the number of people diagnosed by 122%** from 22 to 49 people with haemophilia, successfully achieving their target of reaching a 6% diagnosis rate.
    - Outreach sessions carried out during this project to increase awareness on haemophilia in the capital and in the regions allowed the identification of 27 new people with haemophilia.
    - As haemophilia care was almost non-existent in Togo, awareness raising trainings among healthcare professionals in the capital city and outside the capital have made it possible to increase knowledge on haemophilia of 109 healthcare professionals. The trainings were conducted in five regions by Dr Yao Layibo and Dr Womey (Maritime, Plateaux, Kara, Savanes and the Central region) for doctors, lab technicians and nurses on diagnosis and basic treatment of haemophilia.
- A national operational protocol on the management of haemophilia was developed, awaiting endorsement from the Ministry of Health and dissemination to healthcare professionals.
- A key aim of the project was to expand and strengthen the medical team in Togo. One haematologist, Dr Womey and one paediatrician, Dr Hemou from the Campus Hospital Centre in Lome, the capital city, were trained at the National Blood Transfusion Centre (CNTS) in Dakar, Senegal for one month. After completing the training in Dakar, Dr Womey actively engaged in awareness raising initiatives for both healthcare professionals and the public in the Kara region (northern Togo). Additionally, Dr Womey contributed to the development of the national protocol of haemophilia management in Togo. Meanwhile, Dr Hemou has been leveraging the in-depth training, providing quality care to children with haemophilia at the main referral hospital in Lomé.

Training of laboratory technicians in Atakpamé, 17 December 2024.

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
NNHF contact	lymw@nnhf.org
Duration	3 years
Start date of activities	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

- National stakeholders, including the Parliamentary Health Committee, were brought together for World Haemophilia Day media engagement, raising policy awareness for women and girls with bleeding disorders.
- Advocacy efforts resulted in deeper engagement and policy dialogue with government and health sector leaders, marking a significant milestone for bleeding disorder care in Zambia. A commitment was secured from the Parliamentary Health Committee to receive formal submissions to improve diagnosis and expand National Health Insurance coverage for bleeding disorders.
- Hosted a patient education camp in Lusaka, empowering people with haemophilia and caregivers with self-care skills and peer mentorship opportunities.
- Healthcare providers (clinical officers, doctors, nurses and physiotherapists) from 15 district and 2 mission hospitals in Southern Province were trained on the diagnosis and management of haemophilia and sickle cell disease.
- Increased national awareness activities through radio, leading to identification of new people with bleeding disorders. Community Health Assistants helped identify 8 new people with haemophilia in Western Zambia and Luapula Provinces through local outreach. In Mansa, 3 people with haemophilia were identified, including a 15-year-old who gained access to treatment after years of unmanaged condition.
- Focused education on self-infusion of clotting factors, musculoskeletal care, and joint protection to improve independence of people with haemophilia and long-term outcomes.
- Facilitated peer mentoring, with experienced patients guiding younger ones during treatment, fostering empowerment and community support.
- Advocacy efforts resulted in deeper engagement and policy dialogue with government and health sector leaders, marking a significant milestone for bleeding disorder care in Zambia.

Victor Amukena, who has haemophilia A, demonstrates self-infusion techniques to fellow patients and healthcare professionals in Choma, Zambia.

Americas

Legend:

- Projects active in H1 2025
- Projects completed in H1 2025

Bolivia 2 project

Programme title	**Developing multidisciplinary care in Bolivia**
Phase	Execution
Partner	Asociación Cochabambina de Hemofilia - Mr José Luis Quino and Dr Suzana Loayza
NNHF contact	eiel@nnhf.org
Duration	3.5 years
Start date of activities	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

- Awareness raising activities were held on World Haemophilia Day, attended by provincial authorities to inform the public about upcoming diagnosis days.
- The multidisciplinary team from Hospital Manuel Ascencio Villarroel, comprised of members trained abroad, developed comprehensive manual addressing various aspects of haemophilia management, including dentistry, laboratory practices, nursing physiotherapy and psychology. This manual is designed for individuals with haemophilia, as well as their families and caregivers, to ensure informed care and support. It has been distributed to multiple hospitals across the region to enhance the quality of care for people with haemophilia.

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
NNHF contact	eiel@nnhf.org
Duration	2.5 years
Start date of activities	Q3 2025

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 was approved during the NNHF Council meeting in May 2025.

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 represented by Dr Donato Milla, haematologist
NNHF contact	eiel@nnhf.org
Duration	2.5 years
Start date of activities	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

- Project Partnership Agreement was signed, and project activities will start in August 2025.

