

After an in-depth training of healthcare professionals from Cambodia in Nottingham, UK, the Nottingham team visited Cambodia for a follow-up visit. This is part of the Cambodia 2 project, which aims at establishing multidisciplinary care.

Selected programme updates

1 January – 30 June 2019

Programmes approved since 2005

- **180 projects** (4 new projects since last half year)
- **74 fellowships**
- **19 awards**

Engaged in **73 countries** leading to

- > 43,200 HCPs trained or re-trained
- > 27,400 patients diagnosed or re-diagnosed
- > 47,000 patients & family educated or re-educated



novo nordisk
haemophilia foundation



Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
Africa	Angola 1 project	Developing haemophilia awareness in Angola	Formalisation	Liga dos Amigos dos Doentes Hematológicos de Angola - Mr Kaunda da Gama and Dr Luis Bernardino (semi-retired from Hospital Pediátrico David Bernardino)	sdtm@nnhf.org	<ul style="list-style-type: none"> - Increase public and authorities' level of knowledge about haemophilia - Empower members of the patient organisation through international exchanges - Develop haemophilia knowledge of healthcare professionals in Luanda and Huambo - Upgrade reference laboratory in Luanda and decentralise diagnosis to Huambo - Improve knowledge of haemophilia amongst people with haemophilia and families 	- Project application approved by NNHF Council on 15 May 2019.	2 years	Q3 2019
Africa	Botswana 1 project	Improve access to diagnosis and bleeding disorders care in Botswana	Execution	TXCH Global HOPE Botswana at Princess Marina Hospital - Dr Jeremy Slone, Medical Director	sysd@nnhf.org	<ul style="list-style-type: none"> - Establish core haemophilia team including doctor and nurses - Strengthen the reference diagnosis centre - Create public awareness to identify new PwH - Empower regional hospitals to identify PwH and provide basic care. 	<ul style="list-style-type: none"> - The project steering committee has been established. The committee engaged in a series of consultative meetings with the relevant authorities to ensure all parties are on board. - In line with the Botswana Ministry of Health training requirements, a request was submitted to assign one doctor and two nurses for training abroad. - Strategic Awareness Creation workshop was conducted on June 19th. The workshop was attended by 21 participants including members of the Botswana Haemophilia Association, nurses, and members of the Global HOPE Botswana team. 	1.5 years	Q2 2019
Africa	Egypt 3 project	Decentralisation of care across Egypt	Execution	Gamaeat Asdika Marda Al Nazf (= Egyptian Society of Hemophilia) - Dr Magda Rakha, president	sysd@nnhf.org	<ul style="list-style-type: none"> - Empower 20 youth for ESH succession planning - Establish a national online bleeding disorder registry - Improve care provided in the regions by organising 6 outreach visits - Decentralise advanced care to the regions by strengthening 2 haemophilia centres. 	<ul style="list-style-type: none"> - Organised 2-day workshop including Strategic Planning workshop and Project Planning workshop. The youth group together with the patient organisation board agreed on the patient organisation mission and vision. Additionally, they developed the organisation's strategic plan and formed 4 working groups to execute the agreed activities. - An outreach visit to Banha was organised including doctors' training, nurses' training and a meeting for PwH. 	2.5 years	Q1 2019
Africa	Ethiopia 1 project	Improve haemophilia care in Ethiopia by decentralisation of care and empowerment of haemophilia community	Execution	Ethiopian Hemophilia Society - Mr Samson Hailemariam	sysd@nnhf.org	<ul style="list-style-type: none"> - Improve access to care by establishing 2 regional haemophilia treatment centres - Improve haemophilia care by updating and disseminating the treatment guidelines - Increase PwH quality of life by improving their self-care skills - Raise awareness in the community about haemophilia. 	<ul style="list-style-type: none"> - 22 nurses from 10 referral hospitals attended intensive training including hospitals for 7 regions and Addis Ababa. Each hospital selected 1 nurse from the paediatric department and internal medicine. The training was facilitated by experts from the Children's Hospital of Minnesota. - In addition to 3 physiotherapists from Addis Ababa, 13 physiotherapists from 7 referral hospitals attended specialised haemophilia training. The training was facilitated by experts from the Children's Hospital of Minnesota. - A coagulometer was purchased after a review process by the Medical and Scientific Advisory Board of Ethiopian Hemophilia Society (MASAC). - WHD was celebrated with a half day event which was used to share the experiences of people with haemophilia and doctors. At the event, 2 educational materials were distributed to the patients 'What is Haemophilia?' and 'Exercises for people with haemophilia'. 	2 years	Q2 2018
Africa	Ghana 2 project	Improve access to haemophilia care and create awareness at the regional and primary health levels in Ghana	Execution	Ghana Haemophilia Society - Mr Martin Boakye	sysd@nnhf.org	<ul style="list-style-type: none"> - Strengthen the patient association - Build HCP capacity in the regions - Improve diagnosis capacity - Organise educational programme for PwH and their families - Increase awareness about haemophilia. 	<ul style="list-style-type: none"> - 70 healthcare professionals from Ho Municipal District and the Volta Region were trained on identification of people with haemophilia and management of haemophilia. - The new coagulometer was installed in Komfo Anokye Teaching Hospital, Kumasi. - 12 laboratory scientists were trained on using the coagulometer. - During the outreach activities, 66 potential bleeding disorders patients were identified. So far, 21 confirmed diagnosis with haemophilia. - 156 people with haemophilia and 42 parents attended 3 regional educational meetings in Kumasi, Accra and Koforidua. The participants were trained on self-infusion and first aid. - The website domain was purchased. The updates of the website are still ongoing with all activities of the society. 	2 years	Q1 2017
