

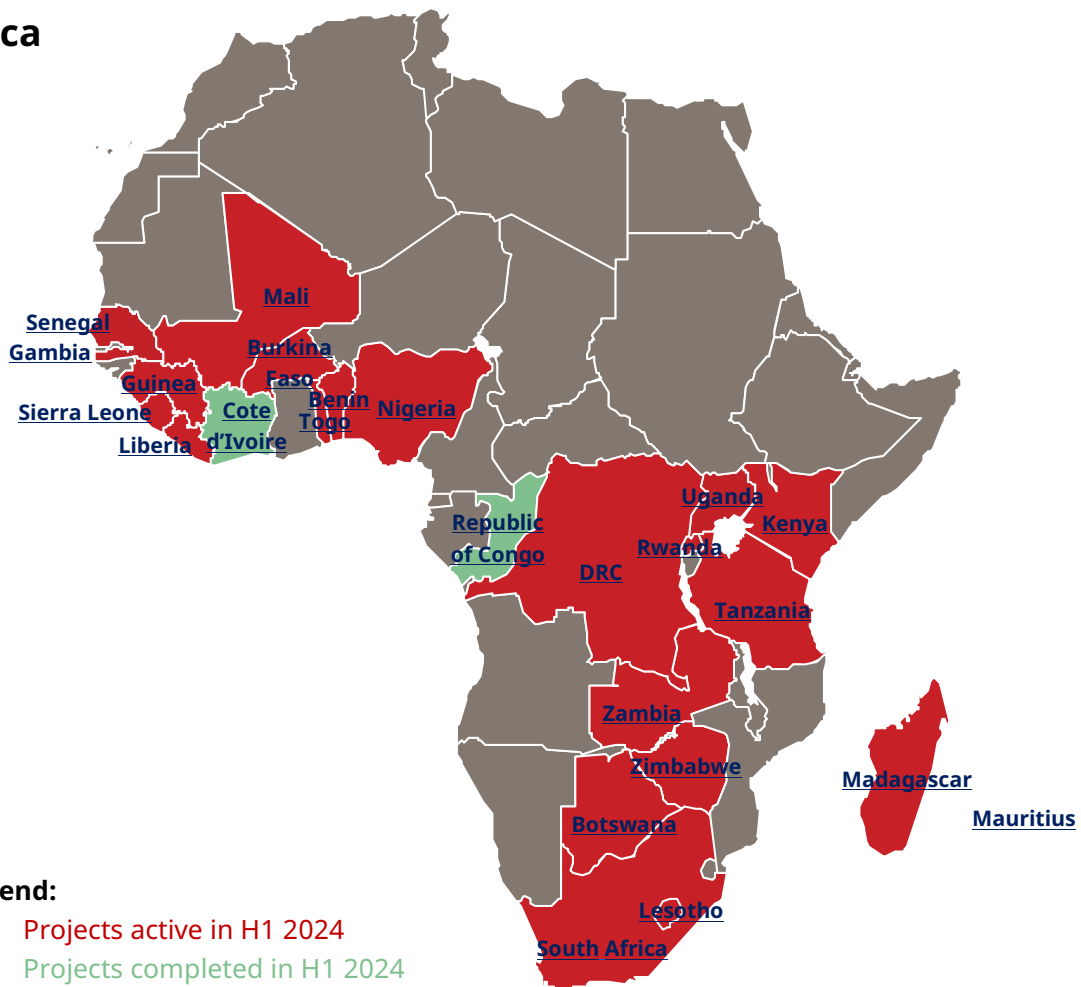
Selected programme updates

1 January – 30 June 2024

Programmes approved since 2005:

- 243 projects (6 new projects since H2 2023)
 - 74 fellowships
 - 29 awards
- in 89 countries

Africa



Legend:

- Projects active in H1 2024
- Projects completed in H1 2024

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 smqy@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

- Training and empowerment of people with haemophilia and families in Kandi.
- 2 refrigerators purchased for the centres of Abomey and Porto Novo to improve factor storage conditions.
- Development of a video film in 6 languages to raise awareness among traditional therapists on haemophilia diagnosis and symptoms.
- Awareness-raising day organised for traditional therapists in Lokossa, Abomey, Parakou and Porto Novo to allow them to recognise the disease and identify warning signs thereby preventing deaths.



Association Béninoise des Hémophilies together with physiotherapists are raising awareness about haemophilia.

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
- 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 physiotherapist from Gaborone underwent a 1-month specialised physiotherapist training at Kenyatta National Hospital in Kenya.
- The Botswana Inherited Bleeding Disorders Association (BIBDA) commemorated World Haemophilia Day 2024 to raise awareness of haemophilia.
- 3 representatives from BIBDA and a haematologist from Princess Marina Hospital attended a 4-day capacity building workshop in Cape Town, South Africa. The South African Haemophilia Foundation (SAHF) delivered a workshop to support BIBDA to build a stronger patient organisation and improve their leadership and advocacy programmes.
- BIBDA held a stakeholder meeting attended by representatives from the Ministry of Health and Welfare, non-communicable diseases department, Central Medical Stores, Botswana Medicines Regulatory Authority, Baylor, and representatives from the private hospitals. The purpose of the engagement was for BIBDA to cultivate a working relationship with the stakeholders and be able to advocate/lobby for the needs of the haemophilia community under one roof with one voice. This would also foster future collaborations.



Advocacy workshop with members of the patient organisation BIBDA.

