



# Selected programme updates

## 1 July – 31 December 2018

Programmes approved since 2005

- **176 projects** (13 new projects since last half year)
- **74 fellowships**
- **18 awards**

Engaged in **73 countries** leading to

- > 41,500 HCPs trained or re-trained
- > 25,500 patients diagnosed or re-diagnosed
- > 42,500 patients & family educated or re-educated

*As part of the NNHF Armenia 1 project outreach visits were organised to improve haemophilia care in 6 regions of the country.*

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
Africa	Botswana 1 project	Improve access to diagnosis and bleeding disorders care in Botswana	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	- Project partnership agreement was signed and activities will start in H1 2019.	1.5 years	Q1 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	- Empower 20 youth for ESH succession planning - Establish a national online bleeding disorder registry - Improve care provided in the regions by organising 6 outreach - Decentralise advanced care to the regions by strengthening 2 haemophilia centres	- Project partnership agreement was signed and activities will start in H1 2019.	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	- 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	- 14 youth were trained for 2 days on strategic planning and project management. The participants identified 5 strategic objectives for Ethiopian Hemophilia Society. They were divided into 5 groups and each group is leading a project based on one strategic objective.	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	- 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	- 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	- 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	- A new haemophilia clinic in Muranga was officially opened by the Dr Kanyi, Director of Medical Services in Muranga County, Kenya Haemophilia Association team and the hospital management. The clinic is providing care to PwH living in Central Kenya. - An awareness training was conducted to the HCPs from Muranga subcounty hospitals to sensitize them on availability of the new clinic and the referral process. - The haemophilia team from Muranga Hospital conducted home visits to train the families on haemophilia management at home. - A youth camp was organised for youth above 18 years old with focus on leadership, advocacy, awareness creation, haemophilia management and self-infusion. - A workshop was organised to develop the haemophilia referral system structure. Representatives of PwH, HCPs and MoH shared their experience and vision of the optimal care. The referral system draft was shared with the MoH for review and approval. - New executive board members were elected during November AGM. New positions were elected to accommodate new chapters which were established in the last 2 years. - A training policy was developed to train the new elected board on leadership and management skills. - A technical committee was established to review the registry and the data acquisition and management. - The team held two brainstorming sessions and developed a draft of the data capture tool.	2 years	Q2 2018
Africa	Madagascar 1 project	Empower the haemophilia community and strengthen the multidisciplinary care in Madagascar	Formalisation	Hopital Universitaire Joseph Ravoahangy Andrianavalona (CHU JRA), Antananarivo - Prof Aimee Olivat Rakoto Alson	sysd@nnhf.org	- Increase the diagnosis rate to 10% through awareness creation to general public, medical school and regional hospitals - Strengthen the 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 patients by decentralisation of care to two other regions	- The Project Partnership Agreement was prepared for signature.	2 years	Q1 2019
Africa	Malawi 2 project	Expand haemophilia care to the South region of Malawi	Formalisation	Society of Haemophilia and Allied Disorders (SHAD) - Mrs Chimwemwe Chande and Dr Yohannie Mlombe	sysd@nnhf.org	- 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 prepared for signature.	2 years	Q1 2019
Africa	Mali 2 project	Improving knowledge and support to haemophilia at national level	Formalisation	Association Malienne de Lutte contre l'Hémophilie (AMALHEC) - Dr Yacouba Diallo	sdtm@nnhf.org	- 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	- Project partnership agreement was signed and activities will start in H1 2019.	3 years	Q1 2019
Africa	Mauritius 1 project	Establish a multidisciplinary care team and improve haemophilia care in Mauritius	Closing	Haemophilia Association of Mauritius - Mr 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.	- Haemophilia treatment guidelines were printed and distributed to ensure a standard treatment to PwH. - Two-days Haemophilia Symposium was successfully conducted by Professor Alok Srivastava, Professor Suresh Nair, Professor Johnny Mahalangu for 200 local HCPs. - Physiotherapy equipment was purchased as recommended by the Chief Physiotherapist in CMC Vellore. - A nurse workshop was conducted for 30 nurses by local nurses who were trained abroad. - The project was presented at an international level and it won the Gold Award.	2 years	Q3 2015
Africa	Mauritius 2 project	Improve multidisciplinary care for people with bleeding disorders in Mauritius	Formalisation	Haemophilia Association of Mauritius - Mrs Mohsena Olath-Carramtally and Dr Janaki Sonoo from Victoria Hospital, Candas	sysd@nnhf.org	- Improve 100 patients' self-management of haemophilia - Improve patients' joint function by establishing MSK care - Strengthen psychosocial wellbeing of 75 haemophilia patients and families	- The Project Partnership Agreement was prepared for signature.	2 years	Q1 2019
Africa	Namibia 1 project	Establish a basic multidisciplinary team in Windhoek and improve haemophilia management in Namibia	Formalisation	Namibian Haemophilia Foundation - Mr Immanuel Mayiji and Dr Regina Roeber	sysd@nnhf.org	- 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	- The Project Partnership Agreement was prepared for signature.	18 months	Q1 2019
Africa	Nigeria 2 project	Activate and strengthen the medical and patients community in Nigeria	Closing	Haemophilia Foundation of Nigeria - Mrs 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 project	Establish basic haemophilia care in Rwanda	Execution	Rwanda Federation of Hemophilia - Mr 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 H1 2019.	2 years	Q1 2019