Africa	Kenya 4 project	Provide standardised quality care across Kenya	Execution	Kenya Hemophilia Association - Dr Kibet Shikuku	sysd@nnhf.org	<ul style="list-style-type: none"> - Develop referral system and treatment guidelines - Strengthen Kenyatta National Hospital to become a haemophilia training facility - Bring care closer to PwH by establishing one haemophilia clinic and two satellite clinics - Improve bleeding disorders data management - Improve governance of KHA and ensure proper succession planning - Increase public awareness on haemophilia and improve community knowledge - Increase government support of bleeding disorders. 	<ul style="list-style-type: none"> - Kenya Haemophilia Association celebrated World haemophilia Day by holding a gala dinner which was graced by the Permanent Secretary of the Ministry of Health and attended by 5 county first ladies of Bungoma, Laikipia, Kisumu, Kisii and Kakamega. - On April 17th, a haemophilia treatment centre was opened at the Kisii County Referral Hospital. The event was graced by the first lady of Kisii, H.E Elizabeth Ongwae. - On April 16th, 41 nurses, 6 doctors and 3 lab technologists were trained in Kisii on identification, diagnosis and haemophilia treatment. - A coagulometer was purchased and installed in Muranga County Referral Hospital. 7 laboratory technologists were trained on coagulation tests. - 71 traditional circumcisers from Bungoma County were sensitised on haemophilia symptoms and identification. The event was graced by the first lady H.E Caroline Wangamati. - Kenya Haemophilia Association shared their experience with the sickle cell community. During the meeting, it was agreed that there is a need to form one umbrella sickle cell organisation to have one voice. - A petition about haemophilia was presented in the Kenya Parliament advocating for better haemophilia care in Kenya. - The treatment guidelines and referral system were developed and were submitted to the Ministry of Health for adoption. 	2 years	Q2 2018
Africa	Madagascar 1 project	Empower the haemophilia community and strengthen multidisciplinary care in Madagascar	Execution	Hopital Universitaire Joseph Ravoahangy Andrianavalona (CHU JRA), Antananarivo - Prof Aimee Olivat Rakoto Alson	sysd@nnhf.org	<ul style="list-style-type: none"> - Increase the diagnosis rate to 10% through awareness creation to general public, medical school and regional hospitals - Strengthen multidisciplinary care and facilities in the capital city - Standardise care in Madagascar by establishing treatment guidelines - Empower patient organisation's current board and enhance awareness among people with haemophilia and families - Bring care closer to the people with haemophilia by decentralisation of care to two other regions 	- The Project Partnership Agreement was signed. The activities will start in H2 2019.	2 years	Q3 2019
Africa	Malawi 2 project	Expand haemophilia care to the South region of Malawi	Execution	Society of Haemophilia and Allied Disorders (SHAD) - Mrs Chimwemwe Chande and Dr Yohannie Mlombe	sysd@nnhf.org	<ul style="list-style-type: none"> - Ensure access to haemophilia care and diagnosis in the South - Increase disease knowledge and screening of 50 people with haemophilia - Improve the management of people with bleeding disorders during circumcision in Malawi 	- The Project Partnership Agreement was signed. The activities will start in H2 2019.	2 years	Q2 2019

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
Africa	Mali 2 project	Improving knowledge and support of haemophilia at national level	Execution	Association Malienne de Lutte contre l'Hémophilie (AMALHEC) - Dr Yacouba Diallo	sdtm@nnhf.org	<ul style="list-style-type: none"> - Achieve inclusion of haemophilia in the agenda of Malian Government Health department by 2021 - Strengthen the haemophilia knowledge of 90 HCPs in three regions of the country - Improve knowledge of people with haemophilia, families and traditional practitioners on bleeding disorders in three regions of the country - Increase diagnosis rate in Mali from 6% to 16% by the end of 2021 - Improve joint health of people with haemophilia 	<ul style="list-style-type: none"> - Purchase of a computer for registry activities. - Planning of the training sessions for healthcare professionals, traditional practitioners, people with haemophilia and family members in the region of Koulikoro. 	3 years	Q2 2019
Africa	Mauritius 2 project	Improve multidisciplinary care for people with bleeding disorders in Mauritius	Execution	Haemophilia Association of Mauritius - Mrs Mohsena Olath-Carramtally and Dr Janaki Sonoo from Victoria Hospital, Candos	sysd@nnhf.org	<ul style="list-style-type: none"> - Improve self-management of the condition for 100 people with haemophilia - Improve joint function by establishing MSK care - Strengthen psychosocial wellbeing of 75 people with haemophilia and family members 	- The Project Partnership Agreement was signed. The activities will start in H2 2019.	2 years	Q3 2019
Africa	Namibia 1 project	Establish a basic multidisciplinary team in Windhoek and improve haemophilia management in Namibia	Execution	Namibian Haemophilia Foundation - Mr Immanuel Mayiji and Dr Regina Roerber	sysd@nnhf.org	<ul style="list-style-type: none"> - Increase diagnosis rate from 24% to 35% through awareness creation - Establish a basic multidisciplinary team in Windhoek Central Hospital - Increase knowledge of haemophilia among 100 interns and medical graduates - Improve 75 people with haemophilia's understanding of their condition 	- 6 participants attended the Strategic Awareness Creation workshop which was conducted on June 19th in Botswana. During the workshop, the team agreed on strategic objectives, awareness plan, key message and key audiences.	1.5 years	Q3 2019
Africa	Rwanda 1 project	Establish basic haemophilia care in Rwanda	Execution	Rwanda Federation of Hemophilia - Mr Emmanuel Seromba	sysd@nnhf.org	<ul style="list-style-type: none"> - Establish a haemophilia treatment centre and team - Conduct outreach to start haemophilia care in the regions - Increase national diagnosis rate - Empower people with haemophilia. 	<ul style="list-style-type: none"> - A physiotherapist was trained for 3 weeks in Centre de Traitement de l'Hémophilie Hôtel Dieu, Nantes. - A coagulometer was purchased and will be installed in November. 	2 years	Q2 2019