Burkina Faso 1 project

- Programme title **Expanding haemophilia diagnosis and care in Burkina Faso**
- Phase Execution
- Partner Groupe d'Intervention en Hématologie
- Prof Eléonore Kafando
- NNHF contact smgy@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

Status

- Development and recording of TV and radiophonic spots on disease awareness.
- Training course delivered for medical staff and nurses in the health regions of Koudougou and Kaya.
- Development of an education tool called 'Boite à image' (the image box) intended to be used by community-based health staff in the regions to raise awareness of haemophilia among the population.
- Planning and procedure development for factor dispatchment to regional hospitals.
- *With this project, NNHF is partnering with the Fondation Pierre Fabre to improve diagnosis and care of both haemophilia and sickle cell disease.*



The project team continues their awareness raising activities towards health authorities and the general public.

Cote d'Ivoire 1 Project

- Programme title **Increasing haemophilia awareness and diagnosis in Ivory Coast**
- Phase Closing
- Partner Internationale Hemophilie et Autres maladies de Coagulation du sang - N'dri Moïse Koffi and Prof Ibrahima Sanogo, head of haematology department at CHU Yopougon
- NNHF contact smqy@nnhf.org
- Duration 3 years, Q4 2020 – Q1 2024

Objectives

- Improve haemophilia knowledge in 6 cities in the country
- Strengthen patient organisation's visibility and improve haemophilia knowledge of people with haemophilia and families
- Increase general haemophilia awareness of the public and authorities
- Increase diagnosis rate from 4% to 8% and update registry data

Achievements

- With the aim of raising awareness of haemophilia among healthcare professionals, 282 healthcare professionals including doctors, nurses, lab technicians, and physiotherapists from Korhogo, Yamoussoukro, Bouake, San Pedro, Daloa and Aboisso regions were trained to recognise the clinical signs of haemophilia, refer potential cases to the reference centre and manage emergencies.
- The patient organisation was strengthened through training of its members in strategic planning, media engagement, and advocacy. Additionally, the establishment of regional chapters in Yamoussoukro, Bouake, San Pedro, Daloa and Korhogo has resulted in appointing a focal point in each region, extending its reach, and improving coordination and communication among members. New chapters are also being empowered to have a more active role in the association. For instance, the Bouake chapter has taken charge of organising and hosting World Haemophilia Day 2024 activities.
- Thanks to the impactful awareness raising activities conducted among both the general population and healthcare professionals from 6 regions in Cote d'Ivoire, the country achieved a remarkable 100% increase in the diagnosis rate. As a result of their efforts, a total of 106 people living with haemophilia were successfully diagnosed, doubling the national diagnosis rate from 4% to 8%.
- Specialised training provided of one physiotherapist from Abidjan in Dakar with Dr Sebastien Lobet, who then cascaded his knowledge to 9 other physiotherapists.
- Thanks to the advocacy efforts led by the patient organisation and the medical team, haemophilia has been included in the non-communicable disease programme. As a result, the government has committed to procuring prophylaxis for 50 patients, with ongoing discussions being held to increase this number and cover all patients diagnosed with severe haemophilia A.

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 Formalisation
- Partner Cliniques Universitaires de Kinshasa - Prof Jean Lambert Gini and Prof Léon Tshilolo from CEFA Monkole
- NNHF contact smqy@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 and will soon start with the project activities.

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
- 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

- Patient organisation chapter in Mansa Konko was established with the help of healthcare professionals across the country.
- World Haemophilia Day was celebrated to raise awareness. The event was graced by Ministry of Health officials and healthcare professionals.
- A safe circumcision event was organised at the Edward Francis Small Teaching Hospital which was attended by trained doctors, nurses and lab technicians.
- The number of people with haemophilia has increased from 17 to a total of 28.

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 smqy@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

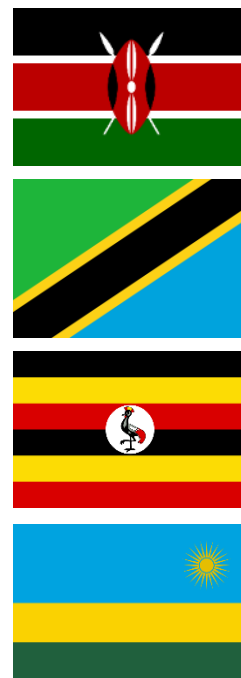
- Organised two 3-day awareness caravans and a diagnosis day both in N'zérékoré and Kankan.
- Purchase of reagents for diagnosis days in N'zérékoré and Kankan.
- 23 people newly diagnosed with haemophilia thanks to the caravans.
- 38 people with haemophilia benefitted from therapeutic educational sessions.
- 57 healthcare professionals were trained to improve haemophilia care.
- *With this project, NNHF is partnering with the Fondation Pierre Fabre to improve diagnosis and care of both haemophilia and sickle cell disease.*



Through the project activities the knowledge of people with haemophilia and their family members about the condition is improving.

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 Emmanuel Seromba
- NNHF contact 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 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

Status updates

Kenya

- Kenya Medical Training College (KMTTC) and Kenya Haemophilia Association (KHA) signed a Memorandum of Understanding (MOU) to collaborate on training and awareness creation on haemophilia and other bleeding disorders.
- KMTTC developed and launched a short course curriculum on these topics and trained a focal team to be trainers.
- KHA also conducted training for patients and parents, identified 29 new haemophilia cases, opened a basic care clinic in Kitui, and held a meeting with the Ministry of Health (MOH) to review policies and legislation.
- KHA also celebrated World Haemophilia Day in two regions and held a meeting with the Non-Communicable Disease Alliance of Kenya (NCDAK) to discuss partnership and collaboration.
- KHA facilitated the training of two pharmacists and two physiotherapists from East Africa in haemophilia comprehensive care centres.