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
Africa	South Africa 4 project	Strengthen South African Haemophilia Federation capacity through youth development and empowerment of health care 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"> <li>- Establish a national web-based registry</li> <li>- Improve capacity and succession planning of SAHF</li> <li>- Improve haemophilia care through multidisciplinary training</li> </ul>	<ul style="list-style-type: none"> <li>- Testing of the national web registry was completed and some amendments were proposed. Currently, most HTC's have obtained approval to capture patients' data onto the registry.</li> <li>- 3rd youth leadership training was organised successfully. The youth are at various levels of development and access to resources. The NNHF Leadership Programme was shared with the participants and it was agreed to include it in the agenda of the upcoming sessions.</li> <li>- 2 basic haemophilia trainings for doctors were organised for 76 junior doctors in Bloemfontein and for 23 doctors in Kimberley.</li> <li>- Train the trainer nurses workshop was organised for 25 nurses. The trained nurses were involved in facilitating and organising other trainings.</li> <li>- The first nurses training was organised for 21 nurses from Limpopo and 1 nurse from Botswana completed a training in Pieterburg.</li> <li>- The second nurses training was held in Gauteng Province for 18 nurses from Chris Hani Baragwanath Hospital (CHBAH), 2 nurses from Charlotte Maxeke Hospital, 1 nurse from Piet Retief, 1 nurse from Witbank, 2 nurses from Mpumalanga and 1 nurse from Eastern Cape.</li> <li>- Advanced haemophilia training was organised for 13 specialised and 3 expert nurses in November by 2 international experts.</li> </ul>	3 years	Q3 2017
Africa	Tanzania 2 project	Empower the patient association to organise successful awareness campaign and advocacy	Closing	Haemophilia Society of Tanzania - Mr Richard Minja	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Empower the haemophilia community</li> <li>- Organise media engagement training</li> <li>- Create awareness in the region of Dar es Salaam</li> <li>- Advocacy meetings with authority</li> </ul>	<ul style="list-style-type: none"> <li>- 63 PwH and family members attended the patient camp organised in Dar es Salaam. The participants were trained on basic knowledge of haemophilia and first aid in case of bleeding.</li> <li>- Following the media awareness campaign, 7 new PwH were identified and diagnosed.</li> </ul>	1 year	Q2 2017
Africa	Uganda 2 project	Create awareness and HCPs training in Uganda	Closing	Haemophilia Foundation of Uganda - Mrs Agnes Kisakye, executive secretary	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Increase public awareness about haemophilia</li> <li>- Organise outreach visits to Eastern, Central and Northern Uganda to identify new haemophilia patients</li> <li>- Increase patients knowledge about haemophilia</li> <li>- Advocate for better care for haemophilia patients</li> </ul>	<ul style="list-style-type: none"> <li>- Four workshops were held in Eastern, Northern, Central and Western Uganda. 447 HCPs including paediatricians, general practitioner, nurses, midwives, dentists, laboratory technicians, physiotherapists received awareness training on symptoms and management of haemophilia.</li> <li>- 400 Village Health Teams (VHT) were trained and equipped with the basic knowledge on haemophilia symptoms and identification of potential cases.</li> </ul>	2 years	Q2 2016
