



NNHF Programmes: selected updates on activities in the 1st half year 2018 (1 January – 30 June 2018)

Overview

Novo Nordisk Haemophilia Foundation H1 2018 update	By end H1 2018
Number of projects approved by NNHF Council since 2005 (new projects since last half year)	163 (7)
- Thereof number of fundraised projects (new projects since last half year)	14 (0)
Number of fellowships (new fellowships since last half year)	74 (0)
Number of awards (new awards since last half year)	18 (2)
HCPs trained since 2005	38'800
Patients and family members educated & patient leaders trained since 2005	39'850
People with haemophilia retested and newly diagnosed since 2005	23'250
NNHF engaged in number of countries (new countries since last half year)	70 (1)

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
Africa	Botswana 1 - BW1	Improve access to diagnosis and bleeding disorders care in Botswana	Project	Formalisation	TXCH Global HOPE Botswana at Princess Marina Hospital - Dr Jeremy Slone, Medical Director	sysd@nnhf.org	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.	- The Project Partnership Agreement was prepared for signature.	1.5 years Q2 2018
Africa	Egypt 2 - EG2	Improving musculoskeletal (MSK) care in Egypt and establishing a MSK-registry to collect outcome data	Project	Closing	Gamaeat Asdika Marda Al Nazf (= Egyptian Society of Hemophilia), Cairo -Represented by Dr Magda Rakha, President, as responsible project applicant and supported by Dr Adly Sabbour, Physiotherapist, as MSK-expert and trainer and as such co-responsible person	sysd@nnhf.org	HCPs training including haematologists and physiotherapists Establish MSK registry in Egypt Start treating the patients and evaluate their joint functions Write a publication about the project and inform the authority about the project results MSK advocacy for policy for inclusion Strengthen the haemophilia dentist clinic in Cairo.	- Project results were presented to NNHF Council. Waiting for the final reports to close the project.	1.5 years Q1 2016
Africa	Egypt 3 - EG3	Decentralisation of care across Egypt	Project	Execution	Gamaeat Asdika Marda Al Nazf (= Egyptian Society of Hemophilia), Cairo -Represented by Dr Magda Rakha, President	sysd@nnhf.org	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.	- Project partnership agreement was signed and activities will start in H2 2018.	2.5 Q3 2018
Africa	Ethiopia 1 - ET1	Improve haemophilia care in Ethiopia by decentralisation of care and empowerment of haemophilia community	Project	Execution	Ethiopian Hemophilia Society, Addis Ababa - Mr Samson Hailemariam	sysd@nnhf.org	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.	- Project partnership agreement was signed and activities will start in H2 2018.	2 years Q3 2018
Africa	Ghana 2 - GH2	Improve access to haemophilia care and create awareness at the regional and primary health levels in Ghana	Project	Execution	Ghana Haemophilia Society, Accra - Martin Boakye	sysd@nnhf.org	Strengthen the patient association Build HCPs capacity in the regions Improve diagnosis capacity Organise educational programme for PwH and their families Increase awareness about haemophilia.	- The website of the Ghana Haemophilia Society was updated. Further adjustments will be done until end of 2018. - The purchased lab equipment including fully automated coagulometer were delivered to Komfo Anokye Teaching Hospital (KATH) in Kumasi. - Three patient and parent meetings were organised in Accra, Kumasi and Koforidua with focus on physiotherapy and psychosocial issues and care. 221 participants attended the meetings. - An outreach visit to Cape Coast was organised including the following activities: • 85 HCPs were trained on the basics of haemophilia. • Two lectures were held in the nurses and midwifery training school and the Ankafo Nursing Training School. 420 students attended the training and learnt about the symptoms and management of haemophilia. • 40 new patients were identified and referred for diagnosis.	2 years Q1 2017
Africa	Kenya 3 - KE3	Enhancement of capacity for comprehensive haemophilia management	Project	Closing	Kenya Hemophilia Association, Nairobi - Kibet Shikuku	sysd@nnhf.org	Establish the Kenyatta National Hospital Haemophilia Comprehensive Care Centre Improve the diagnostic facilities and blood bank capacity Create awareness by organising two WHD celebrations and continue lobbying with the media Organise HCP trainings and academic symposia Start the regional haemophilia care in two cities Improve physiotherapy care in both KNH and MOI.	- All project activities have been completed . Waiting for the final project report to be submitted.	2 years Q2 2015
Africa	Kenya 4 - KE4	Provide standardised quality care across Kenya	Project	Execution	Kenya Hemophilia Association, Nairobi - Kibet Shikuku	sysd@nnhf.org	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 to bring care closer to PwH 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 to bleeding disorders.	- During WHD, a Gala dinner was organised by KHA to lobby with healthcare authorities, key stakeholders and potential donors. The dinner was a great success as it was graced by: • The Nominated Member of Parliament representing people with disability who committed to support KHA request for inclusion of Haemophilia as a condition causing disability. • Officials from MoH who have committed to support KHA in the development of treatment guidelines and protocols. • The first lady of Bungoma county who is campaigning for treatment of sickle cell adopted haemophilia as one of the condition she will campaign for. • WFH president. • The media , which was represented heavily in the event and contributed to create awareness about haemophilia. - A training session was organised for PwH and their parents on self-infusion and home treatment.	2 years Q2 2018