Africa	Senegal 1 project	A better life for Senegalese with haemophilia	Formalisation	Association Sénégalaise des Hémophiles - Mr Abdoulaye Loum (president) and Anna Seck (fundraising manager)	sdtm@nnhf.org	<ul style="list-style-type: none"> - Improve ability of 250 healthcare professionals to provide basic haemophilia care in 5 regions of the country - Provide people with haemophilia and family members with a better understanding of the condition - Establish a physiotherapy room at the CNTS - Increase general public and authorities awareness about haemophilia - Strengthen the Association Sénégalaise des Hémophiles (ASH) 	- Project application approved by NNHF Council on 15 May 2019.	2.5 years	Q3 2019
Africa	South Africa 4 project	Strengthen South African Haemophilia Federation capacity through youth development and empowerment of healthcare providers	Execution	South African Haemophilia Foundation (SAHF) and its Medical and Scientific Advisory Council (MASAC) - Mr Johan Potgieter	sysd@nnhf.org	<ul style="list-style-type: none"> - Establish a national web-based registry - Improve capacity and succession planning of SAHF - Improve haemophilia care through multidisciplinary training. 	<ul style="list-style-type: none"> - The online registry has been developed. A workshop was held in Cape Town with the test team to share feedback. Additional changes required before going live. Ethics approval is in progress for all selected centres. The process of manual updates and data cleaning was agreed upon. - Social media platforms have been established to improve reaching out to the youth group. - Basic haemophilia training for 35 doctors was organised at the Grey's Hospital in Pietermaritzburg, KwaZulu-Natal Province. The training focused on introduction to haemophilia, diagnosis, management and treatment protocol. 	3 years	Q3 2017
Africa	Uganda 3 project	Improve haemophilia management in Uganda	Execution	Haemophilia Foundation of Uganda - Agnes Kisakye	sysd@nnhf.org	<ul style="list-style-type: none"> - Improve patients management at 8 regional referral hospitals - Increase diagnosis rate from 5% to 8% through awareness raising among traditional leaders, public and medical teams - Register all people with bleeding disorders in an online registry - Achieve inclusion of haemophilia in the non-communicable diseases programme and budget - Improve diagnosis capacity in the North - Strengthen the haemophilia care unit in the North to improve patient management - Empower next generation of haemophilia community leaders. 	<ul style="list-style-type: none"> - HFU team participated at the Vice President's health camp organised in Kabulasoke, Gomba District. Over three hundred people attended the Health camp - 40 Village Health Team (VHT) were sensitised about haemophilia. - To advocate for better care, the team participated at the parliamentary health week, where educational leaflets were disseminated to visitors and other exhibitors. In addition to the parliament members, the Vice President of the Republic of Uganda, H.E Edward Kiwanuka Ssekandi visited HFU booth. - A media press breakfast meeting was successfully organised. 51 reporters attended the meeting and learned about haemophilia. Wide spread public awareness was created as a result. Over 50 radio stations, 10 television channels and 3 newspaper articles published about haemophilia challenges. - 21 new patients were diagnosed. Currently, 234 patients are registered. - Haemophilia Federation of Uganda participated at the Non-Communicable Diseases Department meeting. The technical team agreed that haemophilia should be included in the list of non-communicable diseases. 	2 years	Q2 2019
East Asia	Cambodia 2 project	Establish multidisciplinary care and strengthen awareness in Cambodia	Execution	Cambodian Hemophilia Association (CHA) - Mr Sokpanha Sem	smqy@nnhf.org	<ul style="list-style-type: none"> - Establish multidisciplinary care teams in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap - Decentralise basic care to 5 provincial hospitals - Strengthen advanced diagnosis in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap - Increase self-management ability of people with haemophilia and family members - Strengthen the patient association by having more active members - Create awareness about haemophilia. 	<ul style="list-style-type: none"> - The team of healthcare professionals from Nottingham University Hospital visited Siem Reap and Phnom Penh, following-up on the in-depth training of 2 doctors, 2 nurses and 1 physiotherapist in UK. - Phnom Penh youth group established. - Two laboratory technicians from Ankor Hospital for Children were trained in the National Pediatric Hospital in Phnom Penh. The training was followed by a follow-up visit. - WHD celebrated in both Phnom Penh and Siem Reap for a total of 106 people with haemophilia and their family members. The focus of the celebration was joint health, putting in action the knowledge of the in-depth trained physiotherapists. The celebration was also used to raise national awareness and five different news channels published about haemophilia signals. 	3 years	Q1 2018
East Asia	China 10 project	Strengthening comprehensive care and empowering children and families in six provinces of China	Formalisation	Beijing Children's Hospital, Capital Medical University - Dr Runhui Wu	smqy@nnhf.org	<ul style="list-style-type: none"> - Strengthen paediatric comprehensive care in 6 provinces, using the BCH comprehensive care model to improve organisation and delivery of care in HTCS - Empower children with haemophilia and their family members and increase their self-care knowledge using the BCH patient camp model - Create awareness of haemophilia amongst people with haemophilia, public and authorities 	- Project was approved in March 2018 and will presumably start its activities in mid-2019.	3 years	Q3 2019

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