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
NNHF contact	eiel@nnhf.org
Duration	2.5 years
Start date of activities	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

- The first national haemophilia registry has been established, using a model similar to that of Honduras. The registry will be enrolled nationally in the second half of 2025.
- Two orthopaedic surgeons from Guatemala City, one affiliated with San Juan de Dios Hospital and the other with Roosevelt Hospital, received five days of specialised training at Policlinico in Milan, Italy under the supervision of Dr Luigi Solimeno.
- Five physiotherapists from Guatemala City, representing San Juan de Dios Hospital, Roosevelt Hospital, and IGSS Hospital, underwent two weeks of specialised training in Panama City under the guidance of Deivis Pitty.
- Wheelchairs and crutches were procured and distributed among several hospitals in Guatemala.

Orthopaedic surgeons being trained in Milan, Italy under the supervision of Dr Luigi Solimeno.

Honduras 2 project

Programme title	**Healthy joints for people with haemophilia in Honduras**
Phase	Closing
Partner	Sociedad Hondureña de Hemofilia - Mr José Padilla and Dr Armando Peña, haematologist at Hospital Escuela Universitario
NNHF contact	eiel@nnhf.org
Duration	3 years, Q2 2022 – Q1 2025

Objectives

- Establish access to rehabilitation to people with haemophilia in Honduras
- Expand the registry database of people with bleeding disorders in Honduras
- Increase medical interest in haemophilia and identify new haematology leaders
- Foster physical activity of people with haemophilia

Achievements

- This project has directly **benefitted 392 people with haemophilia**.
- The improvement of physiotherapy care and patient education on the importance of exercise has led to **positive health outcomes** as shown by a musculoskeletal care survey done in 2025 with 44 people with haemophilia, constituting 11% of the patient population:

  - **100%** of patients reported an **improvement in their quality** of life since 2022
  - **77%** noted **improvements in their ability to carry out daily activities**, such as getting dressed, walking or climbing stairs
  - **75%** are **adhering to the recommendations** provided by their physiotherapist
  - **68%** have **increased the frequency of their physical activities**, ranging from daily to weekly

  This was achieved through:

  - The purchase of equipment and the training of 2 physiotherapists abroad for 2 weeks in Monterrey, Mexico with Dr Laura Villareal and her team.
  - **Creation of a physiotherapy care network thanks to the partnership with Teletón Honduras**, a non-profit organisation supporting people with disabilities which has a total of 6 rehabilitation centres across the country, free to people in need. This collaboration began with the training of a physiotherapist from Teletón abroad, who then cascaded the training to other healthcare professionals from these centres, thus granting better geographical access to people with haemophilia nationwide.
- **New generation of haematologists is now available for haemophilia care** after the training of 2 haematologists from the Hospital Escuela for 1 month in Buenos Aires, Argentina under the supervision of Dr Daniela Neme. Additionally, the project partners

raised the interest of medical students about bleeding disorders through 2 training sessions reaching more than 178 participants.

- **National data and accurate data collection in place** through the implementation of a national registry. The project team is **currently providing support to the Guatemalan haematologists** as part of the NNHF Guatemala 2 project to develop and implement the first national registry based on their format and experience.

Rehabilitation specialist Dr Ricardo Bulnes demonstrating exercises to a patient.

Joint evaluations at Hospital Escuela in Tegucigalpa.

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
NNHF contact	eiel@nnhf.org
Duration	3 years
Start date of activities	Q3 2022

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

- The Standard Operating Procedures (SOPs) for laboratory diagnosis at the referral laboratory at UHWI have been thoroughly reviewed and updated in collaboration with the team from St. Michael's Hospital in Toronto.
- Comprehensive guidelines for haemophilia care and diagnosis are currently being developed and will be finalised by end of 2025 and to be approved by the Ministry of Health.
- Emergency room training sessions were successfully held at hospitals in St Ann's Bay attended by 17 healthcare professionals. Pre- and post-training surveys indicated significant improvements in knowledge.
- A patient training camp was organised for 23 individuals with haemophilia, covering essential topics such as dental care, safe physical activity, and the psychological issues related to stigmatisation. Attendees received cards detailing their diagnoses and outlining the necessary product doses in case of bleeds, to facilitate their care when visiting hospitals and health centres.
- The lead physiotherapist from UHWI has created a training plan to address the needs of different regions across the island. The training will take place in the second half of 2025.

Mexico 8, San Luis Potosí project

Programme title	**Establishing haemophilia multidisciplinary care in San Luis Potosí**
Phase	Execution
Partner	Hospital Central Dr Ignacio Morones Prieto - Dr Lourdes Cecilia Correa González
NNHF contact	eiel@nnhf.org
Duration	3 years, Q1 2022 – Q1 2025

Objectives

- Establish a haemophilia multidisciplinary care team at the Dr Ignacio Morones Prieto Hospital
- Establish diagnosis at the Dr Ignacio Morones Prieto Hospital in San Luis Potosí
- Develop physiotherapy care for people with haemophilia
- Promote the need of multidisciplinary care teams for haemophilia in the country
- Empower people with haemophilia and family members on self-infusion

