

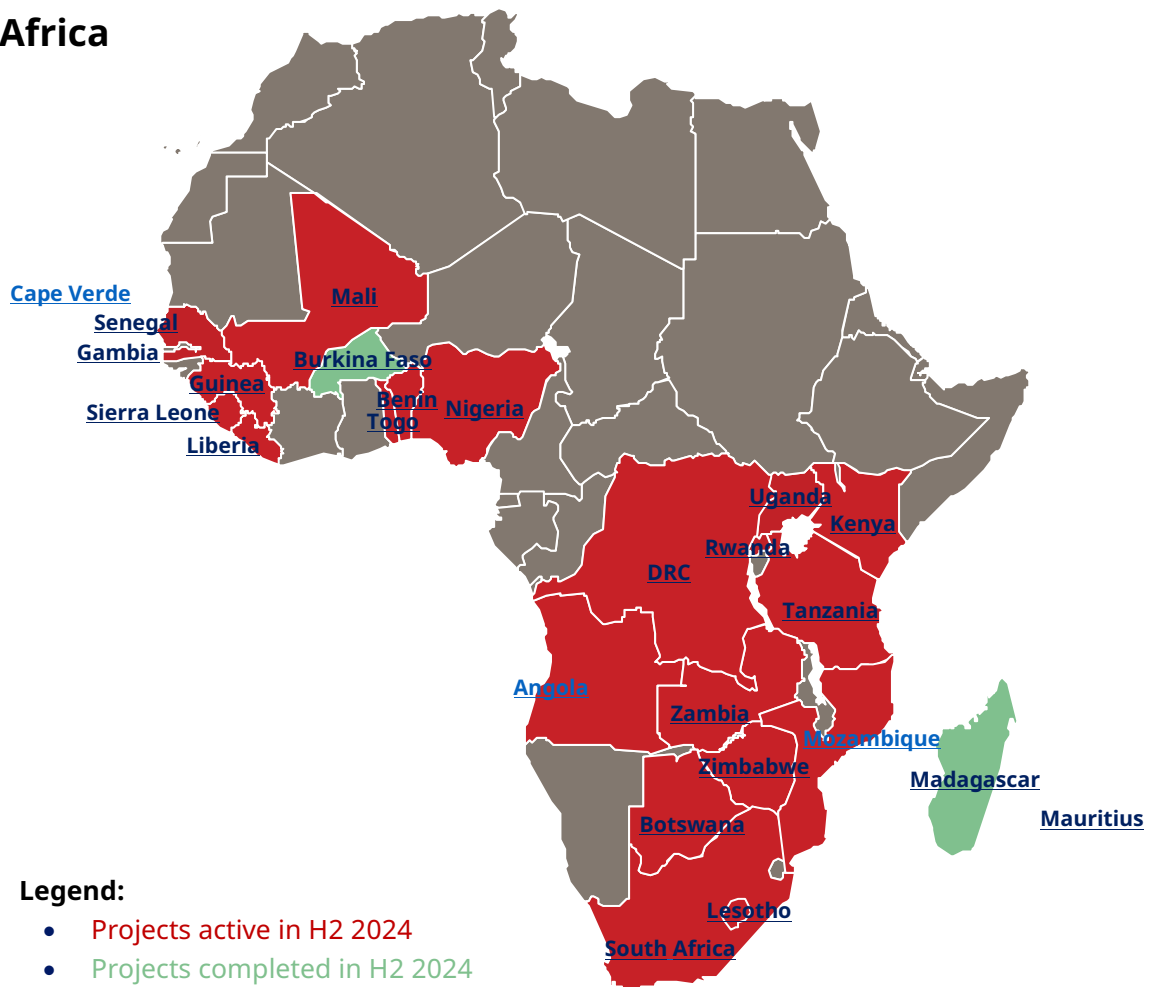
## Selected programme updates

1 July – 31 December

### Programmes approved since 2005:

- 248 projects (4 new projects since H1 2024)
  - 74 fellowships
  - 30 awards
- in 87 countries

### Africa



#### Legend:

- Projects active in H2 2024
- Projects completed in H2 2024

## 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 Associação 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 Manguela  
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](mailto: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

- The project was approved during the NNHF Council meeting in October 2024. All parties have signed the project partnership agreement with the activities now ready to commence.

## 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](mailto:cgtz@nnhf.org)
- Duration 2.5 years
- Start date of activities Q2 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

- Developed and disseminated educational materials on haemophilia for doctors, nurses, and midwives to improve care at the University Hospital Departmental of Ouémé-Plateau and the CNHU - HKM (Hubert Koutoukou MAGA National University Hospital) and other facilities.
- Trained 14 healthcare professionals from the University Hospital Departmental of Ouémé-Plateau in Porto-Novo, including paediatricians, internal doctors, emergency doctors, and surgeons.
- Trained 31 nurses and midwives in the diagnosis and management of haemophilia and male circumcision at the University Hospital Départemental De Ouémé-Plateau in Porto-Novo for 2 days.
- Launched and equipped the Ouémé haemophilia treatment centre in Porto-Novo.
- Sensitised and informed at least 200 people about haemophilia.



*Conducting blood disorders diagnosis at the laboratory at CNHU - Hubert Koutoukou MAGA National University Hospital.*

## Botswana 2 project

- Programme title **Decentralisation of care and diagnosis in two regions of Botswana**
- Phase Execution
- Partner Botswana Baylor Children's Centre of Excellence at Princess Marina Hospital – Mrs Baraedi Winnie Mantswe
- NNHF contact [zagi@nnhf.org](mailto: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

- A 2-day training for 20 healthcare workers (medical officers and nurses) to become champions in the district hospitals was conducted at Princes Marina Hospital (PMH).
- Piloting of haemophilia champions to practice acquired knowledge and skills was done in Keng, Mahalapye, Kanye, Gaborone and Malwelwe leading to increased implementation of the family tree tracing.
- The laboratory in Letsholathebe Memorial Hospital, Maun was strengthened through the purchase of a centrifuge machine.
- 1-day educational training in the capital, Gaborone for 28 people with haemophilia and their guardians on self-care management.
- A press conference was held with key stakeholders to highlight on the issues people with haemophilia face and the needed support.



*In July 2024, the NNHF team visited the laboratory at Letsholathebe Memorial Hospital in Maun, where decentralization is planned to reduce the need for patients to travel to the capital.*

## Burkina Faso 1 project



- Programme title: **Expanding haemophilia diagnosis and care in Burkina Faso**
- Phase: Closing
- Partner: Groupe d'Intervention en Hématologie  
- Prof Eléonore Kafando
- NNHF contact: [cgtz@nnhf.org](mailto:cgtz@nnhf.org)
- Duration: 2 years
- Start date of activities: Q2 2022

### Objectives

- Raise haemophilia awareness to health authorities and general public
- Strengthen and increase population's access to haemophilia diagnosis, to reach a diagnosis rate of 9% by 2024
- Develop outreach haemophilia knowledge of at least 300 first contact healthcare professionals
- Ensure country-wide access to haemophilia treatment
- Empower the haemophilia community

### Achievements

- Thanks to the impactful awareness-raising activities conducted among both the general population and healthcare professionals from six regions in Burkina Faso, the country achieved a 60.8% increase in the diagnosis rate. As a result of their efforts, a total of 190 people living with haemophilia were diagnosed and directly impacted, doubling the national diagnosis rate from 6% to 9.5%.
- Thanks to advocacy efforts led by the patient organisation and the medical team, the national treatment guidelines were successfully endorsed by the Ministry of Health, making haemophilia eligible for free care as part of the Universal Health Coverage for chronic diseases as per the August 12 decree following the Council of Ministers concerning chronic diseases.
- 7 haemophilia care centres were established in Dédougou, Koudougou, Kaya, Ouahigouya, Tenkodogo, and Banfora, with basic haemostasis tests, such as PT and APTT, provided in all regional hospitals and with reagents available from the hospital.
- 19 lab technologists were trained on the diagnosis of haemophilia, saving up to 16 hours of travel time for screening.
- The number of people on prophylaxis increased by 18% due to the provision of refrigerators in remote centres.
- A "Boîte à image" tool was developed to educate patients and community healthcare workers on haemophilia in partnership with the Ministry of Health's Technical Working Group, the National Patient Organisation, and a coalition of healthcare professionals.