East Asia	China 5 project	Set up and consolidate five comprehensive treatment centres for haemophilia and von Willebrand disease in Jiangsu Province	Execution	The First Affiliated Hospital of Suzhou University - Prof Ziqiang YU	smqy@nnhf.org	<ul style="list-style-type: none"> - Set up multidisciplinary care and train the teams in Suzhou, Nanjing, Yangzhou, Huaian and Xuzhou - Advance the capacity in the selected centres on factor activity and VWD detection, and the usage of the registry system - Provide technical and patient support, and raise awareness through follow-up visits, project specific meetings and World Haemophilia Day activities. 	<ul style="list-style-type: none"> - Assessment tour of 13 established HTC in Jiangsu Province, all now able to provide multidisciplinary care. - 20 doctors trained about assessment of joints of people with haemophilia in Nanjing. - WHD celebrations in Suzhou, Nanjing, Yangzhou, Huaian and Xuzhou educating people with haemophilia about self-management of their condition and creating awareness about the haemophilia signals. Local media covered the events. 	3 years	Q2 2016
East Asia	China 6 project	Decentralisation of multidisciplinary care in four city level haemophilia centres in Sichuan Province	Execution	Sichuan Centre of Haemophilia Diagnosis and Treatment - Prof Xiaojing LI	smqy@nnhf.org	<ul style="list-style-type: none"> - Select four city-level haemophilia centres in Nanchong, Luzhou, Dazhou and Ya'an - Set up multidisciplinary care and train the teams - Advance the capacity of factor activity detection and the usage of the registry system in the selected centres - Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities. 	<ul style="list-style-type: none"> - Healthcare professionals from the HTCs in Nanchong, Luzhou, Dazhou and Ya'an trained to do ultrasound assessments of people with haemophilia. - 50 people with haemophilia educated about proper home treatment and self-infusion. - WHD celebration carried out together with Chengdu Rare Disease Care Center focusing on creating awareness about haemophilia. - 26 newly diagnosed and registered people with haemophilia. 	3 years	Q2 2016
East Asia	China 8 project	Establishing and strengthening quality haemophilia care in the northeast region of China	Execution	Blood disease hospital, Chinese academy of medical science - Prof Renchi Yang	smqy@nnhf.org	<ul style="list-style-type: none"> - Establish and strengthen haemophilia care in 7 provinces in China - Increase quality diagnosis across 7 provinces - Consolidate patient data in national online patient registry, including medical data - Empower people with haemophilia and families to enjoy better quality of life and becoming an active partner within the haemophilia community - Increase understanding and recognition about haemophilia amongst general public, HCPs and authorities - Improve legislation and reimbursement for haemophilia care by introducing haemophilia within provincial health care agendas. 	<ul style="list-style-type: none"> - More than 300 healthcare professionals from regional hospitals trained in Hebei, Jilin and Heilongjiang province about diagnosis and care of people with haemophilia. - Inspection visit and follow-up training of healthcare professionals in Haerbin medical college - People with haemophilia and their family members in Xi'an province were educated on proper home care, focusing especially on their ability to self-infuse. - WHD celebrated in all 7 provinces with the theme "reaching out - the first step to care". - Four new haemophilia treatment centres established in Liaoning province. - 414 new people with haemophilia registered. - The medical insurance policy improved in Henan, Harbin, Hebei, Inner Mongolia and Heilongjiang province due to strategic advocacy activities. 	3 years	Q2 2017
East Asia	Indonesia 2 project	Improve access to care through strengthened multidisciplinary care teams in regional core centres and focused outreach to 10 provinces	Execution	Indonesian Society of Hematology & Blood Transfusion (ISHBT) - Dr Novie Amelia Chozie, Board member at ISHBT and MD at Cipto Mangunkusumo Hospital	smqy@nnhf.org	<ul style="list-style-type: none"> - Establish and strengthen multidisciplinary haemophilia care and emergency management in 9 regional HTCs and 1 CCC - Perform outreach in 10 selected provinces by educating primary and secondary healthcare providers about haemophilia - Educate people with haemophilia and families in 10 selected provinces about self-infusion and better self-management. 	<ul style="list-style-type: none"> - Education and awareness programme for primary and secondary healthcare providers in Surabaya, a newly established HTC. - Healthcare professionals in Bandung trained about emergency management of people with haemophilia. - 186 people with haemophilia and 83 family members educated about self-management in Surabaya and Bandung. - Educational materials distributed to healthcare professionals, people with haemophilia and families in Surabaya and Bandung. - 15 new patients diagnosed. 	3 years	Q2 2017
East Asia	Nepal 2 project	Improving diagnosis and multidisciplinary care in Nepal	Execution	Nepal Hemophilia Society - Mr Manil Shrestha and Mrs Suraksha Thapa	smqy@nnhf.org	<ul style="list-style-type: none"> - Identify 100 new cases of haemophilia each year through awareness and education - Develop diagnostic capabilities in Nepalgunj (Far West) and increase the capacity of Civil Service Hospital (CSH) to perform as the knowledge hub on issues of haemophilia diagnosis and periphery activities - Enable people with haemophilia to become physically strong and fit to live a healthy life - Empower and strengthen the haemophilia community through education, training and development - Raise awareness of haemophilia amongst government, civil society and organisations working with people with disabilities through advocacy, discussion, interaction and rapport building at central province level as well as in local chapters. 	<ul style="list-style-type: none"> - Project partnership agreement signed. - Nepal Hemophilia Society has approached the Social Welfare Council of Nepal Government to acquire an official approval to receive instalments from abroad. - Strategic media engagement and advocacy course carried out with Nepal Hemophilia Society and key healthcare professionals from the Civil Service Hospital. 	3 years	Q2 2019