- KHA held a meeting with 12 key stakeholders together with the MOH on 7 June 2024 to review policies and legislation. The team agreed to have a follow up meeting as MOH guides the policies that are not being regulated.
- KHA training for 120 people with haemophilia and parents:
 - 30 people with haemophilia and parents in coast region
 - 90 people with haemophilia and parents in the central region.
- 29 newly diagnosed haemophilia patients have been identified (19 HA and 10 HB).

Rwanda

- Formed a Medical Advisory Committee to provide guidance, advice and representation on medical activities.
- MOH approved and published the Haemophilia Treatment Guidelines.
- Integrated haemophilia into the non-communicable diseases programmes of the Rwanda Biomedical Center (RBC).
- Developed a National Patient Registry to collect and manage data on haemophilia patients.
- Raised awareness on World Haemophilia Day through the Rwanda Broadcasting Agency and a local radio station.
- Two-day workshop in Kampala, Uganda involving Medical Advisory Committee, Youth and Parent representatives, and counterparts from Kenya and Tanzania.
- Trained a physiotherapist in Kenya to provide rehabilitation services for haemophilia patients.

Tanzania

- Launching phase II project.
- Site assessment of new haemophilia clinics which are Mara Regional Referral Hospital (RRH), Kagera RRH, Tabora RRH, Manyara RRH, Tanga RRH, Mnazi Mmoja Referral Hospital and Rukwa RRH.
- Commemorated World Haemophilia Day with participation of Director of Medical Services of Ministry of Health Tanzania, NCD Director MOH, and other dignitaries, health care providers, patients, guardians, media etc.
- Trained 50 health care providers during the Medical Advisory Committee. 15 received training on usage of POCUS, 1 at Kenya, 34 received training during MAC induction and Zoom meeting prepared by HCPs who are received training abroad.
- 24 new patients diagnosed whereby 10 were from Muhimbili National Hospital, 6 from Mnazi Mmoja Referral Hospital (Zanzibar), 5 from Mbeya RRH, 3 from KCMC. Patients were diagnosed through family tree tracing. The total number of diagnosed patients is now 362.
- First Phase 2 Medical Advisory Committee Induction during a celebration of World Haemophilia Day.
- Trained 61 patients and 54 parents during World Haemophilia Day, and 15 patients and care givers during NNHF visit to Zanzibar.
- Handover of Point of Care Ultrasound Machine (POCUS) at Muhimbili National Hospital.
- First Board meeting of Haemophilia Society of Tanzania induction.

Uganda

- The Haemophilia Foundation of Uganda (HFU) team met with NNHF delegation, Ministry of Health officials including the Minister of Health, and the blood bank to discuss improved partnerships and policy gaps. In this meeting the MOH committed to allocate budget for better diagnosis.
- HFU organised World Haemophilia Day with paramedical training school to increase awareness.
- HFU trained gynaecologists and midwives in partnership with their associations.
- HFU conducted basic coagulation training for laboratory staff.
- HFU advocated for improved care with Vice President and legislators on International Day of Nurses.
- Committee formed to support treatment guideline development through MOH.
- Leadership training for youths conducted to involve them in case tracing and advocacy.



Project meeting in Uganda in February 2024.

Kenya and Tanzania 2 project

- Programme title **Strengthening capacity and networks in the Sickle Cell Disease community**
- Phase Execution
- Partner Sickle Cell Fedration Kenya (SFK) –
Dr Fredrick Okinyi, Chairman and
Prof Constance Tenge, Deputy Chairperson



- NNHF contact lymw@nnhf.org
 - Duration 1 year
 - Start date of activities Q2 2024
- Tanzania Sickle Cell Disease Alliance (TSDA) – Dr Elisha Osati,
Chairman and Dr Deogratias Soka, CEO

Objectives

- Align 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

- The project was approved during the NNHF Council meeting in April and will soon start with the project activities.

Lesotho 2 project

- Programme title **Enhancing haemophilia care services in the capital of Lesotho and in the regions**
- Phase Formalisation
- 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

- The project was approved during the NNHF Council meeting in April and will soon start with the project activities.

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
- Duration 2 years
- Start date of activities Q1 2023

Objectives

- Establish haemostasis laboratory at JFK 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 office and laboratory set up were successfully identified at Redemption Hospital, Monrovia.
- Lab equipment for the hospital was successfully procured.
- Capacity building for healthcare professionals was done with 1 doctor trained in Eldoret, Kenya, a nurse trained in Manipal and 2 lab technicians trained in Lucknow, India.

Madagascar 2 project

- Programme title **Improving access to care and treatment for people with haemophilia in Madagascar**
- Phase Execution
- Partner University Hospital Tambohobe Fianarantosa – Dr Mino Fitahiana Danielle and Prof Aimée Olivat Rakoto Alson
- NNHF contact smqy@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

- 100 people newly diagnosed with sickle cell disease and 15 with haemophilia.
- Training of 1 nurse in Geneva and 2 physiotherapists in Cotonou.
- Training of 3 physiotherapists in the capital city and equipping 4 centres with physiotherapy materials.
- Organised joint evaluation sessions for people with haemophilia and sickle cell disease.
- Purchasing of reagents for lab technician training and follow-up training in Fianarantsoa.
- Awareness-raising campaign on circumcision in Fianarantsoa and Toamasina.
- Held monthly coordination meeting with the multidisciplinary team.



Knowledge sharing activities outside the capital city Antananarivo.