Africa	Uganda 3 project	Improve haemophilia management in Uganda	Formalisation	Haemophilia Foundation of Uganda - Agnes Kisakye	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Improve patients management at 8 regional referral hospitals</li> <li>- Increase diagnosis rate from 5% to 8% through awareness raising among traditional leaders, public and medical teams</li> <li>- Register all people with bleeding disorders in an online registry</li> <li>- Achieve inclusion of haemophilia into the non-communicable diseases programme and budget</li> <li>- Improve diagnosis capacity in the North</li> <li>- Strengthen the haemophilia care unit in the North to improve patient management</li> <li>- Empower next generation of haemophilia community leaders</li> </ul>	<ul style="list-style-type: none"> <li>- The Project Partnership Agreement was prepared for signature.</li> </ul>	2 years	Q1 2019
Africa	Zambia 1 project	Haemophilia awareness campaign and outreach across Zambia	Execution	Haemophilia Foundation of Zambia - Mr Chilufya Pikit	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Create awareness through documentaries and materials</li> <li>- Organise outreach programme by training community health workers, traditional and non-medical circumcisers</li> <li>- Improve self-care of people living with haemophilia through education</li> <li>- Establish first haemophilia treatment centre</li> </ul>	<ul style="list-style-type: none"> <li>- 45 participants attended the first self-infusion camp in Lusaka. In addition to the self-infusion training sessions, patients were trained on physiotherapy exercises.</li> <li>- 3 workshops were organised for 150 community health workers. They were trained on identification and referral of suspected patients.</li> <li>- In collaboration with Mufumbwe District Ministry of Health, 25 traditional circumcisers were trained on precautions and management of people with haemophilia.</li> </ul>	1.5 years	Q2 2017
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"> <li>- Establish multidisciplinary care teams in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap</li> <li>- Decentralise basic care to 5 provincial hospitals</li> <li>- Strengthen advanced diagnosis in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap</li> <li>- Increase patients' and families' self-management ability</li> <li>- Strengthen the patient association by having more active members</li> <li>- Create awareness about haemophilia</li> </ul>	<ul style="list-style-type: none"> <li>- Youth group established in Siem Reap.</li> <li>- Laboratory equipment purchased to the National Pediatric Hospital in Phnom Penh.</li> <li>- Planning of visit by team from Nottingham University Hospital to conduct follow-up training in Siem Reap and Phnom Penh.</li> </ul>	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"> <li>- Strengthen paediatric comprehensive care in 6 provinces, using the BCH comprehensive care model to improve organisation and delivery of care in HTCs</li> <li>- Empower children with haemophilia and their family members and increase their self-care knowledge using the BCH patient camp model</li> <li>- Create awareness of haemophilia amongst the patient community, public and authorities</li> </ul>	<ul style="list-style-type: none"> <li>- Project was approved in March 2018 and will presumably start its activities in mid 2019.</li> </ul>	3 years	Q1 2019
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"> <li>- Set up multidisciplinary care and train the teams in Suzhou, Nanjing, Yangzhou, Huai'an and Xuzhou</li> <li>- Advance the capacity in the selected centres on factor activity and VWD detection, and the usage of the registry system</li> <li>- Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities</li> </ul>	<ul style="list-style-type: none"> <li>- Comprehensive care training of health care professionals in Huai'an, Nantong, Taizhou, Nanjing and Yancheng.</li> <li>- HTC inspection visit to Huai'an and Wuxi.