Africa	Malawi 1 - MW1	Establish haemophilia care in Malawi	Fundraised project	Closing	Society of Haemophilia and Allied Bleeding Disorders in Malawi Lilongwe, Malawi - Dr Yohannie Billy Mlombe, haematologist	sysd@nnhf.org	Establish coagulation laboratory facilities and skills Train healthcare professionals in haemophilia Create awareness campaign to identify new patients Empower patients through awareness campaign and national patient education camp.	- All project activities have been completed . Waiting for the final project report to be submitted.	9 months Q1 2016 Prolonged until Q4 2017
Africa	Mali 1 - ML1	Improve haemophilia care in Mali by capacity building and awareness creation	Project	Closing	Association Malienne de Lutte contre l'Hémophilie, Bamako - Dr Yacouba Diallo	sysd@nnhf.org	Improve haemophilia care by building regional HCP capacity Increase awareness about haemophilia among PwH and traditional circumcisers Advocate for better care for haemophilia patients.	- All project activities were completed. Throughout the project, 15 training sessions were organised for 179 HCPs. The training included general knowledge about haemophilia, identification of PwH and providing basic care. A national haemophilia network was created for the first time linking the haemophilia centre in Bamako and 4 of the country's 7 regions. - 7 training sessions were organised for 24 people with haemophilia and 79 family members were trained on home care and first aid. - 5 training sessions were organised for 126 traditional practitioners. The traditional practitioners were trained and empowered to identify and refer suspected patients with bleeding disorders. The number of diagnosed PwH increased from 42 patients in 2016 to 103 patients in 2017. - A haemophilia network was established between people with haemophilia, HCPs and traditional practitioners. - WHD was celebrated in 2016 and 2017. Healthcare authorities were invited as well as the media to create awareness and introduce the advocacy plan. - An abstract about the project results and methodologies was approved and presented at the WFH congress.	2 years Q2 2016
Africa	Mauritius 1 - MU1	Establish a multidisciplinary care team and improving haemophilia care in Mauritius	Project	Execution	Haemophilia Association of Mauritius, Mauritius, Quatre Bornes - Asraf Caunhye	sysd@nnhf.org	Strengthen the diagnostic facilities Establish a multidisciplinary care team Improve the physiotherapy care provided to PwH Empower patients through educational sessions and camps Create awareness by organising two world haemophilia day celebrations Create an electronic medical registry and complete data.	- In the process of building a comprehensive care team, the following HCPs were trained: • A senior paediatrician from JN Hospital, Rose-Belle was trained at CMC Vellore for three months. • A pathologist from VH Hospital, Candos was trained for 6 weeks at CMC Vellore. • A general practitioner from VH Hospital, Candos was trained for 3 months at CMC Vellore. - A MASAC meeting was conducted with all HCPs in Mauritius together with Professor Alok Srivastava. Many of the care issues were discussed and appropriate solutions were found. - Three physiotherapy workshops were organised to train physiotherapists from each regional hospitals and build the haemophilia physiotherapy network. - The physiotherapy equipment was identified and approved and will be purchased by August 2018. - A Health Booklet was launched on WHD and a copy was distributed to all patients and WFH president. A training session was conducted to train people with haemophilia on the usage of the booklet.	2 years Q3 2015 Prolonged until Q2 2018
Africa	Nigeria 2 - NG2	Activate and strengthen the medical and patients community in Nigeria	Project	Closing	Haemophilia Foundation of Nigeria, Kaduna - Megan Buckie Adediran	sysd@nnhf.org	Establish a reference laboratory at the Lagos University Teaching Hospital (LUTH) Create an electronic medical registry and complete the identified patient profiling Empower patients through four educational camps Create awareness by organising two world haemophilia day celebrations and develop awareness publications Establish regional haemophilia care service in the South West Region.	- All project activities have been completed. Waiting for the final reports to be submitted.	2 years Q1 2015
Africa	Rwanda 1 - RW1	Establish basic haemophilia care in Rwanda	Project	Formalisation	Rwanda Federation of Hemophilia, Kigali - Emmanuel Seromba	sysd@nnhf.org	Establish a haemophilia treatment centre and team Conduct outreach to start haemophilia care in the regions Increase national diagnosis rate Empower diagnosed patients.	- Sign project partnership agreement and start activities in H2 2018.	2 years Q3 2018

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
Africa	South Africa 4 - ZA4	Strengthen South African Haemophilia Federation capacity through youth development and empowerment of health care providers	Project	Execution	South African Haemophilia Foundation (SAHF) and its Medical and Scientific Advisory Council (MASAC), Cape Town -Johan Potgieter	sysd@nnhf.org	Establish a national web-based registry Improve capacity and succession planning of SAHF Improve haemophilia care through multidisciplinary training.	- The web registry software is in final production. Testing expected to be completed in August. - Nurses' stations needed to be modified to accommodate the technology. Groote Schuur Haematology assessment room was redesigned to accommodate the hardware. - The 2nd Youth Leadership meeting was organised where 2 youth were empowered to present parts of the programme. During the meeting, the youth elected their leadership structure - 19 doctors were trained at Ladysmith Provincial Hospital, KwaZulu-Natal on 19 April.	3 years Q3 2017