*In September, a media engagement workshop brought together project partners from Burkina Faso and Cote d'Ivoire.*

## 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](mailto: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

- The project was approved during the NNHF Council meeting in April 2024.
- Trained 2 lab technicians from Kisangani and Lubumbashi in Kinshasa on haemophilia and SCD screening and diagnosis for two weeks and equipped the laboratory in Kisangani with a coagulation machine. These efforts led to the screening and diagnosis of 7 people with haemophilia.
- Trained 26 nurses and 2 laboratory technicians serving Kisangani, Mbuji Mayi, Tshilenge, and Dipumba on haemophilia care, management, and diagnosis.
- Raised awareness and advocated for improved haemophilia and SCD care through 2 radio and TV interviews in the local language.



## The Gambia 2 project

- Programme title **Strengthen haemophilia in the capital and expand capacity and awareness in the rural areas of the Gambia**
- Phase Execution
- Partner Safe Motherhood and Hemophilia Foundation The Gambia - Mr Vandy Jayah and Dr Salifi Gaye
- NNHF contact [zagi@nnhf.org](mailto:zagi@nnhf.org)
- Duration 2 years
- Start date of activities Q1 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

- Two new haemophilia patient organisations chapters were set up in Farafenni and Mansa Konko and have been involved in raising awareness in the regions.
- Raised awareness of haemophilia through outreach visits to train healthcare professionals on haemophilia in 3 rural regional areas namely Bansang, Basse and Mansankoku.
- Due to the improved quality of diagnosis achieved in the last months, the diagnosis rate has increased 7% to 10% (i.e. from 17 to 28 people with haemophilia).
- 2 new patients were diagnosed between July and December 2024 through family tree tracing.



*Awareness raising activities in Bansang, Basse and Mansankoku.*

## Guinea 1 project

- Programme title **Increase haemophilia awareness and diagnosis in Guinea**
- Phase Execution
- 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](mailto: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

- Developed and endorsed a protocol for cold chain compliance to be used during factor dispatching in remote areas by the Ministry of Health. The protocol was developed with the assistance of logistics and cold chain compliance agents from the national pharmacy, pharmacists, and lab technicians, leveraging their expertise in distributing drugs in remote areas.
- Signed a partnership agreement between AGUILHAMH and the Ministry of Health to develop and implement health policies, plans, strategies, and programs in accordance with the strategic documents of the Ministry's Health Department.
- Purchased five portable refrigerated showcases to improve transport of factors in 5 regions.
- Thanks to the screening and awareness activities in Kankan, Farannah and Labé 34 new people with haemophilia were diagnosed.
- Trained 25 healthcare professionals on haemophilia management including general practitioners, primary contact agents, and chief nurses from CHU Ignace Deen, CHU Donka, Conakry, Kindia, Boké, Kankan, Mamou, Labe, Faranah, and N'zerekore in Conakry for 3 days.
- Significantly improved health outcomes for people with haemophilia, enabling children and adults who had previously dropped out to return to school or resume daily activities.
- *With this project, NNHF is partnering with the Fondation Pierre Fabre to improve diagnosis and care of both haemophilia and sickle cell disease.*



*34 new people with haemophilia were diagnosed thanks to screening and awareness raising activities.*

## Kenya, Tanzania, Uganda and Rwanda joint project

- Programme title **Expanding access to blood disorders care in Eastern Africa**
- Phase Execution
- Partner Kenya Haemophilia Association (KHA)  
- Dr Kibet Shikuku and James Kago  
Haemophilia Society of Tanzania (HST)  
- Dr Stella Rwezaula and Dr John Rwegasha  
Haemophilia Foundation of Uganda (HFU)  
- Dr Grace Ndeezi and Agnes Kisakye  
Rwanda Federation of Hemophilia (RFH)  
- Dr Gilbert Uwizeyimana and Sylvester Mulindabyuma
  
- NNHF contact [lymw@nnhf.org](mailto:lymw@nnhf.org)
- Duration 2 years
- Start date of activities Q3 2023
- *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 3<sup>rd</sup> and 2<sup>nd</sup> 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

## Status updates

### Kenya

- Established three new treatment centres: Lodwar County Referral Hospital, Kakuma Sub-County Referral Hospital, and IRC Kakuma Hospital, to improve access to care.
- The Medical Advisory Committee assessed seven treatment facilities, including Busia County Referral Hospital, Malindi County Referral Hospital, Kwale County Referral Hospital, IRC-Dadaab Refugee Camp, Marsabit County Referral Hospital, National Spinal Injury Referral Hospital, and Kapenguria County Referral Hospital, to ensure high standards of care.
- Trained 474 healthcare professionals on haemophilia management, family tree tracing and diagnosis distributed as follows: Busia County Referral (47), Taveta Subcounty (29), Marsabit County (26), Malindi County (25), Kajiado County (26), Coast General Referral Hospital (30), Lamu County Referral (51), Msambweni Hospital (Kwale County) (21),

Mpeketoni Hospital (31), Kapenguria County Hospital (54), National Spinal Injury (108), and Kenyatta National Hospital (KNH) Accident & Emergency (26).

- Launched a centre of excellence at the Kenya Medical Training College (KMTTC), Nairobi, to serve as a hub for training and research.
- A psychologist and a pharmacist received specialised training in India and Moi Teaching and Referral Hospital (MTRH) respectively to strengthen the multidisciplinary approach to haemophilia management.
- 209 new patients diagnosed in the same period bringing the total number of haemophilia patients in Kenya to 1,200 a diagnosis rate of 21%.

## **Tanzania**

- Launched two haemophilia satellites at Tanga and Manyara Regional Referral Hospital.
- Participation of Legislators, Ministry of Health, Medical Advisory Committee (MAC) members, patients, parents, and other health stakeholders in a blood disorders leadership forum in Nairobi, Kenya.
- The government pledged to include funding in the new fiscal budget specifically for advocacy related to haemophilia and sickle cell disease.
- Through the blood disorders leadership forum, the legislators' representatives promised to invite the haemophilia team to parliament to educate other members of health planning at parliament regarding these blood disorders and to address health challenges faced by many haemophilia patients in Tanzania.
- Trained over 70 healthcare professionals (doctors, nurses, lab scientists, physiotherapists, pharmacists) both locally and abroad expanding the knowledge base and bridging the gap on bleeding disorder knowledge at the primary and secondary centres.
- More patients and the general public were trained about haemophilia diseases.
- Identification of 72 new patients through family tree tracing at haemophilia satellite clinics.
- Improvement of diagnostics of early bleeding through the introduction of Point of Care Ultrasound (POCUS) machines.
- Conducted community awareness on haemophilia through mainstream media and social media reaching wide audience in the country.
- Improved quality of life for patients in preventing foot disability through the step-by-step project.

## **Uganda**

- Secured government budget allocation for reagents.
- Renovated clinics in Mbarara, Lira and Kawempe and furnished them with necessary lab and physiotherapy equipment.
- Engaged the East Africa Legislative Assembly (EALA) representative for Uganda where there is a commitment on the development of a haemophilia policy.
- Developed capacity of healthcare professionals with at least 5 of them trained abroad and over 45 healthcare professionals trained in Uganda.