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 smgy@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

- Organisation of an intensive awareness-raising activity event involving over 80 people (journalists, patients and their families). This led to the production of 24 press articles, 18 audios and 16 videos, the immediate result of which was the diagnosis of 16 people with haemophilia.
- 2 nurses are currently benefiting from an in-depth training programme in CNTS in Dakar, Senegal.
- Organisation of an awareness and advocacy dinner for World Haemophilia Day which gathered 118 people (people with haemophilia and family members, opinion leaders, government, professional media).
- Training of 13 physiotherapists in Bamako to improve joint management and care.



Physiotherapy training to improve the joints of people with haemophilia.

Mauritius 3 project

- Programme title **Achieving optimal and holistic haemophilia and blood disorders care**
- Phase Formalisation
- Partner Haemophilia Association of Mauritius – Mohsena Olath Carramtally, Operations Manager, and Dr Janaki Sonoo, Victoria Hospital
- NNHF contact smqy@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

- The project was approved during the NNHF Council meeting in April and will soon start with the project activities.

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

- Upgrade of four laboratories: Four laboratories in four centres, namely University of Benin Teaching Hospital (UBTH), the Federal Teaching Hospital Gombe (GFTH), the University College Hospital Ibadan (UCH), and the University of Nigeria Teaching Hospital (UNTH), were upgraded with new equipment and training of lab technicians.
- 2-day virtual nursing training on family tree tracing conducted in February 2024, with 10 nurses participating and benefiting from the experiences of Kenya.
- Workshop/training on laboratory diagnosis of haemophilia for laboratory scientists and doctors took place in April 2024 in Abuja, Nigeria, with 21 participants, including the centre coordinators.
- Guidebook for lab technologists diagnosing haemophilia locally was developed, in addition to the Standard Operating Procedures for centres. These are expected to be launched at the Nigerian Society for Haematology and Blood Transfusion (NSHBT) congress in August 2024.

Republic of Congo 1 project

- Programme title **Building diagnosis and care capacity for people with haemophilia in Congo**
- Phase Closing
- Partner Centre National de Reference de la Drépanocytose " Antoinette Sassou N'Guesso" - Prof Alexis Elira Dokekias
- NNHF contact smqy@nnhf.org
- Duration 2 years, Q1 2022 – Q1 2024



Objectives

- Develop medical competencies on haemophilia, training more than 100 primary healthcare professionals
- Strengthen haemophilia diagnosis in Brazzaville and initiate decentralisation to Pointe-Noire, increasing the diagnosis rate from 18% to 22% by the end of 2023
- Improve people with haemophilia's knowledge on the condition
- Strengthen haemophilia awareness and advocacy in the country

Achievements

- Diagnosis of haemophilia A and B has been decentralised to Pointe-Noire, more than 500 km away from the capital Brazzaville. People with haemophilia living in the region are now saving more than 16 hours (for a return journey) to get diagnosed.
- Established 3 basic haemophilia care centres in Pointe-Noire, Nkayi and Dolisie through increased haemophilia knowledge of 124 healthcare professionals including 7 haematologists, 27 doctors, 28 nurses and 17 lab technicians leading to better recognition of the clinical signs of haemophilia as well as the referral of potential cases to the regional reference centres.
- Awareness raising activities along with capacity building of healthcare professionals led to 22 new people with haemophilia being diagnosed, successfully reaching the target diagnosis rate of 22%.
- Through advocacy and awareness raising efforts during the project, the interest of health authorities already engaged in combating sickle cell disease has steadily increased, demonstrated by their participation in haemophilia-related activities. In 2023 haemophilia, alongside sickle cell disease, was included as a genetic blood disorder in the Non-Communicable-Disease (NCD) strategic plan 2023-2024.
- The partner's next advocacy goal is to obtain the establishment of a subsection within the NCD programme specifically for bleeding disorders.

Senegal 2 project



- Programme title **Expand haemophilia comprehensive care in Senegal and regional care networks in West Africa**
- Phase Formalisation
- Partner Association Sénégalaise des Hémophiles
- Mr Abdoulaye Loum and Centre National de Transfusion Sanguine - Prof Saliou Diop
- NNHF contact smqy@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

- Renovation of the haemophilia clinic of the treatment centre of Dakar has started.
- Organisation of 3 educational sessions on haemophilia for people with haemophilia and their families including newly diagnosed in Dakar and Kaolack Touba.
- 80 people with haemophilia have been trained and empowered during the last 6 months.
- Organisation of a working session to elaborate a protocol for collecting and forwarding of blood samples from regional hospitals to CNTS Dakar.

Sierra Leone 1 project

- Programme title **Establish basic haemophilia care in Sierra Leone**
- Phase Execution
- Partner Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) – Harry Mayeah Koroma and Dr Mavolo Toure
- NNHF contact 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

Status

- 10 people with haemophilia were diagnosed in the last 6 months.
- Frontiers for Hemophilia and Bleeding Disorders Sierra Leone (FHBDSL) has received accreditation as a National Member Organisation (NMO) from the World Federation of Haemophilia (WFH).
- A women and girls advocacy group were formed to reduce stigma and promote empowerment.
- Educational camps for people with bleeding disorders, families, and caregivers about haemophilia were organised.

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
- 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

Status

- Identification of patient registry that may suit SAHF/MASAC requirements.
- Procurement of 3 ultrasound probes.
- Continued community outreach to increase awareness on haemophilia.

Togo 1 project

- Programme title **Expanding haemophilia diagnosis in Togo**
- Phase Execution
- Partner Institut National d'Hygiene - Dr Yao Layibo
- NNHF contact smgy@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

- Development of a video spot in multiple local dialects to raise awareness on haemophilia.
- Purchase of reagents for laboratory technician training and diagnosis day.
- Purchase of two refrigerators to improve factor concentrate storage in both Campus and Sylvanus Olympio university hospitals.