</li> </ul>	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"> <li>- Select four city-level haemophilia centres in Nanchong, Luzhou, Dazhou and Ya'an</li> <li>- Set up multidisciplinary care and train the teams</li> <li>- Advance the capacity of factor activity detection and the usage of the registry system in the selected centres</li> <li>- Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities</li> </ul>	<ul style="list-style-type: none"> <li>- Knowledge sharing meeting with the haemophilia care team in Hefei, Anhui Province regarding treatment schemes, joint arthritis, health insurance policies and advocacy collaboration between health care professionals, patient association and government.</li> <li>- Three patient education sessions carried out on the topic of self-infusion and self-care.</li> <li>- HCP training sessions at Dazhou sub-centre focusing on treatment schemes and emergency treatment.</li> <li>- Annual project summary meeting between Chengdu Hemophilia Center and the four haemophilia sub-centres in Nanchong, Luzhou, Dazhou and Ya'an.</li> <li>- Training of laboratory staff in the four haemophilia sub-centres in Nanchong, Luzhou, Dazhou and Ya'an to ensure standardisation of laboratory processes in Sichuan Province.</li> </ul>	3 years	Q2 2016
East Asia	China 7 (Tibet) project	Development of haemophilia care in Tibet Autonomous Region	Execution	Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang	smqy@nnhf.org	<ul style="list-style-type: none"> <li>- Establish multidisciplinary care at Tibet People's Hospital in Lhasa. The last province in China without haemophilia center</li> <li>- Education of health care professionals in Tibet Autonomous Region including train-the-trainer</li> <li>- To build a multidisciplinary team and Tibet People's Hospital and to assist them to develop cooperation with local government</li> <li>- Establish access to the Chinese national registry and register new patients diagnosed</li> <li>- To guide Tibet Blood Centre on the national quality standards to enable appropriate production of cryoprecipitate in local blood center</li> <li>- Improve the awareness of multidisciplinary care in haemophilia amongst HCP, patients, families and government</li> </ul>	<ul style="list-style-type: none"> <li>- Visit from a haemophilia expert group to Tibet Blood Center in Lhasa.</li> <li>- 22 lab technicians trained in Tibet Blood Center in Lhasa.</li> <li>- 37 health care professionals in Tibet Blood Center in Lhasa trained about haemophilia nurse care, physiotherapy for people with haemophilia, plasma composition preparation and quality control and how to register people with haemophilia in the national registry.</li> </ul>	1 year	Q1 2017
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"> <li>- Establish and strengthen haemophilia care in 7 provinces in China</li> <li>- Increase quality diagnosis across 7 provinces</li> <li>- Consolidate patient data in national online patient registry, including medical data</li> <li>- Empower patients and families to enjoy better quality of life and becoming an active partner within the haemophilia community</li> <li>- Increase understanding and recognition about haemophilia amongst general public, HCPs and authorities</li> <li>- Improve legislation and reimbursement for haemophilia care by introducing haemophilia within provincial health care agendas</li> </ul>	<ul style="list-style-type: none"> <li>- Follow-up visit by the trainer team to the HTC in Inner Mongolia province, assessing care and training health care professionals.</li> <li>- Hebei province launched a "multidisciplinary haemophilia collaboration group" involving haematologists, nurses, physiotherapists, orthopaedics and dentists, enabling higher quality and more standardised care for people with haemophilia.</li> <li>- A specialised haemophilia clinic was opened in Liaoning and Haerbin province.</li> <li>- Five training sessions took place for 242 health care professionals (doctors, nurses, lab technicians and physiotherapists).</li> <li>- 15 educational sessions brought together 204 patients and 147 family members.</li> <li>- All patient and medical data in the national online registry was checked in 12 hospitals in the 7 provinces.</li> </ul>	3 years	Q2 2017