## Rwanda

- Under the collaboration of the Rwanda Biomedical Center (RBC), developed a national patient registry. This system is designed to streamline patient management, facilitate advocacy and research and ensure better healthcare outcomes.
- Received one fully automated coagulation machine and two semi-automated coagulation machines, that will enhance diagnosis at the newly renovated Kibuye Referral Hospital Clinic in the Western Region of Rwanda, University Teaching Hospital of Butare (CHUB) in the South and the CHUK in Kigali.
- Engaged the Rwanda East Africa Legislative Assembly (EALA) representative whose engagement is now bearing fruit with proposed advocacy engagements with the EALA health committee.
- Conducted a series of patient education sessions across the country, reaching four regions: Kigali City, Southern Zone, Eastern Zone, and Western Zone.



*Prof Johnny Mahlangu during the East Africa Blood Disorders Leadership Forum in Kenya in October 2024.*

## Kenya Sickle Cell 1 project



- Programme title **Strengthening capacity and networks in the Sickle Cell Disease community**
- Phase Execution
- Partner Sickle Cell Federation Kenya (SFK) – Dr Fredrick Okinyi, Chairman and Prof Constance Tenge, Deputy Chairperson
- NNHF contact [lymw@nnhf.org](mailto:lymw@nnhf.org)
- Duration 1 year
- Start date of activities Q2 2024

### 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.

### Status

- Created a Federation website and banner that enhanced visibility, enabling access to services offered.
- Held an internal workshop meeting in Kisumu to spearhead SFK unity, strengthen service delivery, and prosperity of the federation.
- Established a data and registry office fully equipped with all stationeries in Eldoret that commenced collecting SCD data across the country.
- Participated in the blood disorders forum held in November, which increased SFK's visibility on the international platform.
- Developed data collection tools for SCD, which were distributed across the country, mostly in high burden areas.
- Sickle Cell Disease recognised by the Social Health Authority/Social Health Insurance Fund (SHA/SHIF) for access to essential medicines and treatment for Sickle Cell Disease (SCD) patients, which currently covers some of the SCD patient's services like laboratory and pharmacy.
- Established a governance manual, HR manual, and travel policy guide to ensure the smooth running of our activities.
- Employed a project officer who oversees all Federation operations related to the project.
- Reactivated all Federation social media platforms, allowing visitors to learn about SFK.
- Engaged in collaboration with Busia, Kilifi, and Kisii counties to advocate for SCD patients. This positively impacted service delivery at the grassroots level, including awareness and education, advocacy, data collection, and livelihood improvement.

## 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](mailto: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

- Partner has had fruitful engagements with the Ministry of Health with discussions that are at advanced stages of government endorsement thus ensuring sustainability of the laboratory placement model after the first year of NNHF support.
- Diagnosis of two new patients in the current project bringing the total number of patients diagnosed to date at 15.
- Through advocacy, the partner has received support from the National Drug Service Organisation (NDSO) through increase in factor procurement.



*Haemophilia Association of Lesotho preparing their advocacy strategy.*



## Liberia 1 project



- Programme title **Establish basic care in Liberia**
- Phase Execution
- Partner Liberia Hemophilia Program (LHP) – Prince Kwenah and Dr Arthur Clarke
- NNHF contact [zagi@nnhf.org](mailto:zagi@nnhf.org)
- Duration 2 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 space for the haemostasis laboratory was successfully renovated at the Redemption Hospital in Monrovia. The renovation of a dedicated space for the haemostasis laboratory at Redemption Hospital in Monrovia represents a significant milestone, as it marks the establishment of the first diagnostic facility in the country
- The lab equipment was installed and put into operation, coupled with a training provided by the equipment vendor.
- Community outreach was conducted by the patient organisation in Montserrado and Margibi Counties to increase awareness on haemophilia and identify any cases.

## 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](mailto:cgtz@nnhf.org)
- Duration 2.5 years
- Start date of activities Q3 2022



## 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

## Status

- Trained 25 dental surgeons in Antananarivo on the management of haemophilia patients requiring dental care over a period of 2 days resulting in sustained advocacy for free dental care for people with haemophilia.
- Diagnosed 9 new people with haemophilia, bringing the total number of people with haemophilia in Madagascar to 199 and the diagnosis rate to 7%.
- Established 4 second-level haemophilia treatment centres. Each centre is equipped with laboratory equipment for PT and APTT tests, a haemophilia referral doctor, a referral physiotherapist, and at least one nurse responsible for haemophilia patients.
- Organised two symposiums to advocate and raise awareness, enhance the visibility of the haemophilia centres and patient association among relevant authorities in Madagascar, and strengthen international relations.
- Conducted awareness-raising sessions with 317 community workers.



*Physiotherapy training for 4 newly established second-level haemophilia treatment centres.*

## 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](mailto:cgtz@nnhf.org)
- Duration 2 years
- Start date of activities Q3 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

- Organised a meeting with the Directorate of Army Health Department as part of the preparation for planning haemophilia training for army health workers.
- Five people with haemophilia were newly diagnosed in the last six months.
- Few activities were conducted this half-year due to issues with bank transfers.



*To improve the quality of life for people with haemophilia through physiotherapy.*

## 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](mailto:zagi@nnhf.org)
- Duration 3 years
- Start date of activities Q2 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

- Emergency guidelines have been drafted, which are currently under review for approval by Ministry of Health (MoH); this will enhance emergency response capabilities.
- Collaboration with the Ministry of Health who have accepted the donation of coagulometer at Victoria Hospital and committed to ensure regular supply of reagents. This marks a vital collaboration with the Ministry of Health and the partnership will strengthen project partner ties and improve diagnostic capabilities.
- Dr. Sonoo and Dr. Vanderbecken conducted a comprehensive training program for 25 healthcare professionals, including physicians, pharmacists, pathologists, and nurses from five regional hospitals. The aim was to enhance their knowledge and skills in diagnosing, treating, and managing bleeding disorders according to standardized protocols. The trainees were drawn from Jawarharlall Nehru Hospital, Victoria Hospital, Jeetoo Hospital, Bruno Cheong Hospital, and Sir Seewoosagur Ramgoolam Hospital.
- Through the home therapy implemented in the previous NNHF project, the partners have reported a reduction in hospitalisations.

## 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](mailto: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

- An in-person workshop was held in Abuja, Nigeria, where a resource person from the UK facilitated training on family tree tracing. Nine nurses, including two representatives from the National Haemophilia Foundation, participated. This workshop resulted into implementation of a family tree tracing program across the 7 centres to identify more patients.
- A comprehensive advocacy workshop was conducted for team members, patients, parent representatives, and two NHF staff members, with support from NNHF staff. Advocacy visits were also made to the Honourable Minister of Health and the Director of the National Blood Transfusion Agency. These visits resulted in expedited clearance of donated factor concentrates and commitments to explore procurement of factor through the National Blood Service Agency and their inclusion in the agency's budget.
- Awareness campaigns were carried out in antenatal clinics across various centres to enhance early diagnosis and care for haemophilia patients.
- Doctors and lab scientists were trained on haemophilia management and screening across the seven centres.
- A handbook for standard operating procedures on the diagnosis, management and treatment of haemophilia has been developed and is currently undergoing a final review.