Achievements

- This project has **benefitted 153 people with bleeding disorders.**
- **Time to receive advanced care and diagnosis has decreased by 10 hours** (based on a round-trip from Mexico City to San Luis Potosí) thanks to:
  - The strengthening of diagnosis capabilities which involved the training of 8 laboratory technicians from Hospital Morones Prieto, facilitated by the international expert Marión Echenagucia from Venezuela. A follow-up training further consolidated knowledge and skills with the help of experts from the state of Toluca. As a result, factor and inhibitor testing is now available in the state of San Luis Potosí. **Since this, 15 new people with haemophilia have been identified, surpassing the initial goal of identifying 10.**
  - The multidisciplinary team at Dr Ignacio Morones Prieto Hospital underwent comprehensive training to strengthen their expertise. This included a specialised 2-week training programme for a physiotherapist in Panama and a follow-up training in Mexico City under the supervision of Dr Jhovany Belmont and Dr Aidee Gibraltar. Moreover, 4-day training sessions were organised for 4 psychologists conducted by Mr Ezequiel Martínez (psychologist from Mexico City) and a 4-day training for the paediatric haematologist Hospital Universitario de Nuevo León in Monterrey.
  - Complemented by the trainings, the physiotherapy area at Dr Ignacio Morones Prieto Hospital was improved through the acquisition of equipment.
- **Increased support from government authorities and hospital management, including the securing of regular reagents and an increased treatment supply** ○ The project activities have generated an increase in awareness and interest in haemophilia among government authorities and hospital management. As a result, the management at Dr Ignacio Morones Prieto Hospital has committed to and **is procuring the necessary reagents**. Additionally, the partner has reported a noticeable increase in treatment supply in the province of San Luis Potosí.
- **Enhanced self-infusion proficiency has led to a reduction in the frequency of hospital visits** ○ As a result of ongoing self-infusion training initiatives, 14 out of the 34

people with haemophilia at Dr Ignacio Morones Prieto are now fully capable of self-infusion, compared to only 1 person at the beginning of the project. Consequently, this has led to a reduction in the frequency of hospital visits for these patients. The remaining patients will be trained to empower them to also be proficient in self-infusion.

- **Improved medical network fostering better collaboration among healthcare professionals, ultimately leading to standardised care across the province** ○ After a national conference on multidisciplinary care, project partner Dr Cecilia Correa highlighted: "***This conference has facilitated the expansion of our network and fostered knowledge-sharing among healthcare professionals, contributing to enhanced collaboration***." In total 84 participants attended the event, exceeding the initial goal of engaging 50 healthcare professionals.


Trained physiatrist Dr Torres Verdes in action.


Lab training facilitated by expert Marion Enchenagucia from Venezuela.

Panama 3 project

Programme title	**Strengthen multidisciplinary care teams and paediatric-adult care transition**
Phase	Execution
Partner	Fundación Panameña de Hemofilia - Ms Luz Villalaz and Ms Alaisa de Melgar
NNHF contact	eiel@nnhf.org
Duration	3 years
Start date of activities	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 increase from 29% to 50% the diagnosis rate 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

- An orthopaedic surgeon from Hospital Santo Tomás received a five-day training at the Policlinico of Milan, Italy, under the supervision of Dr Luigi Solimeno together with two peers from Guatemala City.
- Host institutions in Mexico and Argentina have been identified for the upcoming training of a physiotherapist and radiologist from Hospital Santo Tomás, scheduled for September 2025.
- Several coordination meetings were held with the multidisciplinary team at Hospital Santo Tomás to foster commitment and collaboration to achieve a smooth transition from paediatric to adult care.
- A refrigerator and voltage regulator were purchased for a satellite clinic in Colón to ensure closer access to treatment.
- A three-day educational camp was organised for 62 children and adults with haemophilia and their families, involving ten healthcare professionals from various disciplines. The camp focused on self-management and the importance of exercise and physiotherapy.
- The patient organisation for sickle cell disease, Fundación Infantil de Anemia Falciforme (FIAF), organised three seminars to raise awareness of the disease, targeting 73 nurses from the Hospital del Niño and 24 other healthcare professionals, 11 teachers and 50 people with sickle cell disease and their families.

Children with haemophilia during the three-day educational camp.

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
NNHF contact	eiel@nnhf.org
Duration	3 years
Start date of activities	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

- Two containers were acquired to set up a rehabilitation area for people with haemophilia at Hospital Luque and Hospital Barrio Obrero.
- A four-day coagulation training session was conducted for 16 laboratory technicians from Hospital San Pablo Materno Infantil, Laboratorio Central de Salud, Hospital IPSS, Hospital Luque and Hospital Barrio Obrero, facilitated by expert volunteer Dr Maria Sol from Salta, Argentina. A follow-up training is scheduled in September 2025 coupled with diagnosis days to increase the national diagnosis rate.

Training of laboratory technicians with Dr Maria Sol from Salta, Argentina.