Africa	Tanzania 2 - TZ2	Empower the patient association to organise successful awareness campaign and advocacy	Project	Execution	Haemophilia Society of Tanzania, Dar es Salaam - Richard Minja	sysd@nnhf.org	Empower the haemophilia community Organise media engagement training Create awareness in the region of Dar es Salaam Advocacy meetings with authority.	- The team continued lobbying with the health authorities to get final approval for the drafted National Health Policy. - The youth were contacted to identify the best possible dates to organise the patient camp.	1 year Q2 2017
Africa	Uganda 2 - UG2	Create awareness and HCPs training in Uganda	Project	Execution	Haemophilia Foundation of Uganda, Kampala - Agnes Kisakye, executive secretary	sysd@nnhf.org	Increase public awareness about haemophilia Organise outreach visits to Eastern, Central and Northern Uganda to identify new haemophilia patients Increase patients knowledge about haemophilia Advocate for better care for haemophilia patients.	- The WHD was celebrated for a week with focus on creating awareness to identify new people with haemophilia. The following activities took place: • Launching blood donation campaigns. • A charity walk was organised in Kampala. • Press interviews by 21 news reporters capturing the haemophilia story in Uganda. • Two live TV interviews were conducted, where three patients, two mothers and one father shared their life stories. • HFU team participated at the health radio talk-shows on three different radio channels advertising the world haemophilia day celebrations. • Two newspaper articles were published in Daily Monitor and New Vision. • WHD celebration was featured in the day's news and at some Radio stations. The celebrations were news headlines . • The team received several calls from the audiences leading to identify 22 new PwH . - The team conducted outreach visits to the West Nile, Northern Region: • 65 HCPs including nurses, midwives, doctors and lab technicians were trained . • The village health team who is considered the first point of contact with the patients was contacted for the first time in both regions. 49 of the team members were trained. • In addition, awareness was created in four schools, two churches and one university.	2 years Q2 2016
Africa	Zambia 1 - ZM1	Haemophilia awareness campaign and outreach across Zambia	Project	Execution	Haemophilia Foundation of Zambia, Lusaka - Chilufya Pikiti, Founding member	sysd@nnhf.org	Create awareness through documentaries and materials Organise outreach programme by training community health workers, traditional and non-medical circumcisers Improve self-care of people living with haemophilia through education Establish first haemophilia treatment centre.	- The team got approval from the management of the University Teaching Hospital, Lusaka to establish a Comprehensive Care Centre in the hospital. The allocated space was renovated and equipped to serve the people with bleeding disorders. During the WHD, the centre was officially opened by the hospital director and the Minister of Health deputy. The event was covered by the media as part of the awareness campaign. - 17 new people with haemophilia were identified and diagnosed as a result of the awareness campaign.	1.5 years Q2 2017
East Asia	Cambodia 2 - KH2	Establish multidisciplinary care and strengthen awareness in Cambodia	Project	Execution	Cambodian Hemophilia Association (CHA), Phnom Penh - Mr Sokpanha Sem	nhhn@nnhf.org	Establish multidisciplinary care teams in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap Set up multidisciplinary care and train the teams Strengthen advanced diagnosis in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap Increase patients' and families' self-management ability Strengthen the patient association by having more active members Create awareness about haemophilia.	- 5 HCPs from Siem Reap and Phnom Penh undertook 4 weeks of training at Nottingham University Hospital in UK. - 18 participants attended the strategic media engagement workshop, resulting in a series of feature documentaries being made, receiving a total of 330,000 views. - Printer purchased for CHA.	3 years Q1 2018
East Asia	China 5 (Jiangsu) - CN5	Set up and consolidate five comprehensive treatment centres for haemophilia and von Willebrand disease in Jiangsu Province	Project	Execution	The First Affiliated Hospital of Suzhou University, Suzhou - Prof Ziqiang YU	nhhn@nnhf.org	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.	- On 18 March an educational meeting for HCPs coming from 5 different hospitals from the Jiangsu Province was held in Yangzhou city. - For WHD all the HTCs from the 5 selected hospitals organised educational activities for patients and their families. On 24 April Prof. Poon from Canada was invited to Yangzhou to exchange knowledge on haemophilia comprehensive treatment with the Jiangsu haemophilia expert panel.	3 years Q2 2016