*Nurse Kate Kair, from the UK, conducted a family tree tracing training for nurses in 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](mailto:cgtz@nnhf.org)
- Duration 2 years
- Start date of activities Q4 2023

### 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

- Renovated the haemophilia clinic at the Centre National de Transfusion Sanguine (CNTS) in Dakar to improve care and treatment for people with haemophilia. This included rooms specifically adapted for consultations and treatment, with at least a referral haematologist, lab technician, and a nurse.
- Mobilised and trained 100 community health workers from 10 departments in Saint Louis and Kaolack on haemophilia signs and symptoms management. This resulted in the diagnosis of 18 new people with haemophilia.
- Trained and empowered 233 people with haemophilia on management and care.
- Developed a health booklet serving both as a monitoring tool for patients' treatment and a means to raise awareness about the disease among healthcare professionals and care givers.

## Sierra Leone 1 project

- Programme title **Establish basic haemophilia care in Sierra Leone**
- Phase Closing
- Partner Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) – Harry Mayeah Koroma and Dr Mavolo Toure
- NNHF contact [zagi@nnhf.org](mailto:zagi@nnhf.org)
- Duration 2.5 years
- Start date of activities Q3 2022

### Objectives

- Set up a laboratory for diagnosis in Freetown
- In-depth training of two healthcare professionals abroad
- Raise awareness and interest of health authorities about haemophilia
- Strengthen capacities of the patient organisation
- Outreach and awareness raising for haemophilia community living in rural areas

### Achievements

- The first haemostasis lab in the country was set-up at Connaught Hospital in Freetown, through the purchase of a semi-automated coagulometer.
- 28 people with haemophilia were diagnosed throughout the project marking an increase from 0% to 3%. This was made possible through partner implementation of family tree tracing.
- 2 laboratory technicians received a 2 week's training while 1 nurse and 1 doctor had a one-month in-depth training in Bloemfontein, South Africa. A follow-up training was also conducted by the team from Bloemfontein in Freetown to further consolidate the acquired knowledge.
- Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) received accreditation as a National Member Organisation (NMO) from the World Federation of Haemophilia (WFH), thus allowing them to secure factor donations and improve access to essential treatments for people with haemophilia.
- The patient organisation together with the healthcare professionals conducted educational camps in Freetown, Kono and Karene for people with bleeding disorders, about haemophilia.
- Two representatives of the patient organisation attended a capacity building workshop led by the Kenya Hemophilia Association (KHA). The workshop brought together representatives from patient organisations from the Gambia and Liberia and was aimed at building capacity, sharing knowledge between the patient organisations. This led to further strengthening of the capacities of the patient organisation.



## South Africa 5 project

- Programme title **Raising the standard of care and promoting specialities in haemophilia care**
- Phase Execution
- Partner South Africa Haemophilia Foundation (SAHF) - Mr Bradley Rayner
- NNHF contact [zagi@nnhf.org](mailto:zagi@nnhf.org)
- Duration 2 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

- Held a successful MASAC Educational Symposium where 140 experts, advocates, and healthcare professionals gathered to explore advancements and collaborate on the future of haemophilia care.
- Patient organisation has identified and is exploring how to use technology (Mobile App) for data collection and analysis that could help provide "tailored/personalised" treatment plan to patients.
- 3 ultrasound tablets and probes were procured for Pretoria, Durban and Cape Town haemophilia treatment centres for better patient joint assessment and management.
- Global South Footwear project, whose aim is to test the clinical efficacy of orthotic device "flip-flops", received the ethics committee approval paving way for data collection by Dr Harriet Talbott from the University of Hull. This has paved the way for data collection and capturing through coordination with the team in Stellenbosch.
- Patient organisation has held outreach activities in Western Cape, Kwazulu Natal and Gauteng regions reaching 75 people with Haemophilia. Coupled with previous semester awareness activities and diagnosis, the total number of people with haemophilia is currently 2,836.



*Outreach visits were held in Western Cape, Kwazulu Natal and Gauteng regions.*

## Tanzania Sickle Cell 1 project



- Programme title **Strengthening capacity and networks in the Sickle Cell Disease community**
- Phase Execution
- Partner Tanzania Sickle Cell Disease Alliance (TSDA) – Dr Elisha Osati, Chairman and Dr Deogratias Soka, CEO
- NNHF contact [lymw@nnhf.org](mailto: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.

### Status

- Developed and adopted organisational policies, including human resource, procurement, financial and monitoring & evaluation, to enhance capacity and efficiency.
- Unified SCD patient networks, leading to the establishment of the Network of Sickle Cell Warriors in Tanzania (NeSWO).
- Procured an accounting system for efficient and transparent financial management.
- Improved SCD care and reduced referrals in four hospitals across Mara and Morogoro regions through SCD capacity building activities.
- Established an online mentorship group for HCPs, paving the way for a National Network of HCPs on SCD care.
- Achieved an 80% clinic attendance increase among SCD patients in Rorya District after patient education sessions.
- Established a dedicated SCD clinic in Kilosa District, previously unavailable.
- Secured Ministry of Health endorsement for youth SCD screening in schools and universities.
- Conducted SCD awareness and screening campaigns in Tabora (during World Sickle Cell Day) and Dodoma (during Non - Communicable Disease week).
- Advocated for the inclusion of SCD screening kits in Medical Stores Department (MSD) budgets through the Ministry of Health.
- Developed a National SCD training curriculum.

## Togo 1 project

- Programme title **Expanding haemophilia diagnosis in Togo**
- Phase Execution
- Partner Institut National d'Hygiene - Dr Yao Layibo
- NNHF contact [cgtz@nnhf.org](mailto:cgtz@nnhf.org)
- Duration 2 years
- Start date of activities Q3 2022



## 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

## Status

- Trained doctors, nurses, and laboratory technicians in five regions, namely Tsévié, Atakpamé (9 laboratory technicians, a laboratory assistant, and 1 surgeon), Sokodé (7 laboratory technicians), Kara (6 laboratory technicians and 1 haematologist), and Dapaong.
- Enhanced collaboration between the medical team and the patient organisation following periodic meetings and the implementation of joint activities.
- 14 newly diagnosed people with haemophilia reported, which remains very low despite raising awareness and conducting screening days in the regions.



*Radio interviews were conducted to increase haemophilia awareness.*

## 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](mailto: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

- Conducted training programmes for healthcare professionals at the district level that included doctors, nurses and lab technicians to enhance diagnosis and management of haemophilia.
- Purchased equipment including screening machines; gazelle and electrophoresis and transcranial doppler machines for Kasama.
- Successfully advocated for increased funding and resource allocation towards haemophilia and sickle cell disease resulting in inclusion of some patients in national social cash transfer programmes.
- The government has successfully procured medications essential for managing Haemophilia and Sickle Cell Disease, including hydroxyurea.

## Zimbabwe 1 project



- Programme title **Establishment of basic haemophilia care in Zimbabwe**
- Phase Execution
- Partner Zimbabwe Haemophilia Association  
- Fynn Machona and Dr Moses Chatambudza
- NNHF contact [lymw@nnhf.org](mailto:lymw@nnhf.org)
- Duration 2 years
- Start date of activities Q3 2022

## Objectives

- Strengthen the haemophilia clinic at Parirenyatwa Hospital in Harare and Mpilo Central Hospital in Bulawayo
- Create awareness among the community and healthcare workers to identify 80 new people with haemophilia
- Develop a national registry for inherited bleeding disorders
- Strengthen the Zimbabwe Haemophilia Association

## Status

- Enhanced case finding for haemophilia through family tracing activities. A screening campaign conducted using family tree tracing at Parirenyatwa Hospital has improved the identification of cases.
- Advanced training has been completed for six healthcare professionals at the Charlotte Maxeke Johannesburg Haemophilia Comprehensive Care Centre in South Africa, increasing the number of knowledgeable healthcare personnel.
- Community awareness outreaches have been performed by the Zimbabwe Haemophilia Association (ZHA), including radio and television presentations.
- The haemophilia treatment guidelines draft has been completed and is now awaiting review, adoption, and finalisation by the Ministry of Health.
- A national registry for inherited bleeding disorders has been developed, embracing the World Federation of Haemophilia (WFHH) World Bleeding Disorders Registry (WBDR).
- Advocacy training has been conducted, and a national advocacy goal to procure reagents and treatment set.