East Asia	Thailand 2 project	Improving MSK care in Thailand - through education, outcome measurement and the establishment of two training centres in Bangkok and Chiang Mai	Execution	Faculty of Medicine/Chiang Mai University and IHTC Bangkok - Dr Rungrote Natesirinikul and Prof Ampaiwan Chuansumrit	smqy@nnhf.org	<ul style="list-style-type: none"> - Validate the HJHS 2.1, FISH, PedHAL/HAL, CHOKLAT and HEMOQoL-A into Thai language - Perform a Training of Trainers session on MSK evaluations for the team in Chiang Mai and Bangkok - Delineate the MSK status of patients in Chiang Mai and Bangkok - Provide training to people with haemophilia about the importance of MSK evaluation and physical activity - Share results in local and international journals and at one international conference. 	<ul style="list-style-type: none"> - 59 people with haemophilia or family members in Northern Thailand educated about how to exercise and stay strong with haemophilia. - Thrombosis and haemostasis registry by Thai Society of Hematology (TSH) finalised. - HJHS calculator finalised. 	3 years	Q4 2015
East Asia	Vietnam 3 project	Joint effort continuing to expand the haemophilia network and basic multidisciplinary care across Vietnam	Execution	National Institute of Hematology and Blood Transfusion and Vietnam Hemophilia Association - Dr Mai Nguyen Thi	smqy@nnhf.org	<ul style="list-style-type: none"> - Expand and strengthen infrastructure and care delivery for people with bleeding disorders with 10 new satellite haemophilia treatment centres and 10 new patient clubs - Create awareness about haemophilia through regional WHD events - Raise knowledge amongst people with haemophilia and their families about haemophilia and strengthen the haemophilia network through regional summer camps. 	<ul style="list-style-type: none"> - Assessment of the 10 satellite centres completed. - Planning and assessment meeting with hospital managements of the 10 new satellite HTCs carried out. 	3 years	Q1 2019
Europe	Albania 1 project	Strengthen haemophilia care in Tirana, create awareness across the country and empower the patient organisation	Execution	University Hospital Centre (UHC) "Mother Tereza" - Dr Adela Perolla and Dr Bledi Kalaja	xfov@nnhf.org	<ul style="list-style-type: none"> - Strengthen multidisciplinary care at the haemophilia centre in Tirana including specialised training of 4 healthcare professionals - Raise awareness of haemophilia amongst healthcare professionals across Albania - Empower the patient organisation and community through workshops - Expand diagnosis capability at the haemophilia centre in Tirana to include other coagulation disorders - Increase positioning of haemophilia in the health agenda through strategic media engagement and regular meetings with authorities 	<ul style="list-style-type: none"> - The Project Partnership Agreement was signed. The activities will start in H2 2019. 	2 years	Q3 2019

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
Europe	Romania 2 project	Empowering the haemophilia patient community in Romania	Formalisation	National Association of Romanian Haemophiliacs - Mr Valentin Brabete	xfov@nnhf.org	- Strengthen communication skills of the two patient associations and develop an awareness and engagement campaign - Unite and empower the community of people with haemophilia in 9 regions.	- The project team continues with their national media campaign "Together for Zero bleeds" on Facebook with live videos and interviews of participants. They also had some regional media coverage in Cluj Napoca and Targu Mures. - The first round of regional workshops to strengthen the patient community to advocate for their own care were done. The workshops focused on bleeding episodes and prophylaxis. and were supported by regional healthcare professionals. This led to increased interest of regional healthcare professional for bleeding disorders.	1.5 years	Q2 2018
Near and Middle East	Palestine 2 project	Establish haemophilia care in Gaza Strip and empower the haemophilia community in Palestine	Execution	Ministry of Health - Mr Osama Najjar, director General of Allied Health Professional	sysd@nnhf.org	- Establish basic haemophilia care in Gaza Strip - Establish quality diagnosis in Gaza Strip - Standardise haemophilia care in Palestine by creating and disseminating practical guidelines for home therapy - Increase disease knowledge of 250 PwH and their families to live a better life - Empower the next generation of patient organisation leaders.	- The Project Partnership Agreement was signed. - A committee was formed by the Ministry of Health to develop the treatment guidelines.	2 years	Q2 2019
North and Middle America	Mexico 4 project	National alliance for a cross-sectorial haemophilia programme	Execution	Mexican Haemophilia Federation (FHRM) - Mr Alfonso Quintero Espinoza	sdtm@nnhf.org	- Create or strengthen multidisciplinary care teams across hospitals and healthcare institutions - Consolidate data in national online patient registry and expand registry to include medical data - Reach standardised levels of care and treatment and national guidelines.	- Definition of the parameters for the development of the national online registry. - Planning of the national haemophilia congress in Puebla in July. - Organisation of advocacy meetings to initiate contact with the new direction of the main health institutions.	3 years	Q2 2017
North and Middle America	Mexico 5 (State of Mexico) project	Creation of comprehensive haemophilia clinic of ISSEMyM	Execution	Haemophilia clinic of Maternal-Infant Hospital ISSEMyM - Dr Cecilia Rodríguez Castillejos	sdtm@nnhf.org	- Improve capacity and infrastructure of multidisciplinary care offered to patients - Collect and consolidate medical data of the patients in a registry - Educate and empower people with haemophilia and family members	- Training in June at the University Hospital in Monterrey of a physiotherapist, two social workers and three nurses. - Completion of educational material for people with haemophilia. - Organisation of an educational event for people with haemophilia during World Haemophilia Day. - Planning of the remaining multidisciplinary training sessions abroad.	1.5 years	Q2 2018