Peru 4 project

Programme title	**Leaders for institutional progress**
Phase	Execution
Partner	Asociación Peruana de la Hemofilia (ASPEH) - Mr Guillermo Pareja and Dr Gloria Chumpitaz
NNHF contact	eiel@nnhf.org
Duration	3.5 years
Start date of activities	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 families

Status

- The patient organisation successfully conducted four self-infusion training sessions in Arequipa, Trujillo, Chiclayo and Piura benefiting a total of 57 people with haemophilia and their families. Building on this, the patient organisation plans to expand these workshops to additional regions in the upcoming semester.

Peru 5 project

Programme title	**Standardise haemophilia care and diagnosis across the regions of Peru**
Phase	Formalisation
Partner	Sociedad Peruana de Hematologia - Dr Adriana Bustinza and Dr Enrique Argumanis
NNHF contact	eiel@nnhf.org
Duration	3 years
Start date of activities	Q3 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 project was approved during the NNHF Council meeting in May 2025.

Venezuela donation

Programme title	**Enhancing musculosceletal care and patient empowerment in the regions of Venezuela**
Phase	Execution
Partner	undación de Apoyo a la Asociación Venezolana para la Hemofilia (FAAVH) - Luis Enrique Rojas Marquez, President
NNHF contact	eiel@nnhf.org
Duration	2 years
Start date of activities	Q1 2025

Objectives

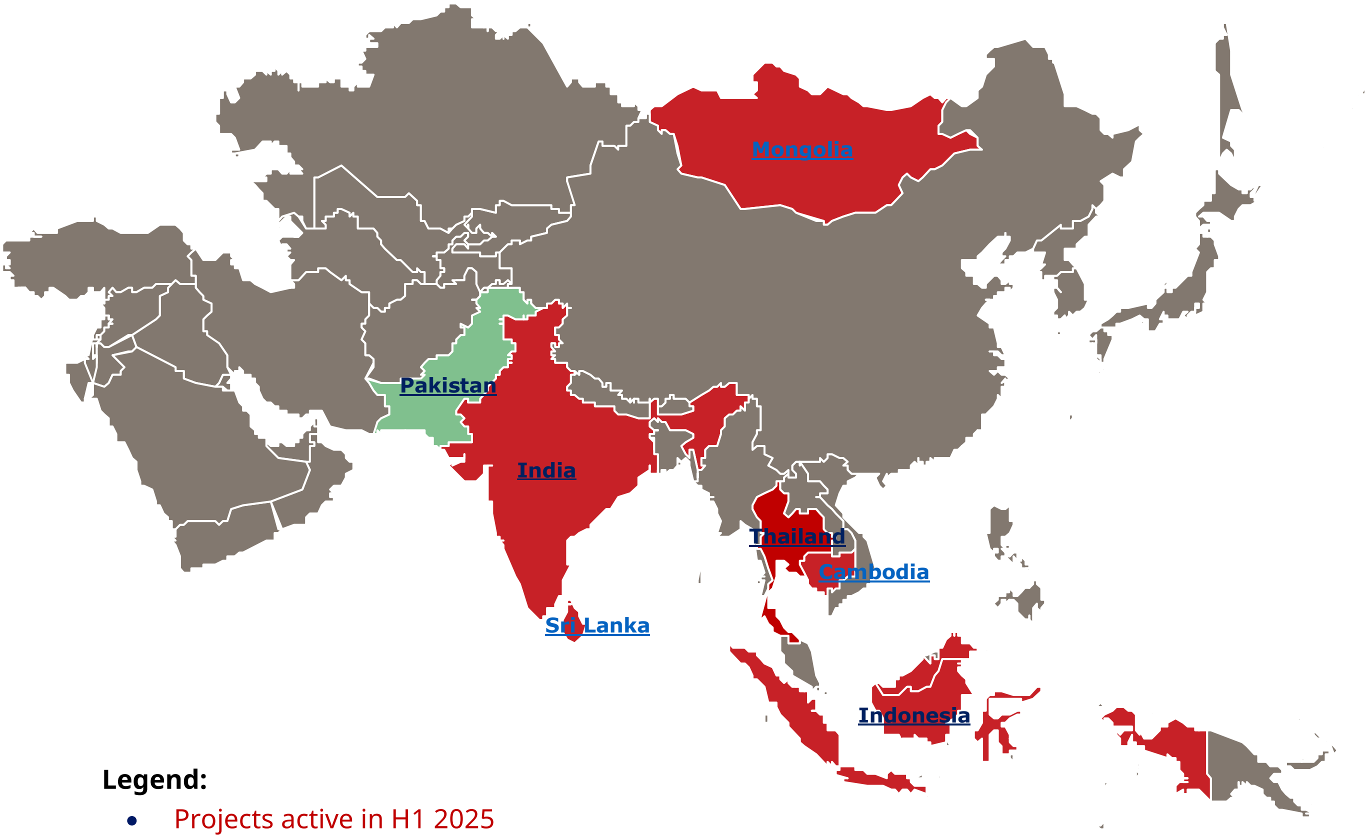
- Improve MSK care and physiatry in 12 states of the country and education for patients
- Procure wheelchairs and crutches for the haemophilia community

Status

- The project team focused their efforts on the north-eastern region of Venezuela, specifically in the state of Anzoátegui.
- Dr Laura Aponte led a two-day training session for two traumatologists and one physiotherapist, who will perform post-evaluation assessments for people with haemophilia in their state.
- Musculoskeletal evaluations were conducted for 17 people with haemophilia.
- Additionally, 34 people with haemophilia received training on the importance of physiotherapy and exercise.
- As part of the fundraising initiative, the referral hospital in Anzoátegui acquired three wheelchairs and three crutches, which will be available for loan to individuals with haemophilia in need.