The project team created a video to raise awareness about haemophilia.

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

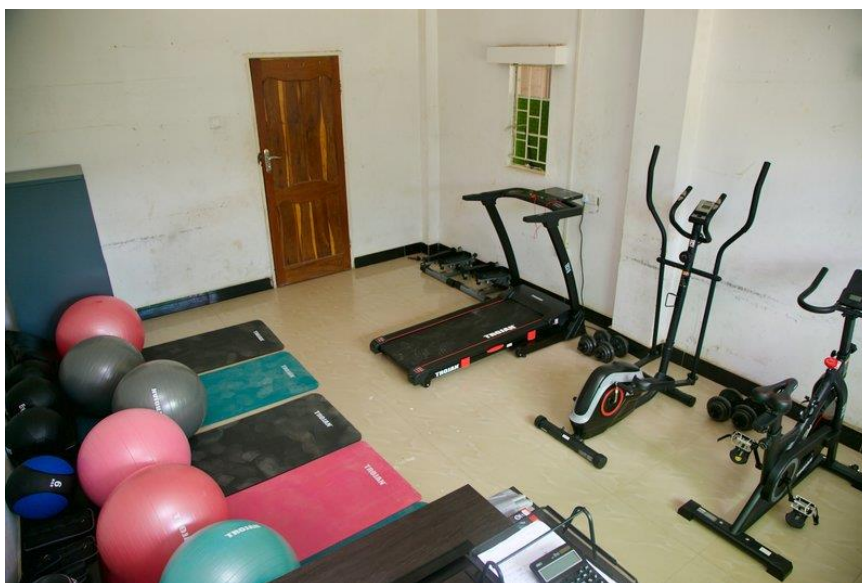


Objectives

- 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

- Established and launched the Haemophilia and Sickle Cell Treatment Centre at the Mansa General Hospital in Luapula Province. Renovated and furnished the outpatient section of Mansa General Hospital to create three private consulting rooms.
- Provided coagulation machine, electrophoresis equipment, and sickle scans for diagnosing haemophilia and sickle cell patients at Mansa General Hospital, and equipping the physiotherapy clinic for improved Musculo-skeletal Care (MSK).
- Held an advocacy event in Lusaka for sickle cell and haemophilia awareness where 45 people from various organisations attended, with one equipment provider donating a semi-automated coagulation machine.
- Trained 37 health workers from district hospitals in Luapula Province on early identification and diagnosis of patients.



In March, Zambia Childhood Cancer Foundation launched the Haemophilia and Sickle Cell treatment Centre in Luapula Province. ©2024 Anthony Kawimbe/Novo Nordisk Haemophilia Foundation/Fairpicture

Zimbabwe 1 project

- Programme title **Establishment of basic haemophilia care in Zimbabwe**
- Phase Execution
- Partner Zimbabwe Haemophilia Association
- Elliot Chintembo and Dr Moses Chatambudza
- NNHF contact 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

- Took part in a family tree tracing training.
- Organised a screening day.

Americas



Legend:

- Projects active in H1 2024

Argentina 6 project



- Programme title **Better joints and quality of life for people with haemophilia in North-Western Argentina**
- Phase Execution
- Partner Fundación de la Hemofilia de Tucumán – Ms Claudia Josefina Castro and Dr María Belén Nieva
- NNHF contact 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

Status

- Continuation of monthly trainings conducted by Dr Guillermo Cambiaggi, orthopaedic surgeon from Buenos Aires for around 30 HCPs from the provinces of North-Western provinces (haematologists, physiotherapists) to improve the understanding of arthropathies.
- Monthly patient assessments were done with ultrasound method.
- Construction work of rehabilitation pool at the Tucumán haemophilia centre has started and will be finalised end of August.
- Awareness raising activities were organised during World Haemophilia Day which included a session on the local radio and television.



Training with Dr Guillermo Cambiaggi on physiotherapy.

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 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

- Laboratory at Hospital Manuel Asencio Villaroel in Cochabamba was refurbished after the new director of hospital agreed to give a bigger space for the laboratory. A microscope was procured for the laboratory.
- Odontologists, orthopaedic surgeons and physiotherapists were selected to be trained abroad.

Guatemala 2 project

- Programme title **Establishing a national haemophilia registry and multidisciplinary care teams in Guatemala**
- Phase Formalisation
- 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 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

- Roles and responsibilities of project activities have been distributed among healthcare professionals from Guatemala City.
- The different teams have been working on planning upcoming trainings abroad.

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 eiel@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

- A haematologist from Hospital Escuela Universitario in Tegucigalpa was trained for one month in Buenos Aires, Argentina.
- Physiotherapy equipment was procured for Hospital Escuela Universitario.
- Registry has been continuously updated and patient ID's were printed for patients living in rural areas.
- More patients have been identified for the shoe procurement as part of the NNHF Step by Step project.

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 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

- Proposal obtained from St. Michael's Hospital in Canada to facilitate sharing of laboratory SOP's and eventually sharing of samples.
- Poster for the emergency rooms have been designed for acute management of persons presenting bleeds.
- Treatment Guidelines have been drafted and will be soon shared with MoH.



Haemophilia care knowledge exchange with the team from Dominican Republic.