## Americas



### Legend:

- Projects active in H2 2024
- Projects completed in H2 2024

## Argentina 6 project



- Programme title **Better joints and quality of life for people with haemophilia in North-Western Argentina**
- Phase Closing
- Partner Fundación de la Hemofilia de Tucumán – Ms Claudia Josefina Castro and Dr María Belén Nieva
- NNHF contact [eiel@nnhf.org](mailto:eiel@nnhf.org)
- Duration 2 years
- Start date of activities Q3 2022

### Objectives

- Create a rehabilitation network and improve joint health of people with haemophilia in 6 provinces in North-West Argentina
- Establish hydrotherapy care in the province of Tucumán and share experience nationally and internationally
- Improve by 50% people with haemophilia's adherence to treatment for better integration in society

### Achievements

- Establishment of hydrotherapy at the Fundación de la Hemofilia in Tucumán and strengthening of physiotherapy care, through the purchase of equipment and training of 20 physiotherapists in 5 North-Western provinces of Argentina, leading to improved care and reduced distances for people with haemophilia.
- The number of people with haemophilia able to self-infuse have increased from 10 to 80 (out of 105) covering 76% of all patients registered in Tucumán. Healthcare professionals have reported an increase in adherence to treatment allowing a higher level of independency and integration into society thanks to reduced joint damages in 60% of the registered patients. In addition, regular haematological consultations have increased by 30% according to healthcare professionals.
- Developed a physiotherapy and hydrotherapy network in North-Western Argentina for continuous best practice sharing on haemophilia care.
- The partners have achieved excellent systemic changes. Argentina introduced a law in 2020 to extend the age of individuals to receive prophylaxis from 18 to 21 years. However, this extension was not uniformly implemented at the provincial level. Through the project activities, they have effectively raised awareness among authorities, leading to the effective implementation of this law in Tucumán.





*Establishment of hydrotherapy at the Fundación de la Hemofilia in Tucumán.*

## 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 [ei@nnhf.org](mailto:ei@nnhf.org)
- Duration 2.5 years
- Start date of activities Q2 2022

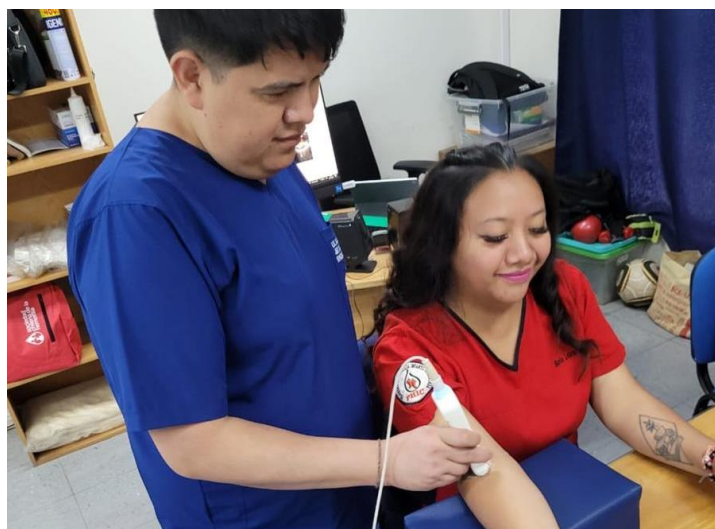


## Objectives

- 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

- Meetings with management of referral hospitals Viedma and Manuel Ascencio Villarroel as well as with health authorities and departmental health services to raise awareness about haemophilia and the project.
- Awareness raising material was developed and shared on social media by the Asociación Cochabambina de Hemofilia.
- 5-day training of an odontologist from Hospital Manuel Ascencio Villarroel in Salta, Argentina.
- 2 physiotherapists from Cochabamba were trained in Santiago, Chile under the supervision of Dr José Lamas Castellanos and Antonio Ibarra.
- 6 orthopaedic surgeons from Cochabamba were trained by Dr Johnathan González from Mexico for 3 days.



*Physiotherapists were trained in Santiago, Chile, aiming to strengthen multidisciplinary care in Cochabamba.*

## El Salvador 2 project



- Programme title **Enhancing bleeding disorders and sickle cell disease care and advocating for decentralisation in El Salvador**
- Phase Formalisation
- 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](mailto:eiel@nnhf.org)
- Duration 2.5 years
- Start date of activities Q1 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

- The project was approved during the NNHF Council meeting in October 2024 and is currently working on the formalities.

## 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](mailto:eiel@nnhf.org)
- Duration 2.5 years
- Start date of activities Q1 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

- Collaborative training initiatives have been successfully conducted in partnership with the hospitals in Panama City, fostering regional collaboration between the two Central American countries. This collaboration has significantly contributed to the consolidation and strengthening of multidisciplinary care teams in Guatemala City and Quetzaltenango.
- Expert volunteer Luz Villalaz from Panama led a 3-day training program in Guatemala City, where 10 nurses from Hospital San Juan de Dios and Hospital Roosevelt received training.
- Two haematologists from Hospital de Occidente and Hospital San Juan de Dios underwent a specialised training programme in Panama for a duration of two weeks. This training also included a visit to the haemophilia treatment centre in the province of Veraguas, providing insights into the care structure beyond the capital.
- Expert volunteer Marión Echenagucia from Venezuela facilitated a 4-day coagulation training programme in Panama, where three lab technicians (including one from Hospital San Juan de Dios and two from Roosevelt) received extensive training.
- A comprehensive 5-day training session in Panama City, led by Dr Laura Forzani from Salta, Argentina, provided specialised training for three odontologists from Hospital San Juan de Dios, Hospital Roosevelt, and Instituto Guatemalteco de Seguridad Social, alongside their counterparts from Panama.
- Expert volunteer Dr Hugo Ubieta met with haematologists from the several reference centres in Guatemala City to explore the establishment of a national haemophilia medical committee.



*Training of nurses by Luz Villalaz, expert volunteer from Panama.*

## Honduras 2 project

- Programme title **Healthy joints for people with haemophilia in Honduras**
- Phase Execution
- Partner Sociedad Hondureña de Hemofilia  
- Mr José Padilla and Dr Armando Peña, haematologist at Hospital Escuela Universitario
- NNHF contact [ei@nnhf.org](mailto:ei@nnhf.org)
- Duration 2 years
- Start date of activities Q2 2022



### 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

### Status

- Two physiotherapists, one from Hospital Escuela in Tegucigalpa and one from Hospital Catarino Rivas in San Pedro Sula, underwent specialised in-depth training at the Universidad Autónoma de Nuevo León in Monterrey, Mexico.
- Physiotherapy equipment procured for Hospital Escuela Universitario has been successfully installed.
- Developed registry has been continuously updated.



*Physiotherapists underwent specialised training in Monterrey, Mexico.*

## 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 – Dr Gillian Wharfe and Dr Magdalene Nwokocha
- NNHF contact [eiel@nnhf.org](mailto: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

- Laboratory SOP's have been reviewed by St Michael's Hospital in Canada and are currently being updated and finalised.
- Lead physiotherapist from the University Hospital of the West Indies (UHWI) was trained on joint care in Canada for 4 days.
- Emergency room trainings were organised in Kingston Public Hospital and Bustamante Hospital for Children.