Joint evaluation of people with haemophilia in the state of Anzoátegui.

Asia



Legend:

- Projects active in H1 2025
- Projects completed in H1 2025

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
NNHF contact	xfov@nnhf.org
Duration	2.5 years
Start date of activities	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 haematologist and a nurse from Calmette Hospital participated in a one-month specialised training programme at Royal Free Hospital in London, under the supervision of Dr Thynn Thynn Yee. This is part of the objective to establish haemophilia care for adults in Phnom Penh.
- To further empower Cambodia Haemophilia Association (CHA), a dialogue was initiated with the Thai Haemophilia Patient Club. The aim is to strengthen the leadership of CHA and support them in their advocacy efforts towards health authorities.

Dr Nou Bona, haematologist, and Lim Leakena, nurse, from Calmette Hospital together with Dr Thynn Thynn Yee during their training in London, UK.

India 14 project

Programme title	**Accelerate access to diagnosis and care in India**
Phase	Execution
Partner	Hemophilia Federation India – Mr Prem Roop Alva, President and National Institute of Immunohaematology, Mumbai, represented by Dr Bipin Kulkarni
NNHF contact	smqy@nnhf.org
Duration	2 years
Start date of activities	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

- Strategy workshop on integrated care solutions for haemophilia and haemoglobinopathies organised with key healthcare professionals, health officials and patient organisation representatives from Assam and Rajasthan.
- Equipment procured to establish/strengthen haemophilia care infrastructure in 7 centres as well as the integrated care setup for haemophilia and haemoglobinopathies in 3 centres. The grouped procurement of both laboratory and physiotherapy equipment across states ensured a discount of more than 10% from the vendors.
- To strengthen the patient organisation, two youth leadership workshops were carried out in the Western and Northern region of India. 64 second-line leaders were part of the workshops, ensuring through succession planning of the future leadership of both the board of Hemophilia Federation India and its chapters.
- A Psychosocial Committee was formed, followed by a 2-day roundtable meeting. Diverse stakeholders including people with haemophilia, parents, doctors, nurses and physiotherapists participated in the roundtable. The sessions focused on identifying psychosocial challenges faced by youth, women, and people with haemophilia at different life stages. Based on this, tailored education modules and tools will be developed.
- Advocacy is still a key focus, accelerating access to bleeding disorders care in India. Additionally, Hemophilia Federation India, for the first time, had a seat in the Health Assessment technology meeting of ICMR, New Delhi, focusing on opportunities and challenges with a newly developed registry for blood disorders.

Strategy workshop on integrated care solutions for haemophilia and haemoglobinopathies with key stakeholders from Assam and Rajasthan.

Indonesia 3 project

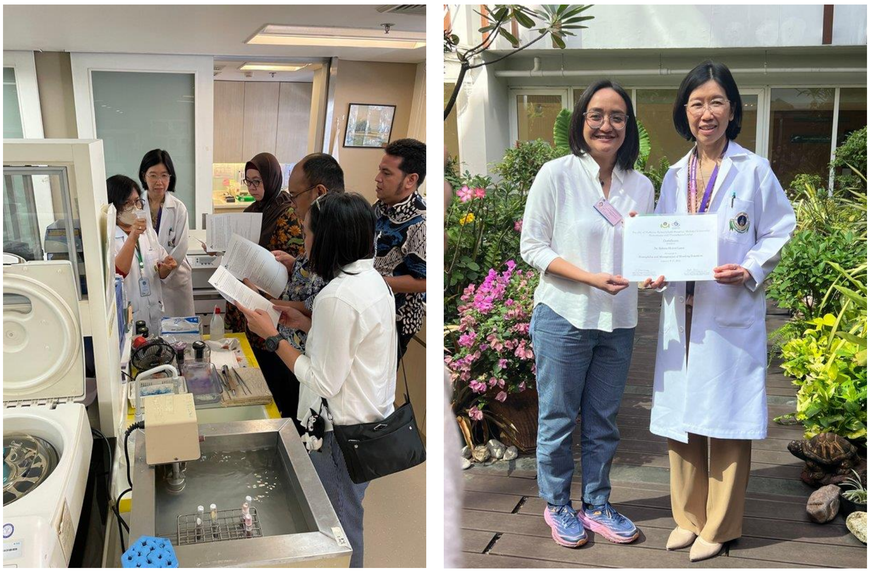
- Programme title — **Decentralise basic haemophilia care and diagnosis to 4 regions in Indonesia**
- Phase — Execution
- Partner — Indonesian Society of Hematology and Blood Transfusion – Dr Novie Amelia Chozie
- NNHF contact — xfov@nnhf.org
- Duration — 2 years
- Start date of activities — Q3 2023