Latin America 1 project

- Programme title **Stories of haemophilia carrier women to expand awareness in Latin America**
- Phase Execution
- Partner Fundación de la Hemofilia Argentina, Córdoba chapter
- Mrs María Belén Robert and Mrs Yuri Andrea Arango
- NNHF contact ei@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

Status

- Proposals were developed for mini-projects in Argentina, Mexico, Panama, Colombia and Uruguay.
- The last focus group was held in Panama City which was attended by 15 carrier women representing different regions of the country.
- 200 educational booklets were distributed to 7 countries in the region.



Focus group discussion in Panama.

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 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

- Authorisation from local authorities to carry out modifications in the rehabilitation area of the Hospital Morones Prieto.
- Host institutions identified for the training of haematologist and physiatrist.
- 2 additional patients were diagnosed in the region of San Luis Potosí.

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
- 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

- 2- day training for social workers from satellite clinics was conducted by Laura Paez from Monterrey, Mexico.
- 1- day training for pharmacists from satellite clinics was conducted.
- 3- day camp was organised for children with haemophilia to improve knowledge about disease management. In total 47 participants attended the camp.



3-day patient camp for 47 people with haemophilia and family members.

Paraguay 2 project

- Programme title **Strengthen haemophilia care structures and network in Paraguay**
- Phase Formalisation
- 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

- Project Partnership Agreement signed and activities will start in August 2024.

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 2.5 years
- Start date of activities Q2 2022



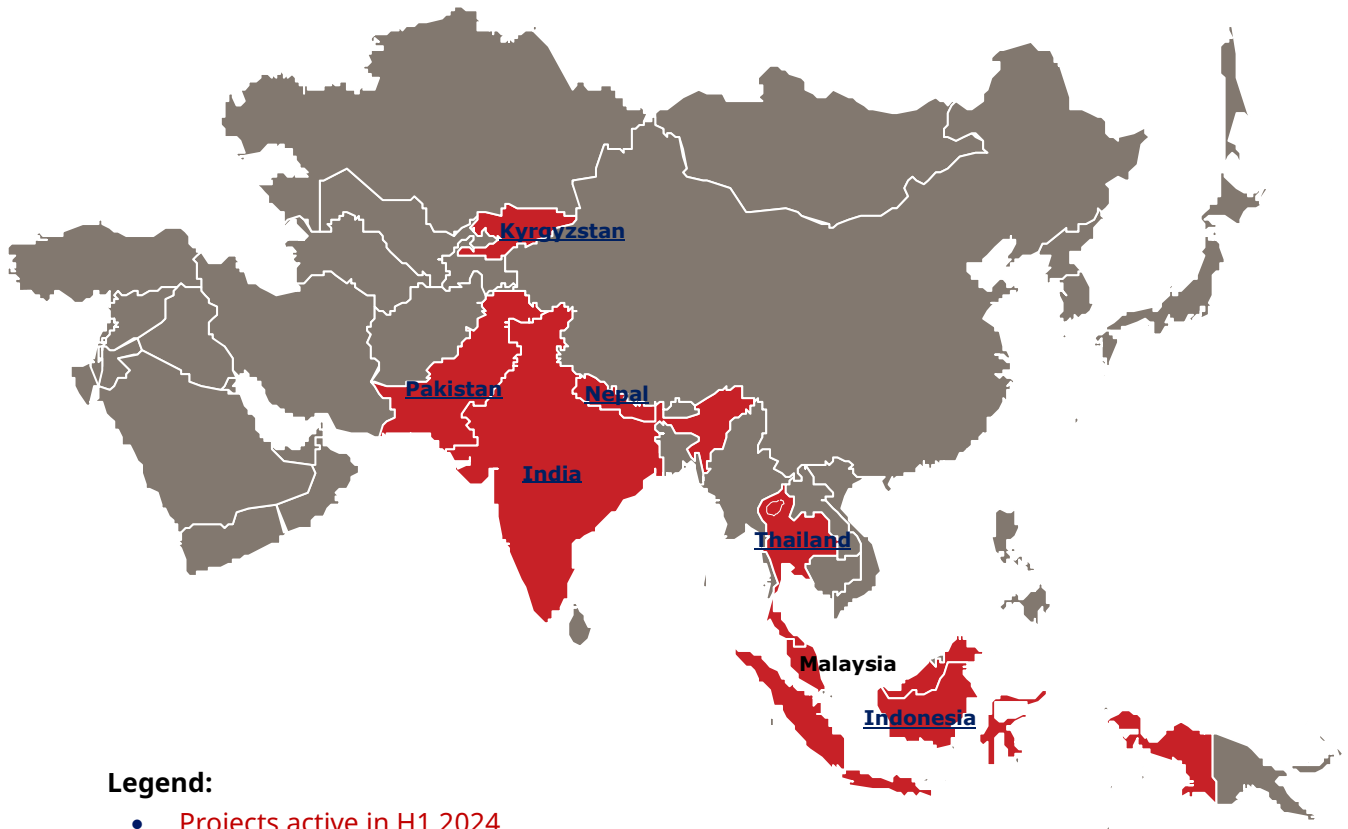
Objectives

- 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

- 5 committees (mothers, youth, political, institutional and communications) were formed as part of the patient organisation with clear roles and responsibilities.
- ASPEH participated in a roundtable at the Congress of the Republic advocating for regulations to improve treatment of rare and orphan diseases, aiming at shortening the approval time for medicines.