*In December 2024, the emergency personnel were trained on haemophilia care.*

## Latin America 1 project

- Programme title **Stories of haemophilia carrier women to expand awareness in Latin America**
- Phase Closing
- Partner Fundación de la Hemofilia Argentina, Córdoba chapter  
- Mrs María Belén Robert and Mrs Yuri Andrea Arango
- NNHF contact [eiel@nnhf.org](mailto:eiel@nnhf.org)
- Duration 2 years
- Start date of activities Q4 2021

## Objectives

- Document and make visible the challenges faced by haemophilia carrier women in Latin America
- Develop a haemophilia carrier women's network and encourage changes in healthcare models in Latin America

## Achievements

- This project has directly benefitted 155 haemophilia carriers surpassing the initial goal of 55.
- Creation of a best practice sharing network with haemophilia carrier leaders in seven Latin American countries: Argentina, Colombia, Costa Rica, Honduras, Mexico, Panama and Uruguay.
- 7 national patient organisations from the targeted countries have now a committee in place for haemophilia carriers and started developing local activities through mini-projects for enhanced awareness and consideration.
- Increased awareness has led to a shift in the mindset within the haemophilia patient and medical community, now considering the health-related issues of haemophilia carriers in the same way as those of people with haemophilia. This achievement has been possible amongst others, thanks to initiatives such as the development of the podcast 'La vida no vista' 'Life unseen' on Spotify as well as the dedicated social media campaign: 6 podcasts, 264 listens on Spotify, 155 carriers reached
- Development of regional guidelines for haemophilia carriers which will be distributed across healthcare professionals and patient organisations of 7 counties in the region.
- A toolkit titled 'Once Upon a Time', available in Spanish and English, containing inspirational stories, prompts and exercises to encourage women from around the world to reflect on their own lives and share their stories. We will collaborate with the partners to ensure effective dissemination of this toolkit to targeted countries, and actively foster meaningful exchange and collaboration between the countries.



## 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](mailto:eiel@nnhf.org)
- Duration 2 years
- Start date of activities Q2 2021

### 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

### Status

- Rehabilitation and physiotherapy workshop was organised for parents and people with haemophilia with the support of Dr Aidee Gibraltar from Mexico.
- Rehabilitation specialist from Dr Ignacio Morones Prieto Hospital was trained for 3 days in Mexico City under the supervision of Dr Belmont and Dr Gibraltar.
- A paediatric haematologist from Dr Ignacio Morones Prieto Hospital was trained at the Hospital Universitario de Nuevo León in Monterrey, Mexico.
- The physiotherapy area at Dr Ignacio Morones Prieto Hospital was expanded through the acquisition of equipment.
- Awareness raising trainings were organised for the healthcare professionals from Rioverde, Ciudad Valles and Matehuala to improve the recognition of symptoms.



*Self-infusion training for people with haemophilia and family.*

## 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 [ei@nnhf.org](mailto:ei@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

- Marión Echenagucia from Venezuela led a comprehensive 4-day training session for 14 lab technologists from Hospital Santo Tomás and the satellite clinics. Additionally, three lab technologists from Guatemala City participated in the training programme.
- Dr Laura Forzani, an odontologist from Salta, Argentina, conducted a 2-day training programme for odontologists from Hospital Santo Tomás and the satellite clinics. The training was also attended by three odontologists from Guatemala City.
- 18 doctors and nurses from the satellite clinics were trained in Panama City on basic haemophilia care.
- A coordination meeting was arranged between Fundación Panameña de Hemofilia, Fundación (FUNPAH), and Infantil Anemia Falciforme (FIAF) to strategise for next year's activities.



*Laura Paez held a training on haemophilia for social workers.*

## 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 [ei@nnhf.org](mailto:ei@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

- Expert volunteer Luz Villalaz provided training to 72 nurses from various regions on basic haemophilia care.
- Three lead physiotherapists from Hospital Barrio Obrero, Hospital General de Luque, and Hospital Regional de Encarnación underwent a two-week training program in Salta, Argentina.
- A total of 17 psychologists and social workers from across Paraguay received a 4-day training from expert volunteers Ezequiel Martínez and Laura Páez from Mexico.
- A patient camp was conducted in Asunción, where 50 individuals with haemophilia received training on haemophilia management.
- A refrigerator was procured for a satellite clinic, and essential equipment (laptop, printer, and projector) was obtained for ASOHEMO's day-to-day operations.
- Due to improved adherence and an enhanced care network resulting from the various organised trainings, the frequency of emergency admissions reduced from 4-7 admissions per month to 1-3 admissions in 2024.



*Physiotherapists underwent a two-week training program in 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](mailto: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

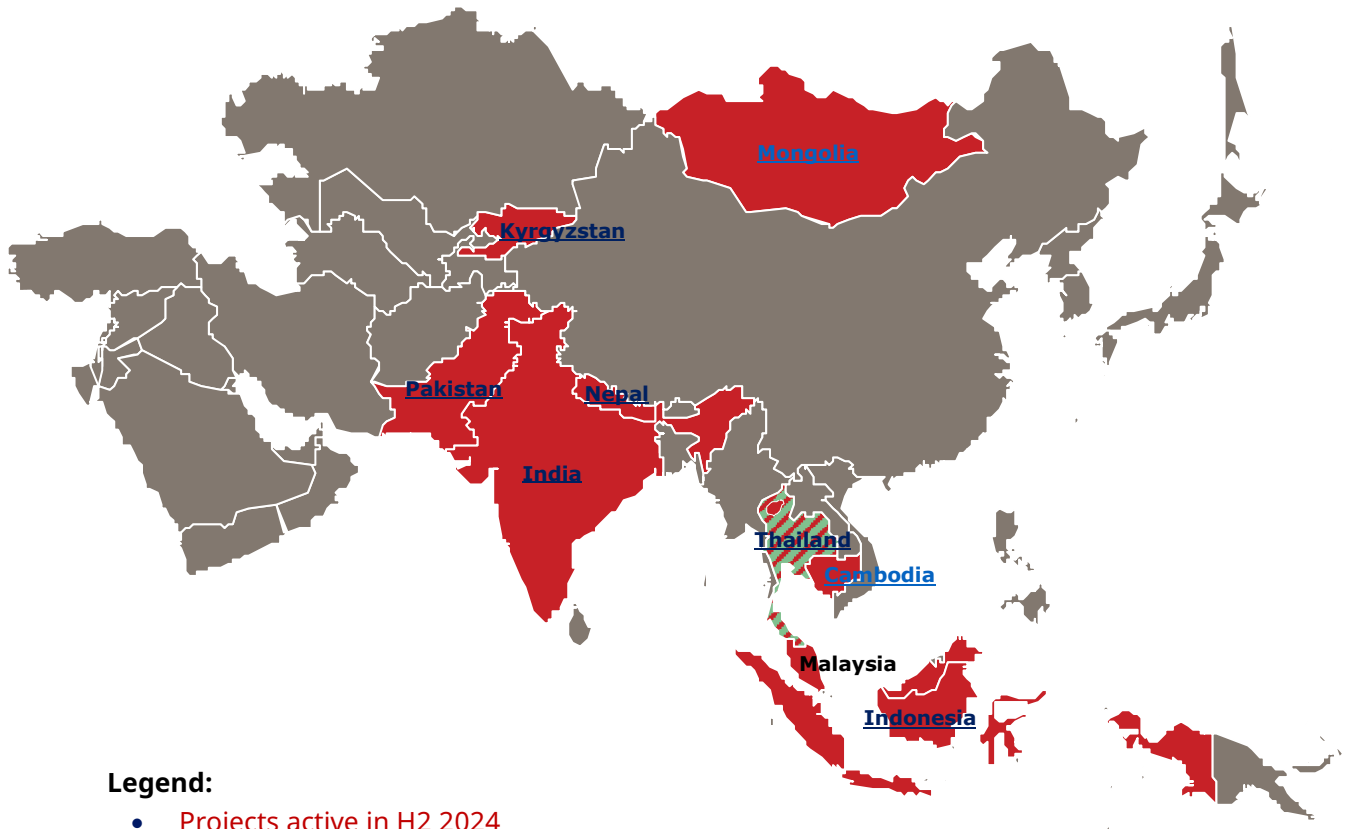
## Status

- NNHF collaborated with the Sociedad Peruana de Hematología (SPH) to organise a strategic workshop in Lima, Peru. The event brought together 25 healthcare professionals and 9 community representatives from across the country to define a vision, impact, and objectives for the future.