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

- Beginning of 2025, a two-week specialised training programme was held at Ramathibodi Hospital in Bangkok, Thailand for 4 paeditricians from each of the four provinces. The training covered key aspects of haemophilia care, aiming to strengthen clinical expertise and improve patient outcome.
- An outreach visit to Padang, West Sumatera was executed to raise awareness and train healthcare professionals and government representatives about haemophilia care and diagnosis.
- Educational sessions were organised for people with haemophilia and their family and covered topics on self-infusion and physical rehabilitation, using the Haemophilia Joint Health Score (HJHS) and musculoskeletal ultrasonography.
- In Jakarta, an education workshop saw the attendance of 74 people with haemophilia and their parents, covering topics such as prophylaxis vs on-demand therapy, home treatment, data registry, and self-infusion techniques.



Specialised haematology training at Ramathibodi Hospital, Bangkok under the supervision of Prof Nongnuch Sirachainan and her team.

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
NNHF contact	xfov@nnhf.org
Duration	2.5 years
Start date of activities	Q4 2024

Objectives

- Establish advanced haemophilia and thalassemia 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

- Celebration of World Haemophilia Day 2025 across East Java, raising awareness amongst healthcare professionals and the general public.
- Preparation has started for the specialised training abroad for the multidisciplinary care team from Airlangga University.

World Haemophilia Day 2025 celebration and awareness creation across East Java.

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
NNHF contact	xfov@nnhf.org
Duration	2.5 years
Start date of activities	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 will be sent for specialised training abroad. The team identified suitable candidates in the fields of paediatric care, physiotherapy and laboratory. A candidate for dentistry care and a suitable training institution are yet to be determined.
- The national treatment guidelines are currently being reviewed and updated, making sure it is in alignment with the recommendations from the World Federation of Haemophilia (WFH) and the International Society on Thrombosis and Haemostasis (ISTH). The revised version will be finalised in August and ready for distribution and implementation.
- To enhance diagnostic quality, the team is revising the current referral system while also exploring the procurement of laboratory equipment.
- The patient organisation has identified key focus areas to strengthen its capacity including governance structure and strategic planning.

Pakistan 7 project

Programme title	**Enhancing community outreach initiatives through awareness creation and improving access to care**
Phase	Closing
Partner	Hemophilia Foundation – Pakistan (HFP) - Mr Masood Fareed Malik
NNHF contact	xfov@nnhf.org
Duration	3.5 years, Q4 2021 – Q2 2025

Objectives

- Empower HFP and its youth and women's groups to run the organisation sustainably
- Increase awareness about haemophilia on a national level through strategic media engagement
- Establish multidisciplinary care and a lab centre within a government hospital and build capacity of healthcare professionals across the country
- Improve the national registry and gathering of epidemiological information for people with bleeding disorders

Achievements

- This project has directly **benefitted 5,165 people with haemophilia.**
- Establishment of **Pakistan's first public haemophilia treatment centre at the Children's Hospital in Lahore.** Offering round-the-clock care, children with haemophilia in and around Lahore now have access to a basic haemophilia care and are no longer reliant on the limited opening hours of private centres. Being anchored in the public health system, the centre also addresses the challenges of sustainability, as the private centres are purely funded through philanthropic donations and headed by a doctor approaching retirement.
- **Standard operating procedures are currently being developed** to support the scale-up and replication of the haemophilia treatment centre model within government hospitals.
- **A 37% increase in haemophilia diagnosis rate was achieved with 887 new cases identified**, surpassing the initial target of 300. This progress **raised the diagnosis rate from 10.1% to 13.9%,** increasing the number of diagnosed people with haemophilia from 2,348 to 3,235. To achieve this, targeted awareness raising materials were developed on a national level and four provincial media engagement campaigns executed in Karachi, Lahore, Peshawar and Rawalpindi. Provincial World Haemophilia Day celebrations saw the attendance of 480 participants in total.
- National strategy workshop organised for key healthcare professionals, health authorities and patient organisations. **A concrete roadmap for haemophilia care developed, with a view to gaining health authorities' commitment**. As part of this exploration, an integrated approach between haemophilia and thalassaemia was explored, as it could improve the engagement with health authorities, given that approximately 5% of Pakistan's population (12 million people) carry the thalassaemia trait. The dialogue with the partner and relevant stakeholders is ongoing.
- **Youth and women's groups empowered** to support the implementation of the 2026-2030 national strategy with clear roles and responsibilities. One national and four

provincial workshops were conducted for the youth and women's groups, aimed at strengthening their leadership, organisational, planning and communication skills.