East Asia	China 6 (Sichuan) - CN6	Decentralisation of multidisciplinary care in four city level haemophilia centres in Sichuan Province	Project	Execution	Sichuan Centre of Haemophilia Diagnosis and Treatment, Chengdu - Prof Xiaojing LI	nhhn@nnhf.org	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.	- Train-the-trainer with Canadian Haemophilia experts to share knowledge about lab procedures, imaging, joint assessment, quality of life assessment and Haemophilia Salon Activity to discuss haemophilia individualised treatment research. - WHD 2018: Haemophilia experts from Sichuan province, Jiangsu province and Guangdong province participated in the academic exchange. Educational material was distributed for the HCPs to take back to their respective hospitals. - Nanchang-Chengdu Haemophilia MDT Exchange Visits and Meeting: in-depth lectures about haemophilia for HCPs. - Participation in WFH Conference with a poster. - Patient education session on the topic of self-infusion and self-care. - Awareness creation through a launch of a radio programme that counted with Prof. Xiaojing Li's participation. - Distribution of 450 copies of education materials to medical staff and patients.	3 years Q2 2016
East Asia	China 7 (Tibet) - CN7	Development of haemophilia care in Tibet Autonomous Region	Project	Execution	Shandong Centre of Haemophilia Diagnosis and Treatment, Jinan - Dr Xinsheng Zhang	nhhn@nnhf.org	Establish multidisciplinary care at Tibet People's Hospital in Lhasa. The last province in China without haemophilia center Education of health care professionals in Tibet Autonomous Region including train-the-trainer To build a multidisciplinary team and Tibet People's Hospital and to assist them to develop cooperation with local government. Establish access to the Chinese national registry and register new patients diagnosed To guide Tibet Blood Centre on the national quality standards to enable appropriate production of cryoprecipitate in local blood center Improve the awareness of multidisciplinary care in haemophilia amongst HCP, patients, families and government.	- Specialised 1-week training of one doctor, one nurse, one lab technician and one physiotherapist of Tibet People's Hospital in Shandong Haemophilia Treatment Centre and Tianjin Hemophilia Treatment Centre. - The four HCPs from Tibet People's Hospital also visited Shandong Blood Centre and learned about surgery at the Shandong Provincial Qianfoshan Hospital. Additionally, they were trained in physiotherapy at the Shandong Provincial Traditional Chinese Medical Hospital.	1 year Q1 2017
East Asia	China 8 - CN8	Establishing and strengthening quality haemophilia care in the northeast region of China	Project	Execution	Blood disease hospital, Chinese academy of medical science, Tianjin - Prof Renchi Yang	nhhn@nnhf.org	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 patients 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.	- The 7 involved provinces continue carrying out the activities initiated in 2017 with the aim to establish new haemophilia centres, train medical personnel and educate people with haemophilia. - WHD activities in the 7 provinces attracted large number of people including local government, health insurance officials, charity associations and local media. - WHD was reported by media in Dalian and Liaoning province. - Henan province has now 8 new HTCs. - Six training sessions took place for 189 HCPs (doctors, nurses, lab technicians, physiotherapists). - 17 educational sessions brought together 450 patients and 265 family members.	3 years Q2 2017
East Asia	China 10 - CN10	Strengthening comprehensive care and empowering children and families in six provinces of China	Project	Formalisation	Beijing Children's Hospital, Capital Medical University, Beijing - Dr Runhui Wu	nhhn@nnhf.org	Strengthen paediatric comprehensive care in 6 provinces, using and tailoring 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 educational model Create awareness of haemophilia amongst the patient community, public and authorities.	- Project was approved in March 2018 and will presumably start its activities in the end of 2018.	3 years Q3 2018
East Asia	Indonesia 2 - ID2	Improve access to care through strengthened multidisciplinary care teams in regional core centres and focused outreach to 10 provinces	Project	Execution	Indonesian Society of Hematology & Blood Transfusion (ISHBT), Jakarta - Dr Novie Amelia Chozie, Board member at ISHBT and MD at Cipto Mangunkusumo Hospital	nhhn@nnhf.org	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 health care providers about haemophilia Educate patients and families in 10 selected provinces about self-infusion and better self-management.	- Educational and medical symposia held at newly established HTC in Banjarmasin in January 2018. - 361 people with haemophilia and family members attended an educational session in Medan in May 2018. - Revised educational materials (haemophilia in pictures booklet and self-infusion and home treatment book) distributed in Banjarmasin and Medan. - 176 people with haemophilia and family members trained in self-infusion. - Emergency management training delivered to primary and secondary HCPs in Medan.	3 years Q2 2017
East Asia	Thailand 2 - TH2	Improving MSK care in Thailand - through education, outcome measurement and the establishment of two training centres in Bangkok and Chiang Mai	Project	Execution	Faculty of Medicine/Chiang Mai University and IHTC Bangkok - Dr Rungrote Natesiririkul - Prof Ampaiwan Chuansumrit	nhhn@nnhf.org	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 patients about the importance of MSK evaluation and physical activity Share results at local and international journals and at one international conference.	- Two MSK training sessions delivered by Thai trainers for HCPs in 2 HTCs (Lampang and Chiangrai). - The NNHF Stretch out for Hemophilia and Exercise has been translated into Thai, with 5,000 copies printed and distributed to other HTCs. - Two abstracts were accepted as poster presentation at World Federation of Hemophilia (WFH) 2018 World Congress in Scotland, United Kingdom.	3 years Q4 2015