*Project partners during the strategic workshop in Lima.*

## Asia and Near & Middle East



### Legend:

- Projects active in H2 2024
- Projects completed in H2 2024

### 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 Formalisation
- Partner Cambodia Hemophilia Association – Sithan Kong and Dr Sing Heng from Angkor Hospital for Children
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 2.5 years
- Start date of activities Q1 2025

### Objectives

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

### Status

- The project was approved during the NNHF Council meeting in October 2024 and is currently working on the formalities.

## 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](mailto:smqy@nnhf.org)
- Duration 2 years
- Start date of activities Q3 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

- Centre assessments carried out for all relevant hospitals in Kerala, Odisha, Rajasthan, and Assam. Quotations from vendors are received and are pending approval from health authorities.
- Planning meetings were held in Kerala, Odisha, Rajasthan, and Assam with state health authorities and healthcare professionals, tailoring the development of care in each of the states.
- First haemophilia awareness raising programme conducted in Sikkim state, involving the Health Minister of Sikkim, the MD of the National Health Mission and key healthcare professionals. Launching developed educational materials in both English and Nepali.
- Advocacy training and alignment meetings carried out for 4 patient organisations (Thalasseemics India, Thalassemia Welfare Society, National Alliance of Sickle Cell Organisations and Hemophilia Federation India), establishing a coalition to jointly advocate for improved and integrated care solutions for people living with haemophilia and haemoglobinopathies.
- In Kerala, haemophilia awareness training of the newly appointed District Nodal Officers and District Nurse Coordinators, leading to low-dose prophylaxis approved for all people with haemophilia below 18 years.
- Strengthened coordination is seen between the National Health Mission Director and the State Nodal Officer improving distribution of treatment across the state of Uttar Pradesh, following meetings between representatives of Uttar Pradesh's patient organisation chapters and the Deputy Chief Minister of the state, National Health Mission Director, State Nodal Officer, and other health officials.
- Initiation of a National Council of Doctors representing the four regions of India.



### 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 Choizie
- NNHF contact [xfov@nnhf.org](mailto: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

- An outreach visit was organised to Pontianak, West Kalimantan. During the visit, awareness raising activities were held for the general practitioners. Lab technicians gained knowledge on factor assay diagnosis, physiotherapists supported the execution of physical examinations on people with haemophilia and nurses attended a self-infusion workshop. Through the visit 3 new people with haemophilia were diagnosed.
- For the next semester, there's an outreach visit planned to the last two centres in West Sumatra and Papua.
- An online meeting with Ramathibodi Hospital in Bangkok, Thailand prepared for sending 4 haematologists from East Nusa Tenggara, West Kalimantan, West Sumatra, and Papua for specialised training.

## 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](mailto:xfov@nnhf.org)
- Duration 2.5 years
- Start date of activities Q3 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

- Advocacy efforts directed towards the government insurance BPJS resulted in the approval of prophylaxis for both adults and children with severe and moderate haemophilia in East Java. Additionally, for the implementation of prophylaxis, BPJS requires an annual joint assessment of individuals with haemophilia.
- Airlangga University Hospital will appoint a paediatric haematologist to implement prophylaxis for children with haemophilia. To enhance care for haemophilia and thalassemia, specialised training abroad is planned for the multidisciplinary care team, including a paediatric haematologist and physiotherapist, beginning of 2025.



*An outreach visit was organised to Madiun to get a better understanding of the situation and improve haemophilia care in East Java region.*

## Kyrgyzstan 1 project



- Programme title **Improve paediatric haemophilia care in Bishkek and decentralise basic care across the 7 provinces of Kyrgyzstan**
- Phase Formalisation
- Partner National Center of Oncology and Hematology – Dr Meeri Eralieva, haematologist and Nurbek Orozaliev, President of Community of handicapped – hemophiliacs in Kyrgyz Republic
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 2.5 years
- Start date of activities Q3 2024

### Objectives

- Improve multidisciplinary haemophilia care and diagnosis at the Bishkek Children's Hospital
- Decentralise basic multidisciplinary haemophilia care to 7 provinces across Kyrgyzstan
- Empower people with haemophilia to self-manage their condition for improved joint health and strengthen the patient organisation chapters to advocate for improved provincial care

### Status

- The project partnership agreement was signed, and the partner will soon start with the project activities.

## Mongolia 1 project



- Programme title **Improve organisation of care and diagnosis in Ulaanbaatar and decentralise basic care to the regions**
- Phase Formalisation
- Partner Mongolian National University of Medical Sciences, Mongolia – Japan Hospital – Prof Odgerel Tsogabadrakh, Head of the Haemophilia Centre
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 2.5 years
- Start date of activities Q1 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

- The project was approved during the NNHF Council meeting in October 2024 and is currently working on the formalities.

## Pakistan 7 project

- Programme title **Enhancing community outreach initiatives through awareness creation and improving access to care**
- Phase Execution
- Partner Hemophilia Foundation – Pakistan (HFP)  
- Mr Masood Fareed Malik
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 2.5 years
- Start date of activities Q4 2021



## 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

## Status

- A Memorandum of Understanding was signed between Hemophilia Foundation Pakistan and Children's Hospital in Lahore to establish basic haemophilia care at the public hospital. The centre will be equipped with appropriate office and medical equipment. The launch of the haemophilia centre is planned early 2025.



*Representatives from Children's Hospital in Lahore and Hemophilia Foundation Pakistan during the MoU signing ceremony.*

## 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](mailto:xfov@nnhf.org)
- Duration 4.5 years
- Start date of activities Q1 2021

## Objectives

- Strengthen the referral system and basic multidisciplinary care in 8 HTC's
- 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

- Execution of a regional meeting for 8 centres across Southern Thailand for better practice sharing and improved standardisation of care.
- Printing and distribution of haemophilia and von Willebrand disease booklets to centres across Thailand, used for awareness raising and disease follow up.
- Preparation of specialised training on point of care ultrasound early 2025.

## Thailand 6 project

- Programme title **Strengthen haemophilia care in Northeast Thailand**
- Phase Closing
- Partner Srinagarind Hospital – Dr Patcharee Komvilaisak, Paediatrician at Srinagarind Hospital and Associate Professor, Department of Pediatrics, Faculty of Medicine, Khon Kaen University
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 3 years
- Start date of activities Q1 2022

## Objectives

- Strengthen haemophilia care in Srinagarind Hospital to become a training hub for Northeast Thailand
- Standardise haemophilia care in Northeast Thailand focusing on strengthening 6 Haemophilia Treatment Centres in Chaiyaphum, Kalasin, Sisaket, Udonthani, Sakon Nakhon and Khon Kaen
- Increase 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 self-infusion and MSK care
- Establish a specialist MSK trainers team in the Northeast focusing on ultrasound in haemophilia care as started in the NNHF Thailand 3 project.