North and Middle America	Mexico 6 (Yucatan) project	Comprehensive outreach approach to the benefit of people with bleeding disorders in the state of Yucatan	Closing	Hospital General Agustin O'Horan - Dr Eric Gutierrez	sdtm@nnhf.org	- Improve knowledge and care offered by HCPs at the Haemophilia Clinic, General Agustín O'Horan Hospital - Empower people with haemophilia and their families to take a bigger role in self-care.	- All project activities according to the project plan have been executed. - The project will be closed as completed as soon as all necessary final documentations have been received.	1 year	Q3 2017
North and Middle America	Mexico 7, Jalisco project	Improve the diagnosis and comprehensive care system in the State of Jalisco	Execution	Hospital General de Occidente - Dr Natalia Padilla	sdtm@nnhf.org	- Initiate diagnosis at the hospital's laboratory - Improve the knowledge of the multidisciplinary team and standardise care delivery in the HTC - Empower PwH and relatives to achieve a better quality of life - Create awareness on haemophilia and coagulation disorders to promote timely diagnosis.	- Completion of the second phase of the analysis of the current processes in the clinic. - Training in March of a nurse, a dentist, a social worker and a psychologist in a reference centre in Villahermosa. - Purchase of a bain-marie equipment for the hospital's laboratory. - Planning of the rest of the multidisciplinary team abroad.	2.5 years	Q3 2018
North and Middle America	Nicaragua 2 project	Haemophilia care outreach in Nicaragua	Execution	Asociación Nicaragüense de Hemofilia - Mr Engels Rolando Reyes Sánchez and Dr René Berrios Cruz from Banco de Sangre, Ministerio de Salud	sdtm@nnhf.org	- Decentralise diagnosis to Chinandega and improve the diagnosis rate in the Central region from 25% to 40% - Develop and implement national diagnosis guidelines in collaboration with the Ministry of Health - Improve knowledge on haemophilia of 75 healthcare professionals in Managua, Chinandega, Matagalpa, Bluefields and Puerto Cabeza - Empower 80 PwH from Matagalpa, Chinandega and Managua through 7 training sessions - Strengthen patient organisations from Nicaragua, Guatemala, Honduras and El Salvador through a 3-day training in Managua	- Completion of formalisation phase (agreement and dedicated bank account).	2 years	Q3 2019
South America	Argentina 4 project	Comprehensive muscle and osteoarticular approach for people with bleeding disorders	Execution	Haemophilia Foundation of Salta - Dr Maria Sol Cruz	sdtm@nnhf.org	- Initiate MSK care and occupational therapy in Salta - Create a network of HCPs and patients trained in MSK care and occupational therapy across the province of Salta - Strengthen MSK care and occupational therapy across Argentina building a national network.	- Development of protocols for joint assessment and rehabilitation in physiotherapy room and rehabilitation pool. - Organisation in June of a 3-day training including 1 day for aquatic rehabilitation with participation of 9 kinesiologists and 2 days on occupational therapy with participants from Argentina, Mexico, Brazil, Chile and Bolivia.	2 years	Q3 2017
South America	Brazil 5 project	Training of haemostasis laboratories and patient associations as strategy for sustainable diagnosis	Execution	Brazilian Federation of Hemophilia - Mr Francisco de Paula Careta	sdtm@nnhf.org	- Advance level of diagnosis in 8 pre-selected Haemophilia Treatment Centres at national level - Achieve diagnosis sustainability by training local patient organisation members and HTCs on advocacy and communication - Analyse and improve VWD subtype classification.	- In-depth assessment of the centres selected for receiving laboratory training. - Definition of the specific needs in each selected centre.	2.5 years	Q2 2018
South America	Chile 3 project	Consolidating care and treatment for haemophilia and allied bleeding disorders across Chile	Execution	Hospital Roberto del Río - Dr Veronica Soto Arellano	sdtm@nnhf.org	- Improve the diagnosis of congenital coagulopathies in the national reference centre - Improve the outcome in patients with orthopaedic maintained flexo disease and who require knee replacement - Introduce MSK diagnosis and training - Have an updated track record of patients with congenital coagulopathies.	- Completion of the development of the online registry. - Development of a rehabilitation mobile application.	1.5 years	Q4 2017
South America	Colombia 2 project	Knowledge and skills for better lives	Execution	FAHES Colombia - Mrs Gina Patricia Bolaño Suarez	sdtm@nnhf.org	- Improve awareness and care given to people with bleeding disorders in the main public and private healthcare centres in Santander - Educate people with haemophilia on bleeding disorders' prevention, care and rehabilitation.	- Organisation in January of a self-infusion training at the University Hospital in Bucaramanga. - Organisation of several training sessions for healthcare professionals in Bucaramanga and suburbs.	2 years	Q2 2018
South America	Colombia 3 project	Strengthening our life skills	Execution	Liga Antioqueña de Hemofílicos - Mr David Andrés Cuartas Bolivar	sdtm@nnhf.org	- Establish and promote life skills at interpersonal and family levels, to 250 PwH and 250 family members to improve relationship, adherence to treatment and life projects - Sensitise 50 HCPs from 10 hospitals in the department on humanised and comprehensive care that promotes psychosocial accompaniment and education within the care models - Improve knowledge of teachers from 20 educational institutions in the department to promote better integration and performance of children with haemophilia - Implement a digital platform to foster access to educational material to PwH and their families in the different regions of Antioquia and Colombia ensuring continuity over time	- Definition of the image and branding of the project. - Development and printing of educational material. - Development of theatre play to foster interactive learning about the condition and life skills by people with haemophilia. - Organisation of 13 educational sessions for people with haemophilia and family members.	2 years	Q1 2019

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