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
East Asia	Thailand 4 - TH4	Improving haemophilia care in Thailand through the Chronic Care Model, strengthening of comprehensive care teams and development of leadership talents	Project	Execution	National Health Security Office (NHSO), IHTC Bangkok, Faculty of Medicine/Chiang Mai University and the Thai Haemophilia Patient Club, Bangkok - Hathaiwut Lamthean - Prof Ampaiwan Chuansumrit - Dr Rungrote Natesirinilkul - Mr Ekawat Suwataroj	nhhn@nnhf.org	Strengthen the regional reference centre in Southern Thailand in Prince of Songkhla Hospital Strengthen the comprehensive care teams in 8 haemophilia treatment centres (HTCs) Improve awareness and quality of care at district and provincial hospitals in 8 provinces Develop national patient guidelines regarding the care set up and the right to care in Thailand Develop young, leadership talents in all 5 patient clubs in Thailand.	- Site visit to Phrapokklao Hospital, Chantaburi on 24 April 2018, which included consultations with 14 people with haemophilia and a lecture for medical students and paediatric residents about managing haemophilia with limited resources. - Impact assessment and follow-up visits conducted in Chiang Rai, Trang, Krabi, Chonburi, Chanthaburi, and Phuket/Phang Nga. Results of the assessment include reduced incidences of bleeding, and people with haemophilia having an improved level of self-care.	2 years Q1 2017
East Asia	Vietnam 3 - VN3	Joint effort continuing to expand the haemophilia network and basic multidisciplinary care across Vietnam	Project	Formalisation	National Institute of Hematology and Blood Transfusion and Vietnam Hemophilia Association, Hanoi - Dr Mai Nguyen Thi	nhhn@nnhf.org	Expand and strengthen infrastructure and care delivery for patients with bleeding disorders with 10 new satellite haemophilia treatment centres and 10 new patient clubs Create awareness about haemophilia through regional WHD events Raise patients' and families' knowledge about haemophilia and strengthen the haemophilia network through regional summer camps.	- Project was approved in March 2018 and will presumably start its activities in the end of 2018.	3 years Q3 2018
Europe	Latvia 2 - LV2	Set up of a web-based bleeding disorders registry in Latvia	Project	Execution	Latvia Hemophilia Society, Riga - Baiba Ziemele	xfov@nnhf.org	Create infrastructure for data collection and analysis Provide training on the use of the registry and the importance of it for patients and healthcare professionals Have solid, evidence-based facts in place for advocacy purposes.	- By the end of 2017 the Council has approved the prolongation of the project until Q1 2019. - A volunteer with experience in web project management was found to support the project partner in collaborating with the IT company. - New agreements were signed between the partner and the IT company to finalise the registry. - Half a year has passed; still the IT company is not able to deliver according to the partners requirements. The project partner will therefore try to find another provider and the project will be re-discussed in the NNHF Council meeting in November 2018.	1 year Q2 2016 Prolonged until Q1 2019
Europe	Romania 2 - RO2	Empowering the haemophilia patient community in Romania	Project	Execution	National Association of Romanian Haemophiliacs, Bucharest - 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 was approved in March and the project partnership agreement signed in June. - End of June the project was kicked off with a strategic media engagement workshop facilitated by NNHF and the first steps taken to develop a national media campaign.	1.5 years Q2 2018
North and Middle America	Cuba 2 - CU2	Decentralisation of comprehensive care to two centres in the East and establishment of a national reference centre for women with bleeding disorders in Havana	Project	Execution	Instituto de Hematologia e Immunologia (IHI), Habana - Prof. José M. Ballester Santovenia and Dr Dunia Castillo	sdtm@nnhf.org	Decentralisation of comprehensive care to two centres in the East and establishment of a national reference centre for women with bleeding disorders in Havana.	- Development of educational material for dentists and patients on dental care. - Development of educational material for teachers as well as for patients on self-infusion. - Organisation of 2 training sessions in Holguin on nursing during which a total of 33 nurses participated from different hospitals. - Organisation of a training session in Santiago de Cuba on nursing (3 May) with the participation of 3 doctors and 25 nurses. - Workshop session on orthopaedics with specialists from paediatric and adult centres from Holguin and Santiago de Cuba. - Purchase of laboratory equipment for the paediatric hospital in Holguin.	2 years Q3 2016
North and Middle America	Dominican Republic 2 - DO2	Expanding diagnosis and registry of haemophilia in Dominican Republic	Project	Formalisation	Fundacion Apoyo al Hemofílico (FAHEM) - Dr Rosa Nieves and Dr Betty Perez from Hospital General Universitario Dr. Jose Maria Cabral y Baez	sdtm@nnhf.org	Strengthen and decentralise diagnosis in Dominican Republic. Raise awareness and interest of haemophilia amongst HCPs. Increase PwH and family members knowledge about haemophilia. Update and digitalise the national registry.	- Project approved by NNHF Council.	2 years Q2 2018