Asia and Near & Middle East



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 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

- Participated in Purple Fest 2024, a collaborative festival organised by the Directorate of Social Welfare in Goa state. The festival advocated for diversity encompassing the 21 types of disabilities recognised under the Rights of Persons with Disabilities Act in India.
- During the Purple Fest, a Blood Disorder side-event was hosted with key decision makers and healthcare professionals discussing the needs of the blood disorder community and gaining media coverage.
- Strategy workshop between Hemophilia Federation (India), the National Thalassemia Welfare Society and the National Alliance of Sickle Cell Organizations, discussing how to pilot an integrated awareness raising and care model in two selected states.
- Four regional advocacy training workshops conducted with Hemophilia Federation (India), where a total of 170 participants received training in advocacy and developed action plans tailored to their respective states.
- Representatives from Hemophilia Federation (India) met with the National Health Mission state officials to discuss future collaborations and policymaking between the patient organisation and state authorities in four states: Rajasthan, Kerala, Maharashtra and Telangana.
- Four states (Maharashtra, Tamil Nadu, West Bengal and Karnataka) successfully advocated for increased budget allocation for haemophilia. Additionally, Maharashtra state government has instructed to have treatment available in all district hospitals of the state, increasing from 9 to 36 haemophilia treatment centres.



An advocacy workshop for the Western Region took place beginning of the year.

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

- Following the outreach visit to Kupang at the end of 2023, the project team continues to have regular check-ins with the team there to observe the progress.
- The team started with the preparation for the second outreach visit to Pontianak, West Kalimantan. Two online meetings were organised with the committee in Pontianak, and the Provincial Health Authorities as well as the provincial hospital have been informed about the upcoming visit. The visit is planned for the second half of 2024.
- At the same time, the project team is also procuring two educational videos on musculoskeletal care examination and joint health maintenance. The videos are soon to be finalised.

Indonesia 4 project

- Programme title **Establish a regional referral centre in Surabaya and sustainable diagnosis and treatment in East Java, Indonesia**
- Phase Formalisation
- 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 Q3 2024

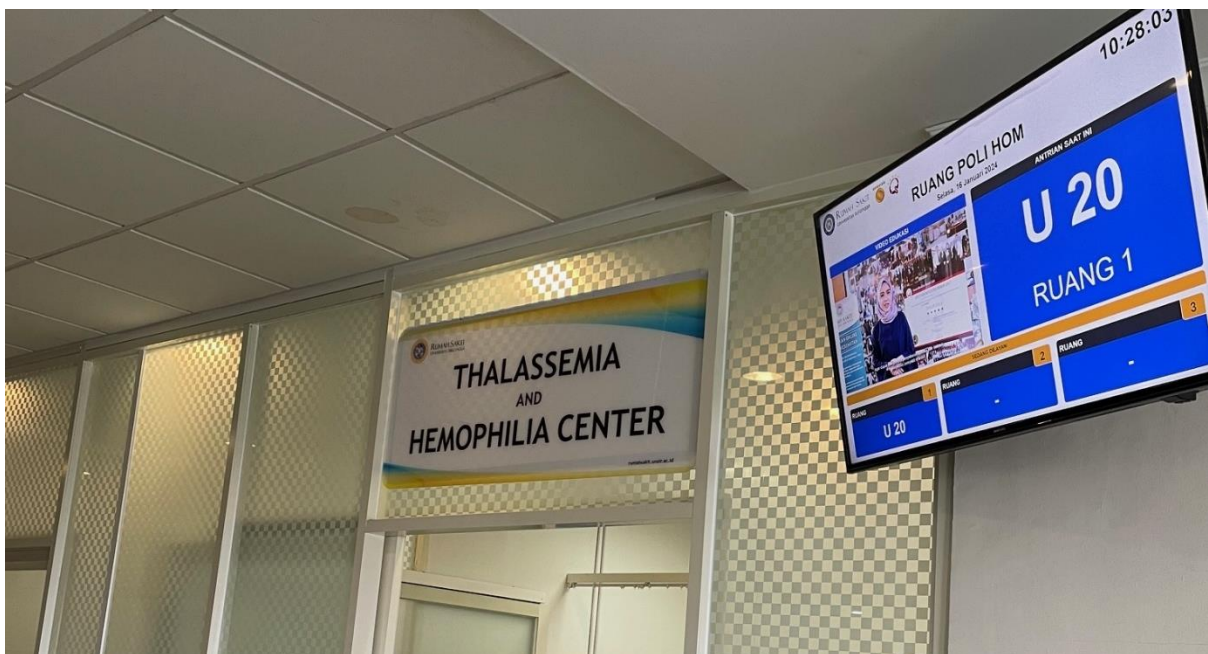


Objectives

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

Status

- The project was approved during the NNHF Council meeting in April and will soon start with the project activities.



In January 2024, a fact-finding visit to Surabaya took place.

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
- 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 was approved during the NNHF Council meeting in April and will soon start with the project activities.



First in-person meeting with the project team during the WFH congress 2024 in Madrid.

Nepal 3 project

- Programme title **Strengthen multidisciplinary care teams in Kathmandu and 7 provinces**
- Phase Execution
- Partner Nepal Hemophilia Society
- Mr Mukunda Mani Ghimire, President and Bir Hospital, represented by Dr Niraj Singh, haematologist
- NNHF contact eiel@nnhf.org
- Duration 3 years
- Start date of activities Q3 2023



Objectives

- Strengthen capacity of the multidisciplinary care teams at 2 government referral hospitals in Kathmandu
- Continue improving the level of care and diagnosis in the 7 main provincial hospitals
- Increase the diagnosis rate from 25% to 33%
- Sustain advocacy gains and increase budget allocation for people with haemophilia by 30%
- Strengthen capacity of new board of patient organisation through an international collaboration and empowerment of the haemophilia community through workshops on self-management

Status

- Project is currently on hold. Further updates will be given in due course.