South America	Peru 3 project	Strengthen and expand network and structure of haemophilia care across sectors in Peru	Execution	Peruvian Haematology Society - Dr Wilson Ruiz and Dr Nancy Loayza	sdtm@nnhf.org	<ul style="list-style-type: none"> - Organise care on a national level strengthening and creating multidisciplinary care teams - Achieve quality diagnosis in the reference centres and create basic diagnosis hubs in other regions of the country - Reflect the national epidemiological picture of haemophilia and allied bleeding disorders in a web-based registry. 	<ul style="list-style-type: none"> - Printing of educational material shared with centres from different provinces. - Training sessions for healthcare professionals and people with haemophilia in Arequipa and Piura. 	2 years	Q4 2017
South America	Uruguay 3 project	Decentralising care and diagnosis network in Uruguay	Execution	Hospital Tacuarembó - Dr Maria Teresa Faguaga González and Hospital Paysandu Dr Ana Gabriela Chalkling	sdtm@nnhf.org	<ul style="list-style-type: none"> - Strengthen the haemostasis laboratory in Tacuarembó for people with haemophilia living in the northern part of Uruguay - Improve the expertise of HCPs caring for PwH in Tacuarembó and Paysandú - Educate people with haemophilia in Tacuarembó and Paysandú on disease knowledge. 	<ul style="list-style-type: none"> - Purchase of a freezer for Tacuarembó Hospital's laboratory to store reagents. - Organisation of an educational session with people with haemophilia and families on 17 April and participation in a press conference to inform the general population about the condition. - Testing of 177 blood samples, rechecking 120 patients and diagnosing 57 new cases. 	2 years	Q4 2017
South and Central Asia	Armenia 2 project	Establish rehabilitation capacity and decentralise haemophilia care in Armenia	Execution	Haematology Center after Prof. R.H.Yeolyan - Prof Samvel Danielyan and Dr Heghine Khachatryan	smqy@nnhf.org	<ul style="list-style-type: none"> - Strengthen haemophilia team capacity across Armenia - Bring care closer people with haemophilia by setting up 2 satellite centres and organising 6 outreach visits - Establish rehabilitation capacity and care in the haemophilia centre in Yerevan - Increase disease knowledge of 160 PwH and family members to live better lives - Gain health authority support for the haemophilia programme 	<ul style="list-style-type: none"> - The Project Partnership Agreement was signed. 	2 years	Q3 2019
South and Central Asia	Azerbaijan 2 project	Establish haemophilia care in Nakhchivan region and improve physiotherapy care across Azerbaijan	Execution	Azerbaijan Republic Association of Hemophilia - Mrs Gulnara Huseynova	smqy@nnhf.org	<ul style="list-style-type: none"> - Establish haemophilia care in Nakhchivan - Advocate for better care in Nakhchivan - Improve physiotherapy care - Raise awareness amongst people with haemophilia and families. 	<ul style="list-style-type: none"> - In-depth training of two doctors abroad. After their training, meetings were organised with members of the haemophilia society and officials of the Ministry of Health of Azerbaijan. The two trained doctors presented their new knowledge and experiences gained abroad. - Assessment visit to Nakhchivan Autonomous Republic planning for the in-depth training to come. During the visit, 32 people with haemophilia were invited to the hospital in Nakhchivan for a consulting with the healthcare professionals from Baku focusing especially on emergency treatments. - Physiotherapy equipment purchased to Nakhchivan Republican Hospital. - 126 people with haemophilia and their family members from Baku, Ganja and Shirvan were educated about exercise and musculoskeletal care. 	2 years	Q3 2017
South and Central Asia	Bangladesh 1 project	Improving quality of care for haemophilia in three centres in Bangladesh	Execution	Dhaka Medical College - Prof Salma Afrose	smqy@nnhf.org	<ul style="list-style-type: none"> - Increase capacity of the multidisciplinary teams in Dhaka, Rajshahi and Rangpur - Develop diagnostic facilities for coagulation studies - Educate people with haemophilia and families and encourage them to attend the newly trained centres - Engage authorities and the public for more support for bleeding disorders. 	<ul style="list-style-type: none"> - One haematologist, one physiotherapist and two patient association representatives visited the Super Speciality Pediatric Hospital and Post Graduate Teaching Hospital in Noida, India to be inspired about how to improve haemophilia care in Bangladesh with limited resources. - Haemophilia strategy workshop carried out. - National alignment meeting carried out. 	1 year	Q3 2015
South and Central Asia	India 12 project	Unify Hemophilia Federation India	Execution	Hemophilia Federation India (HFI) - Mr Vikash Goyal and Mr Mukesh Garodia	smqy@nnhf.org	Strengthen and unify HFI to advocate for standardised national care.	<ul style="list-style-type: none"> - Project partnership agreement signed. - Chapter assessment completed ensuring that the training content is tailored to the different regional challenges, putting the strategy "One country, one treatment" in action. 	1 year	Q2 2019
South and Central Asia	India 7 project	Preventing and decreasing musculoskeletal morbidities among people with haemophilia in Southern India	Execution	Hemophilia Federation India - Dr Pamela Narayan	sysd@nnhf.org	<ul style="list-style-type: none"> - Map the musculoskeletal morbidities and physiotherapy practices prevalent in factor limited settings, particularly India - Delineate and implement a clinical pathway of MSK care for PWH - Increase awareness and access to physical therapy in the management of MSK morbidities amongst PWH. 	<ul style="list-style-type: none"> - Two abstracts were accepted for presentation at the MSK Congress. The MSK project overview was accepted as a poster presentation. The study on the physiotherapy protocols was accepted for platform presentation. - The impact of the MSK project was presented also in the Annual Hemophilia Federation of India Women's group meeting held in Hyderabad in February 2019. - MSK physiotherapy awareness camps were organised in Kolhapur, Surat and Vizag. The trainings were facilitated by physiotherapists trained and motivated through the MSK project. - The government of India (GOI) has taken on board that any optimal treatment plan for haemophilia should include physiotherapy. - The number of patients on the MSK registry increased to 329. 13 new patients were added to the registry between Jan to June 2019. - On July 20th, MSK-physiotherapy workshop at the Noida was executed for haemophilia treatment centres in Delhi region. - A national level workshop was organised at the Haematocon meeting. It was organised as a joint workshop for both haematologists and physiotherapists. 	3 years	Q3 2015