North and Middle America	Mexico 4 - MX4	National alliance for a cross-sectorial haemophilia programme	Project	Execution	Mexican Haemophilia Federation (FHRM), Mexico City - Alfonso Quintero Espinoza	sdtm@nnhf.org	Create or strengthen multidisciplinary care teams across hospitals and healthcare institutions in Mexico by increasing the capabilities and haemophilia knowledge of healthcare professionals Consolidate data in national online patient registry and expand registry to include medical data Reach better levels of care and treatment for all patients through advocacy initiatives.	- Second regional training in Mexico City (26-27 January) on haematology, rehabilitation and orthopaedics with the participation of 13 speakers and 54 HCPs from 6 different States of the country. - Organisation of the third regional training in Oaxaca (20-21 April) on haematology, rehabilitation and orthopaedics as well as on the role of nurses and social workers. This event counted with 10 speakers and 51 participants attended the training. - Development and review of parameters for the clinical registry.	3 years Q2 2017
North and Middle America	Mexico 5 (State of Mexico) - MX5	Creation of comprehensive haemophilia clinic of ISSEMyM	Project	Execution	Haemophilia clinic of Maternal-Infant Hospital ISSEMyM, Toluca, State of Mexico - Dr Cecilia Rodríguez Castillejos	sdtm@nnhf.org	Form a multidisciplinary care team at Maternal-Infant Hospital Train HCPs from partner hospital, the ISSEMyM network (1st and 2nd level of care) and selected HCPs across the healthcare institutions of the State of Mexico Provide education, guidance and psychological support to patients and their families Formalise a complete haemophilia patient database for the hospital Improve the quality of diagnosis in the hospital laboratory and beyond.	- The project partnership agreement has been signed and the project activities will start in the second semester of 2018.	1.5 years Q1 2018
North and Middle America	Mexico 6 (Yucatan) - MX6	Comprehensive outreach approach to the benefit of people with bleeding disorders in the state of Yucatan	Project	Execution	Hospital General Agustín O'Horan, Merida - Dr Eric Gutierrez	sdtm@nnhf.org	Improve knowledge and care offered by HCPs at the Haemophilia Clinic, General Agustín O'Horan Hospital Set up basic care points in various villages of the State of Yucatan Empower patients and their families for better self-care.	- Organisation of 6 self-infusion training for patients and family members. - Completion of 18 home visits from the hospital's social worker to make sure adequate storage is available for factor, that the different medical appointments are followed and in order to provide guidance. - Printing of educational material for patients and HCPs.	1 year Q3 2017
North and Middle America	Mexico 7 (Jalisco) - MX7	Improve the diagnosis and comprehensive care system in the State of Jalisco	Project	Formalisation	Hospital General de Occidente, Guadalajara - 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.	- The project partnership agreement has been signed and the project activities will start in the second semester of 2018.	2.5 years Q2 2018
South America	Argentina 4 - AR4	Comprehensive muscle and osteoarticular approach for people with bleeding disorders	Project	Execution	Haemophilia Foundation of Salta, 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.	- Testing phase of the rehabilitation pool before official inauguration. - Acquisition of material for pool. - Rehabilitation training using the pool. - Organisation of 2 training sessions (27 April and 4 May) with respectively 67 and 29 HCPs (mainly kinesiologists) participating. The main topics tackled were general concepts about haemophilia, haemarthrosis, sinovitis and arthropathy. - MSK evaluation of 21 patients was performed.	2 years Q3 2017
South America	Brazil 4 - BR4	Strengthening the care and education network for haemophilia in the state of Pará in Brazil	Project	Execution	FBH - Federação Brasileira de Hemofilia, Sao Paulo - Christianne Maria Oliveira Costa	sdtm@nnhf.org	Prepare and deliver training activities for health care professionals of primary health care and municipal hospitals Prepare and deliver training activities for patients and their families Reproduction and distribution of educational materials, posters and infusion diaries for patients Draw the psychosocial profile of patients and their situation to promote the appropriate treatment Publicise the results in a national meeting and at the Haemophilia journal.	- Multidisciplinary training in Santarem on 1-2 March with the presence of 115 HCPs including haematologists, dentists, physiatrists, nurses and social workers. Patients and family members were also trained on self-infusion. - World Haemophilia Day training in Belem on 17 April with presence of authorities, media, HCPs as well as patients and families. The main themes were overview of haemophilia, von Willebrand disease, raising patient's voice, rights and duties of people with haemophilia, MSK and arthropathy. - Infusion techniques training for 14 parents of people with haemophilia on 18 April. - Continuation of patient research study on adherence to treatment considering socio-economic aspects.	2.5 years Q3 2015
South America	Brazil 5 - BR5	Training of haemostasis laboratories and patient associations as strategy for sustainable diagnosis	Project	Execution	Brazilian Federation of Hemophilia, Sao Paulo - 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 association members and HTCs on advocacy and communication Analyse and improve VWD subtype classification.	- The project partnership agreement has been signed and the project activities will start in the second semester of 2018.	2.5 years Q2 2018