- **Data accuracy and safety of the patient registry improved,** as the current patient registry was updated and additional fields added based on the WBDR registry.

In February 2025, the inauguration of the first public haemophilia centre was celebrated in the presence of Ministry of Health representatives (Punjab Province), hospital leadership, the haemophilia and medical communities, media and the NNHF team.

Sri Lanka 3 project

Programme title	**Decentralise haemophilia care across Sri Lanka and increase support from health authorities**
Phase	Formalisation
Partner	Hemophilia Association of Sri Lanka (HASL) – Shantha Karunarathne and Sri Lanka College of Haematologists – Dr Visaka Ratnamalala
NNHF contact	xfov@nnhf.org
Duration	3 years
Start date of activities	Q2 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 project was approved during the NNHF Council meeting in May 2025.

National strategy meeting between key stakeholders across Sri Lanka, including healthcare professionals, patient organisation and Ministry of Health representatives.

Thailand 5 project

Programme title	**Strengthen haemophilia awareness and care in Southern Thailand**
Phase	Execution
Partner	Songklanagarind Hospital, Prince of Songkla University - Dr Natsaruth Songthawee
NNHF contact	xfov@nnhf.org
Duration	4.5 years
Start date of activities	Q1 2021

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

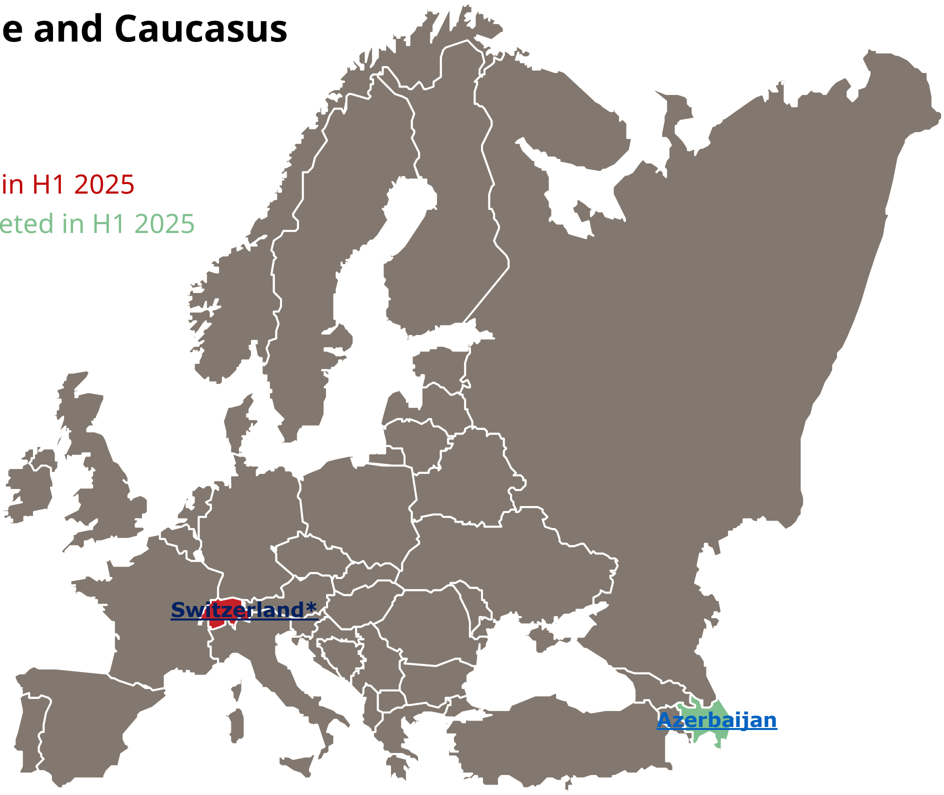
Status

- Preparation of specialised training for radiologists from Bangkok and Songkhla on Point of Care Ultrasound (POCUS), to be held at the Indiana Haemophilia and Thrombosis Center (IHTC) in Indianapolis in August. This marks the final project activity.

Eastern Europe and Caucasus

Legend:

- Projects active in H1 2025
- Projects completed in H1 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.