South and Central Asia	India 8 project	Empowering parents in South and West India	Execution	Hemophilia Federation India and Empowering Minds Society for Research & Development - Dr Richa Mohan	smqy@nnhf.org	<ul style="list-style-type: none"> - Customise and update the Parents Empowering Parents (PEP) programme and materials with the international PEP - Train the trainers programme on PEP for 150 parents from 8 states in South and West India. 	<ul style="list-style-type: none"> - Train-the-Trainer workshop of West India carried out in Goa with parents from 10 states participating. - State level workshop completed in Gujarat with parents from 7 chapters participating. - State level workshop completed in Maharashtra with parents from 9 chapters participating. 	2 years	Q1 2016
South and Central Asia	India 9 (West Bengal) project	Identify, diagnose and empower people with haemophilia in West Bengal	Execution	Hemophilia Society Durgapur - Mr Roy Ajoy Roy	smqy@nnhf.org	<ul style="list-style-type: none"> - Build care capacity in 12 medical colleges and 17 district hospitals - Create awareness to identify undiagnosed PwH - Organise diagnosis campaign - Empower newly diagnosed PwH. 	<ul style="list-style-type: none"> - Training of healthcare professionals in Birbhum, Bankura, Malda and Kolkata. - Self-infusion training and physiotherapy camps in Siliguri, Maldam, Burdwan, Durgapur, Birbhum and Bankura districts. - Walkathon creating awareness about haemophilia in Durgapur. - Article written about haemophilia signals to be published in several newspapers to create awareness. - Awareness programme on dental hygiene. 	3 year	Q3 2018
South and Central Asia	Myanmar 3 project	Strengthening haemophilia care and diagnosis in Northern Myanmar	Execution	Mandalay General Hospital - Dr Moe Hein	smqy@nnhf.org	<ul style="list-style-type: none"> - Establish a haemophilia treatment centre in Northern Myanmar - Decentralise basic care to two regions - Strengthen the patient association chapter and empower people with haemophilia and families living with haemophilia - Strengthen the communication skills of the patient association chapter and raise awareness about haemophilia. 	<ul style="list-style-type: none"> - WHD celebration organised in Mandalay focusing on creating awareness about haemophilia having the state senator, journalists and 200 people with haemophilia and family members attending. - Psychosocial workshop for people with haemophilia carried out in Mandalay focusing on improving self-confidence and discussing career possibilities. 	3 years	Q2 2018

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
South and Central Asia	Pakistan 6 project	Building partnerships to create awareness and improve care	Execution	Pakistan Hemophilia Patients Welfare Society - Mr Hassan Raza, president	sysd@nnhf.org	<ul style="list-style-type: none"> - Empower the community through capacity building - Identify people with bleeding disorders through awareness raising activities - Improve access to care in the regions through advocacy activities in partnership with the provincial and national authority - Improve diagnosis rate and update national patient registry. 	<ul style="list-style-type: none"> - National Hemophilia Retreat was organised as follow-up training to enhance the understanding of the patient organisation mission and the volunteering work. Two similar sessions were organised to engaged youth and women group members. - Completed all the policies and the guidelines manual for the patient organisation. The draft policy manual has been shared with different stakeholders for feedback. - A contract with an IT company to develop a mobile application was signed. The mobile application will serve as a learning portal which will be linked to the organisation website. - Peshawar chapter successfully organised the final psycho-social aspects event for 100 patients. 	2 years	Q3 2017
South and Central Asia	Sri Lanka 2 project	Improve diagnosis and multidisciplinary care across Sri Lanka	Formalisation	Hemophilia Association of Sri Lanka - Mr Chandana Weerasekara and Mrs Ganga Wijewardhana	smqy@nnhf.org	<ul style="list-style-type: none"> - Improve diagnosis capacity and quality in Kurunegala, Batticaloa, Galle and Anuradhapura regional hospitals - Increase diagnosis rate by 10% through awareness creation - Improve multidisciplinary care of haemophilia treatment centres in Kurunegala, Batticaloa, Galle and Anuradhapura - Empower 250 people with haemophilia and their families through 4 workshops and 2 patient camps 	<ul style="list-style-type: none"> - The project was approved in November 2018 and the project partnership agreement will be prepared for signature when Haemophilia Society of Sri Lanka (HASL) has carried out their election of a new board in mid-August 2019. 	2 years	Q2 2019
South and Central Asia	Uzbekistan 5 project	Empower the haemophilia community and strengthen multidisciplinary care in Uzbekistan	Execution	Scientific Research Institute of hematology and Blood Transfusion - Dr Aziza Makhmudova	smqy@nnhf.org	<ul style="list-style-type: none"> - Include orthopaedic and traumatological surgery in MSK care in Tashkent - Increase HCP knowledge on managing haemophilia in 12 regions. - Strengthen diagnostic facilities in Tashkent. - Establish laboratory in Bukhara and support further decentralisation of diagnosis. - Enable people with haemophilia to become physically and psychologically fit to live a healthy life. 	<ul style="list-style-type: none"> - Project partnership agreement signed. 	3 years	Q3 2019