South America	Chile 3 - CL3	Consolidating care and treatment for haemophilia and allied bleeding disorders across Chile	Project	Execution	Hospital Roberto del Río, Santiago - Dr Veronica Soto Arellano	sdtm@nnhf.org	Improve diagnosis of congenital coagulopathies in the national reference centre Improve MSK care and training Consolidate data of haemophilia and congenital coagulopathies in national online patient registry.	- Acquisition of laboratory equipment (washing device) and ultrasound device. - Completion early March of the 1-month training of a laboratory expert (Dr Daniela Cortez) in Valencia who shared her experience with the rest of team when back in Chile. - Kinesiology training took place on 7-8 April with 20 participants.	1.5 years Q4 2017
South America	Colombia 2 - CO2	Knowledge and skills for better lives	Project	Execution	FAHES Colombia, Bucaramanga - Nurse Gina Patricia Bolaño Suarez	sdtm@nnhf.org	Improve awareness and care given to PwH and other bleeding disorders in the main public and private healthcare centres in Santander Educate PwH on bleeding disorders' prevention, care and rehabilitation.	- Organisation of 7 HCP training in different hospitals in Bucaramanga divided in four modules with the aim to familiarise medical teams with haemophilia: overview of haemostasis, haemophilia and other bleeding disorders (background and situation in Colombia), management of bleedings and other complications and therapeutic plan for haemophilia and other bleeding disorders. - Organisation of one patient and family members training during World Haemophilia week with the assistance of 36 participants. This event hosted in the University Hospital of Santander included topics such as background of haemophilia, new methods for care and treatment, women with bleeding disorders as well as the role of the nurse to provide care for patients.	2 years

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
South America	Peru 3 - PE3	Strengthen and expand network and structure of haemophilia care across sectors in Peru	Project	Execution	Peruvian Haematology Society, Lima - Dr Wilson Ruiz and Dr Nancy Loayza	sdtm@nnhf.org	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.	- Completion of a survey sent to the different centres in the country to learn more about the haemophilia situation and needs. - Organisation of first training "Juntos por la Hemofilia" from 19 to 21 April in Lima with the participation of physicians and nurses from 19 hospitals of the country belonging to the Ministry of Health (MINSA) and the Social Security (ESSALUD). Speakers such as Dr. Miguel Escobar and Luz Villalaz stressed the importance of multidisciplinary care, diagnosis and registry.	2 years Q4 2017
South America	Uruguay 3 - UY3	Decentralising care and diagnosis network in Uruguay	Project	Execution	Hospital Tacuarembó, Tacuarembó - Dr Maria Teresa Faguaga González and Hospital Paysandu Dr Ana Gabriela Chalkling	sdtm@nnhf.org	Decentralise bleeding disorders care to Tacuarembó and Paysandú Establish the haemostasis laboratory in Tacuarembó for patients living outside of Montevideo Create patient/medical networks in both regions including the patients' social environment.	- Reception of laboratory equipment (coagulometer and thromboelastograph) and training of 4 HCPs from Tacuarembó on its use. Following the training, 30 patients were retested, 15 new patients and 5 carrier women diagnosed. - Multidisciplinary training on 20 April of HCPs from different departments (Salto, Paysandú, Rio Negro, Rivera, Cerro Largo and Montevideo). - Workshop organised on 21 April with PwH and family members on several topics such as quality of life, treatment options, nutrition, oral health as well as the importance of exercise and prophylaxis. - Training provided to teachers of primary, secondary school as well as physical education teachers on 28 April.	2 years Q4 2017
South and Central Asia	Azerbaijan 2 - AZ2	Establish haemophilia care in Nakhchivan region and improve physiotherapy care across Azerbaijan	Project	Execution	Azerbaijan Republic Association of Hemophilia, Baku - Gulnara Huseynova	sysd@nnhf.org	Establish haemophilia care in Nakhchivan Advocate for better care in Nakhichevan Improve physiotherapy care Raise awareness of patients and families.	- In March, a training for children with haemophilia and their mothers was organised at the Lenkoran Health Centre. The training was attended by 80 participants. The training included sessions about the importance of physiotherapy and practical exercises to prevent consequence bleeds in the musculoskeletal system. In addition, PwH were examined by the medical team and provided with practical advice. - A seminar was conducted for 240 HCPs from Shirvan on the joint complications and physiotherapy care to prevent disability for PwH. - In May, a meeting was held between Azerbaijan Republic Association of Haemophilia, the Head of Ganja Department of Public Health, Institute of Medicine of the Haematology Department and the Haemophilia Centre Manager to agree on the development of physiotherapy care for PwH. A seminar was conducted on the importance of physiotherapy to the hospital team. - The project team conducted a site visit to Nakhchivan. The team had a meeting with the deputy Minister of Health and the chief doctor of the Republican Hospital to discuss the further development of haemophilia care as well as provide support to the newly trained haemophilia team. - Physiotherapy equipment as purchased to the haemophilia centre in Shirvan including electrotherapeutic equipment. - The diagnosis campaign was organised in Baku and Nakhchivan. So far, 21 people with haemophilia were identified in Nakhchivan, and 37 PwH and 5 patients with von Willebrand were diagnosed in Baku.	2 years Q3 2017