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
- 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

- The project team is continuing the discussion with the Children's Hospital in Lahore to establish basic haemophilia care. The hospital shows great interest and is committed to support people with bleeding disorders. The hospital agreed to allocate a consultation room for people with haemophilia and the parties are currently working on signing the Memorandum of Understanding.

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 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

- Training session in January at Hat Yai Hospital for 17 healthcare professionals on haemophilia symptoms and how to care for people with haemophilia.
- In February, a training was organised on the use of point-of-care ultrasound in Bangkok. The training was led by SickKids Canada and saw the participation of 33 Thai and Nepalese healthcare professionals. Later in the year, three radiologists will travel to Canada for an in-depth training.
- In May, the project team celebrated World Haemophilia Day at Songklanagarind Hospital with 43 people with haemophilia and family members. There were sessions on treatment and self-care as well as the possibility to exchange and share learnings.



In February, the team from SickKids Canada led a point-of-care ultrasound training for healthcare professionals across Thailand.

Thailand 6 project

- Programme title **Strengthen haemophilia care in Northeast Thailand**
- Phase Execution
- 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
- Duration 2.5 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.

Status

- In January, a training for healthcare professionals was organised in Chaiyaphum together with the support of Prof Nongnuch Sirachainan from Ramathibodi Hospital in Bangkok.
- The core project team joined the training on point-of-care-ultrasound in Bangkok in February. The training was led by the Canadian team from SickKids. The radiologist will attend an in-depth training in Canada later in the year.
- In May, a training session was held for nurses and the emergency personnel from Srinagarind hospital.

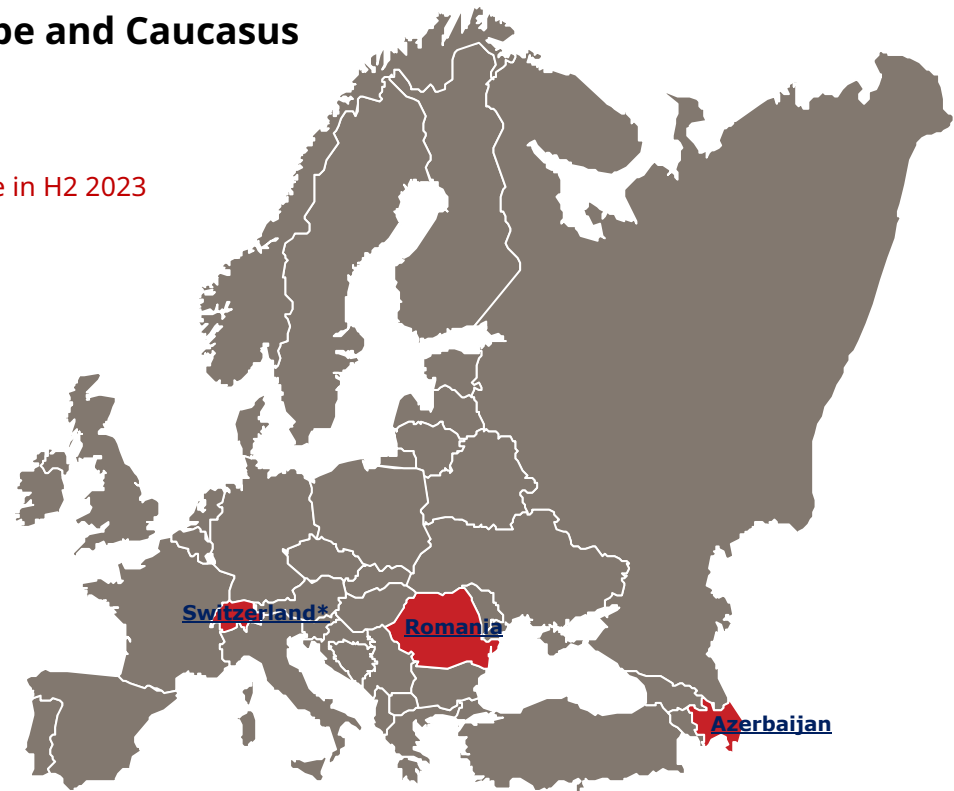


Training for nurses and emergency personnel in Khon Kaen.

Eastern Europe and Caucasus

Legend:

- Projects active in H2 2023



*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 Execution
- Partner Azerbaijan Republic Association of Hemophilia, Baku
- Gulnara Huseynova
- NNHF contact 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

- The patient organisation met with the State Agency for Compulsory Health Insurance and Administration of the Regional Medical Divisions (TABIB) to discuss a joint action plan for 2024. This includes the ongoing training of physiotherapists, haematologists, paediatricians and dentists across the country.
- A seminar was held for healthcare professionals at the Absheron District Central Hospital in collaboration with TABIB focusing on the importance of MSK and dental care.



Dental care workshop for healthcare professionals at the Absheron District Central Hospital.

Romania 4 project

- Programme title **Strengthen haemophilia care in North-Eastern Romania and improve dentistry care across the country**
- Phase Execution
- Partner Romanian Hematology Society (RHS) – Dr Ciprian Tomuleasa
- NNHF contact 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

Status

- The team continues to raise awareness and diagnose new people with haemophilia, especially from Iasi, Eastern Romania.
- All activities are to be finalised and the project will be closed soon.

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 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.

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 2.5 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 from the NNHF partner network

Status

- A second cohort of participants was held from February – April 2024, with participants from 14 countries.
- Based on feedback and monitoring framework, an evaluation of the programme is now underway that will lead to recommendations for the refinement of the next proposed phase of the programme.