Azerbaijan 3 project

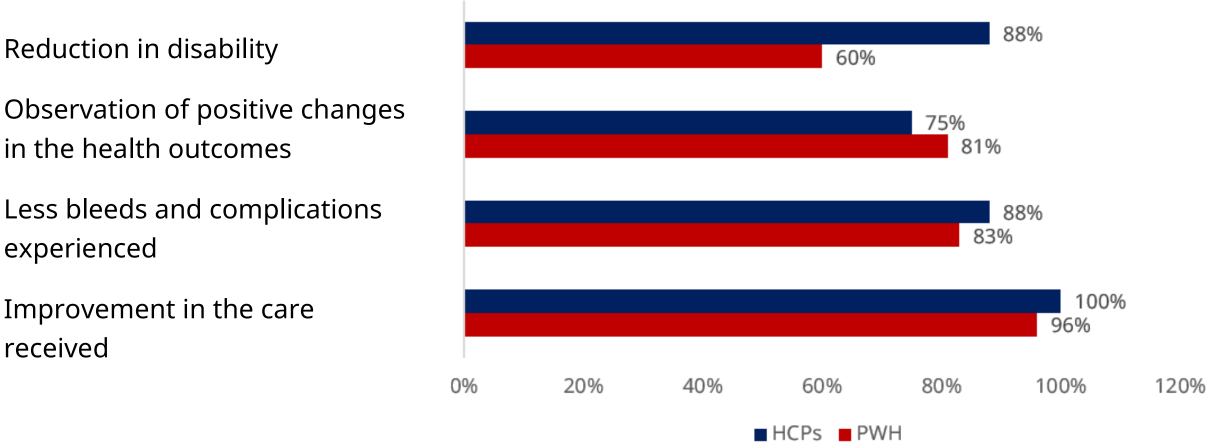
Programme title	**Creation of multidisciplinary care teams for people with haemophilia living in the regions of Azerbaijan**
Phase	Closing
Partner	Azerbaijan Republic Association of Hemophilia, Baku - Gulnara Huseynova
NNHF contact	eiel@nnhf.org
Duration	3 years, Q1 2022 – Q1 2025

Objectives

- Improve multidisciplinary care in 5 regions of Azerbaijan
- Improvement of dental services in Baku and Nakhchivan and creation of dental expert network in the regions
- Raise awareness and improve self-management skills for people with haemophilia and their families
- Advocacy and regular exchange with state representatives regarding project activities

Achievements

- This project has **directly benefitted 1,750 people with bleeding disorders**.
- **Significant advocacy uptakes achieved including a 35% increase in budget allocation for haemophilia**, enabling a higher factor procurement and no more out-of-pocket payments for dental care.
    - The budget allocated for treatment has seen a steady increase over the project duration, rising from CHF 6.28 million in 2022 to CHF 7.31 million in 2023 and further to CHF 8.41 million in 2024 and CHF 8.46 million in 2025.
    - This marks an approximate 35% increase from 2022-2025. **In CHF, this translates to additional funding of 2.2 million.**
    - In 2023, the State Agency for Compulsory Health Insurance and Administration of the Regional Medicine Divisions announced that dental services (extraction, fillings and dental hygiene) are free of charge in Baku and Nakhchivan for people with haemophilia. By end of 2024, it was announced that **dental services are free of charge in all the regions of Azerbaijan**.
    - These achievements were possible through the regular and systematic meetings with government authorities and the State Agency for Compulsory Health Insurance and Administration of the Regional Medical Divisions (TABIB). The online dentistry seminar led by Dr Jecko Thachil and Dr Petrina Wood from Manchester Royal Infirmary, which drew over 100 participants, and the upgrade of the dentistry facilities at the Republican Hospital of Baku and the reference hospital in Nakhchivan Autonomous Region further increased the awareness of the authorities.
- **Significant health outcomes have been shown by a nationwide musculoskeletal survey** targeting 52 people with haemophilia (3% of diagnosed patients) and 8 healthcare professionals, representing the community benefiting from project activities:



Possible answers in the survey: yes, to some context, no

- This was achieved through the strengthening and refurbishment of the physiotherapy areas in 5 regional hospitals in Guba, Lenkoran, Fuzuli, Goychay and Zaqatala. Moreover, 106 physiotherapists as well as 163 nurses were trained by the team in Baku. The patient organisation, in collaboration with the trained healthcare professionals, organised regular physical as well as virtual trainings on the importance of physiotherapy and exercise benefitting in total 631 patients throughout the project duration.

Launch of physiotherapy area in Goychay Regional Hospital.

Dental examinations done at Fuzuli Regional Hospital.

Global 6 – Advocacy programme

Programme title	**Fostering advocacy to influence haemophilia care provision: Phase 3**
Phase	Execution
Partner	International and National Advocacy Experts
NNHF contact	nhhn@nnhf.org
Duration	4 years
Start date of activities	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

- The first French-speaking virtual programme was completed by Benin, Côte d'Ivoire, Guinea, Mali and Senegal, comprising three online modules and one on-site session in Dakar, Senegal. All countries now have an advocacy goal and work plan in place.
- Partnerships with advocacy expert organisations in Portuguese-speaking Africa and Latin America have been formed, with planning underway for advocacy training in these countries in Q3 and Q4
- To-date, 12 alumni countries have achieved significant advocacy uptakes following or during their participation in the programme.

Global 7 – Leadership programme

Programme title	**Virtual leadership programme for haemophilia practitioners**
Phase	Execution
Partner	NSRF Consulting – Robert Lugo
NNHF contact	nhhn@nnhf.org
Duration	4 years
Start date of activities	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 Q3 2025 and integrated into projects as part of our capacity building offering to partners.