South and Central Asia	Bangladesh 1 - BD1	Improving quality of care for haemophilia in three centres in Bangladesh	Project	Execution	Dhaka Medical College, Dhaka - Prof Salma Afrose	nhhn@nnhf.org	Increase capacity of the multidisciplinary teams in Dhaka, Rajshahi and Rangpur Develop diagnostic facilities for coagulation studies Educate patients and families and encourage them to attend the newly trained centres Engage authorities and the public for more support to bleeding disorders.	- No activity in H1 2018	1 year Q4 2015 Prolonged until Q4 2018
South and Central Asia	India 7 - IN7	Preventing and Decreasing Musculoskeletal Morbidities among People with Hemophilia in Southern India	Project	Execution	Haemophilia Federation India, New Delhi - Dr Pamela Narayan	sysd@nnhf.org	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.	- In January, a midterm meeting of the physiotherapists involved in the MSK project was held in Hyderabad to discuss the challenges of applying and following up on the established guidelines. - MSK follow-up and data collections were run at 14 centres across India. Data collection and analysis was completed according to schedule. - The project leader presented the project results at the SAARC countries workshop in Bangalore in the presence of the WFH president.	3 years Q3 2015
South and Central Asia	India 8 - IN8	Empowering parents in South and West India	Project	Execution	Haemophilia Federation India and Empowering Minds Society for Research & Development, New Delhi - Dr Richa Mohan	sysd@nnhf.org	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.	- In January, Parents Empowering Parents (PEP) training workshop was organised for three days in collaboration with Pondicherry Chapter. The workshop was attended by 15 parents from different parts of the southern HFI chapters. The PEP manual was translated into Tamil and distributed to the participants. The highlight for facilitators and participants was the session about how to understand the physical, emotional and intellectual developmental needs of children with haemophilia. - During the WFH 2018 Congress in Glasgow, the results of the current and previous PEP programmes in India were presented in the Psychosocial PRE-Congress Workshop. Participants from different countries approached NNHF to support a similar programme in their country.	2 years Q4 2016
South and Central Asia	India 9 (West Bengal) - IN9	Identify, diagnose and empower people with haemophilia in West Bengal	Project	Execution	Hemophilia Society Durgapur, Durgapur - Roy Ajoy Roy	sysd@nnhf.org	Build care capacity in 12 medical colleges and 17 district hospitals Create awareness to identify undiagnosed PwH Organise diagnosis campaign Empower newly diagnosed PwH.	- The project partnership agreement was signed and activities will start in H2 2018.	3 years Q3 2018
South and Central Asia	Myanmar 3 - MM3	Strengthening haemophilia care and diagnosis in Northern Myanmar	Project	Execution	Mandalay General Hospital, Mandalay - Dr Moe Hein	smqy@nnhf.org	Establish a haemophilia treatment centre in Northern Myanmar Decentralise basic care to two regions Strengthen the patient association chapter and empower patients and families living with haemophilia Strengthen the communication skills of the patient association chapter and raise awareness about haemophilia.	- Strategic media engagement workshop delivered with 14 participants including people with haemophilia, family members and HCPs. - Committee meeting held to plan project activities and delivery.	3 years Q2 2018
South and Central Asia	Pakistan 6 - PK6	Building partnerships to create awareness and improve care	Project	Execution	Pakistan Hemophilia Patients Welfare Society, Lahore - Hassan Raza, President	sysd@nnhf.org	Empower the community through capacity building Identify new patients 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.	- 3-day capacity building workshop was organised for the newly elected executive council members including orientation of National Youth and Women Group Members. - A consultant was hired to prepare the Standard Operating Procedures for the HFP. - 100 people with haemophilia and their family members from different parts of Punjab were sensitised about the ways to deal with the psychosocial issues. A psychologist briefed the participants about the most effective ways of managing stress and having a positive persona. A peer-support exercise and motivational talks were included in the agenda. - A creative designer was engaged to work on the layout of the newsletter promoting the new identity of HFP.	2 years Q3 2017
South and Central Asia	Sri Lanka - LK1	Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community	Project	Closing	Haemophilia Association of Sri Lanka, Colombo - Pinsiri B. Godamunna, president	sysd@nnhf.org	Publish the national treatment guidelines for adult and children and general guideline about physiotherapy care of haemophilia. Improve physiotherapy and MSK care in the five main centres Strengthen the Sri Lanka Haemophilia Association through education and awareness sessions Empower carriers and women with bleeding disorders.	- In February 2018, the first national training for nurses and MD doctors was organised in Colombo. 80 participants from 22 centres from across the country attended the training. The training was facilitated by Dr Kate Khair and Prof Alok Srivastava and included theoretical and practical sessions. - All project activities have been completed and waiting for the final reports to be submitted.	2 years Q2 2015 - prolonged until Q1 2018