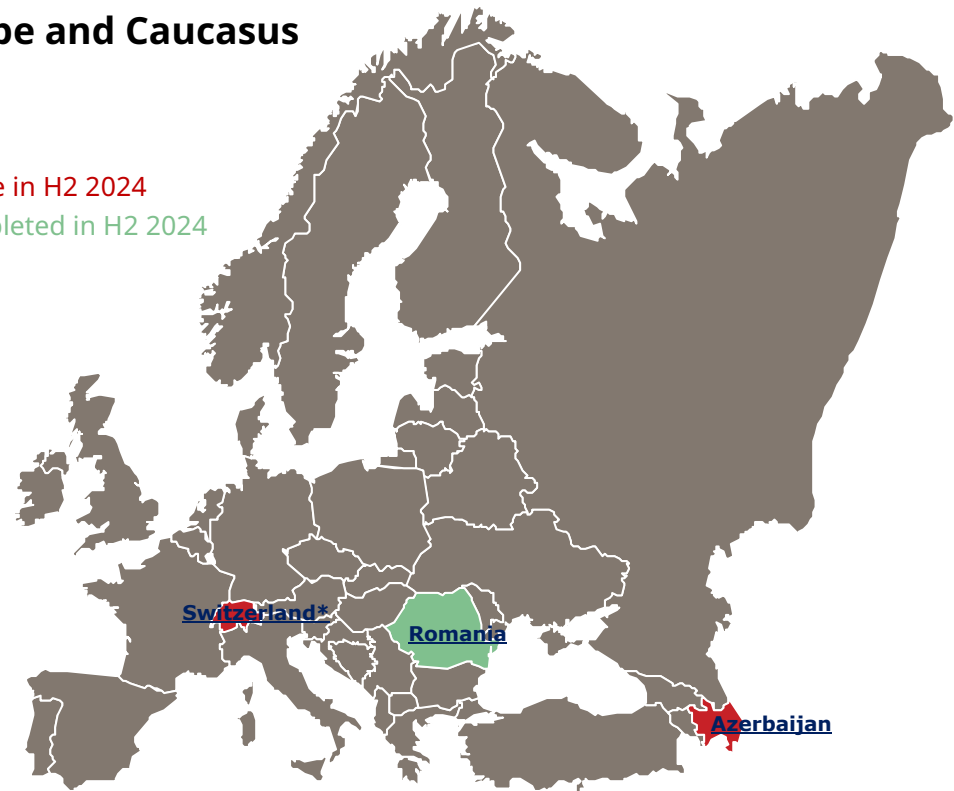
## Achievements

- Srinagarind Hospital in Northeast Thailand has been strengthened to serve as a regional referral and training centre for the country.
- 6 outreach visits were organised to decentralise emergency and basic care. Travel times have reduced by up to 5 hours (based on a round trip from Srisaket to Khon Kaen) and collaboration between Srinagarind hospital with the other regional centres has improved.
- In total 257 healthcare professionals from these 6 centres have been trained, taking a collaborative approach that saw Prof Nongnuch Sirachainan from Ramathibodi hospital in Bangkok and Dr Rungrote Natesirinilkul and his team from Chiang Mai delivering parts of the training.
- Through this project, healthcare professionals in the region started collecting patient data in a systematic way, meaning they have a diagnosis baseline for the first time. This currently stands at 11.5% (compared to the national diagnosis rate of 32.4%), and can be used to measure progress, set targets and support advocacy activities.
- 111 people with haemophilia and their family members received educational training on the management of haemophilia, including MSK care, dental care, nutrition and self-infusion. Of the 75 people with haemophilia treated at Srinagarind hospital, nearly 90% are now proficient to self-infuse factor and are on low-dose prophylaxis. Thanks to the available home treatment they only need to visit the centre every three months for regular consultation.

## Eastern Europe and Caucasus

### Legend:

- Projects active in H2 2024
- Projects completed in H2 2024



\*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 [iel@nnhf.org](mailto:iel@nnhf.org)
- Duration 3 years
- Start date of activities Q1 2022

### 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

### Status

- Collaborative educational seminars were conducted in partnership with the State Agency for Compulsory Health Insurance and the Administration of the Regional Medical Divisions (TABIB) across multiple regions including Absheron, Salyan, Lankaran, Shirvan, Goychay, Guba, Shemakha, and Zaqatala. These seminars aimed to enhance the standard of care provided to patients with bleeding disorders and successfully engaged a total of 366 healthcare professionals (including haematologists, physiotherapists and psychologists).
- The establishment of the physiotherapy area at Guba district hospital marks a significant milestone. This addition, along with the four others established in the previous semesters, have significantly expanded access to physiotherapy services for individuals with haemophilia. Prior to this, such services were only available in Baku. Now, residents in the regions have convenient access to physiotherapy services closer to their homes, eliminating the need for travel to Baku and significantly enhancing their quality of life.
- An educational camp for individuals with haemophilia and their families was organised, with a primary focus on raising awareness about the significance of physiotherapy and dental treatment. The event drew participation from 55 attendees.
- A nationwide survey was conducted to assess the impact of the project on health outcomes for individuals with haemophilia and healthcare professionals. The results revealed a significant improvement in health outcomes, including a reduction in disability and the frequency of bleeds.



*Dental care and treatment was a primary focus during the educational patient camp.*

## Romania 4 project



- Programme title **Strengthen haemophilia care in North-Eastern Romania and improve dentistry care across the country**
- Phase Closing
- Partner Romanian Hematology Society (RHS) – Dr Ciprian Tomuleasa
- NNHF contact [xfov@nnhf.org](mailto:xfov@nnhf.org)
- Duration 2 years
- Start date of activities Q3 2022

### Objectives

- Improve haemophilia diagnosis and raise awareness in Iasi to diagnose at least 75 new people with bleeding disorders
- Train 4 multidisciplinary care team members from Iasi
- Improve dentist care across Romania through training of 200 dentistry students
- Increase international visibility through submission of 3 scientific papers and foster knowledge sharing in the region

### Achievements

- Haemophilia diagnosis (incl. factor assays) and care were successfully established in Iasi. Next to the purchased coagulation analyser there were also 2 haematologists, 2 nurses and 2 lab technicians from Iasi who received training at the haemophilia centre in Cluj-Napoca. With this, diagnosis and care are now available in all four major cities across Romania: Bucharest (southern Romania), Cluj-Napoca (northwestern Romania), Timisoara (western Romania) and Iasi (eastern Romania). This marked the last step in decentralising care and ensuring access closer to where people with haemophilia live.
- The team diagnosed 250 new people with haemophilia and 120 people with von Willebrand disease (the majority from Iasi and the region), surpassing their initial objective of identifying 75 new people with bleeding disorders. The diagnosis rate has seen a significant increase, rising from 59% (1,266 people with haemophilia) at the beginning of the project in 2022 to 71% (1,516 people with haemophilia) at its completion in 2024, marking a 12% increase. The close collaboration with the patient organisation Asociatia Romana de Hemofilie has been instrumental in achieving this outstanding outcome. The patient organisation has been doing an excellent job in raising awareness. They also organised transportation for potential cases to and from the hospital on specific diagnosis days.
- The curriculum for dental students was successfully developed. However, the enrolment of students proved more challenging than expected, with only 50 students enrolled in the programme due to limited interest in bleeding disorders. The partners are continuing to promote the programme and intensifying efforts to generate greater interest among dental students.

## 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](mailto:nhhn@nnhf.org)
- Duration 2 years
- Start date of activities Q2 2024

### 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

- A 2-year expansion of the programme was approved in April, incorporating and building on the learnings from the previous two phases.
- Partnered with advocacy experts to provide tailored support to partners in Nepal, Lesotho with preparations underway to support 4 additional countries spanning Latin America, French and English-speaking Africa and Asia.