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
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	- Establish and strengthen multidisciplinary haemophilia care and emergency management in 9 regional HTC 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	- Printing and distributing patient ID cards. - Printing of educational and awareness raising materials. 1,000 copies of the "Haemophilia in pictures" book, 800 copies of awareness posters, and 700 copies of an awareness flyer.	3 years	Q2 2017
East Asia	Nepal 2 project	Improving diagnosis and multidisciplinary care in Nepal	Formalisation	Nepal Hemophilia Society - Mr Manil Shrestha and Mrs Suraksha Thapa	smqy@nnhf.org; nhhn@nnhf.org	- 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	- The project was approved in November 2018 and the project partnership agreement will be prepared for signature.	3 years	Q1 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	- 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	- In-depth training on MSK care of four physiotherapists and one haematologist in Toronto, Canada hosted by the Hospital for Sick Children and St. Michael's Hospital. The trained Thai health care professionals were from Chiang Mai, Bangkok and Khon Kaen. - Two MSK training sessions for health care professionals carried out by Thai trainers. A total of 39 health care professionals were trained from Phitsanulok, Chiang Mai, Ubonratchathani and Songkhla. - The thrombosis and haemostasis registry developed by the Thai Society of Hematology (TSH) has been finalised. - The HJHS calculator has been finalised.	3 years	Q4 2015
East Asia	Thailand 4 project	Improving haemophilia care in Thailand through the Chronic Care Model, strengthening of comprehensive care teams and development of leadership talents	Execution	National Health Security Office (NHSO), IHTC Bangkok, Faculty of Medicine/Chiang Mai University and the Thai Haemophilia Patient Club - Hathaiwat Lamthean, Prof Ampaiwan Chuansumrit, Dr Rungrote Natesirinikul and Mr Ekawat Suwantaraj	smqy@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	- Workshop to increase awareness of exercise and nutrition carried out to strengthen mental and physical health for people with haemophilia. 5 chapter presidents, 6 Thai Hemophilia Patient Club board members and 20 patient representatives were educated. - Follow up visit by doctors from IHTC Bangkok to the province of Ubon Ratchathani.	2 years	Q1 2017
East Asia	Vietnam 3 project	Joint effort continuing to expand the haemophilia network and basic multidisciplinary care across Vietnam	Formalisation	National Institute of Hematology and Blood Transfusion and Vietnam Hemophilia Association - Dr Mai Nguyen Thi	smqy@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 start its activities in beginning of 2019.	3 years	Q1 2019
Europe	Albania 1 project	Strengthen haemophilia care in Tirana, create awareness across the country and empower the patient organisation	Formalisation	University Hospital Centre (UHC) "Mother Tereza" - Dr Adela Perolla and Dr Bledi Kalaja	xfov@nnhf.org	- 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	The project was approved in November 2018.	2 years	Q1 2019
Europe	Romania 2 project	Empowering the haemophilia patient community in Romania	Execution	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 has launched their media campaign "Zero bleeds", aiming to empower the haemophilia patient community to play an active role in advocating for their own care based on the national treatment guidelines. - The project started with the first two educational workshops in Bucharest and Buzias. The workshops were supported by the medical team and the participants were informed about their rights and the importance of prophylaxis. - Regional workshops will follow in 2019.	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	Formalisation	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 prepared for signature.	2 years	Q1 2019
North and Middle America	Cuba 2 project	Decentralisation of comprehensive care to two centres in the East and establishment of a national reference centre for women with bleeding disorders in Havana	Closing	Instituto de Hematología e Inmunología (IHI) - Prof José M. Ballester Santovenia and Dr Dunia Castillo	sdtm@nnhf.org	- Set up of project with authorities - Creation and development of SANTIAGO DE CUBA province hemophilia center - Creation and development of HOLGUIN province hemophilia center - Systematic updating of educational materials for patients, relatives and professionals involved in their care, including haemophilia and von Willebrand acting protocols - Regular organization of workshops, seminars and educational courses and practical trainings for health personnel including hematologists and other specialists, laboratory technologists and other technicians and administrative assistants, as well as visits to the provinces to check the development and quality of their work. - Promote exchange between patient - Optimize the National Congenital Coagulopathies Registry and data management	- Laboratory training organised in Havana on 12-13 November with 7 participants from Holguin and the capital city. - Agrometer received in December in Santiago de Cuba and training provided on its use for the laboratory team. - Development and printing of educational material (for schools, physicians and parents) as well as national treatment guidelines and posters for distribution in the different hospitals of the country. - Organisation of final project event on 18 December in Havana with more than 30 participants from different regions of the country. This event also covered the sustainability of the activities run under the NNHF Cuba 1 project.	2 years	Q3 2016
North and Middle America	Dominican Republic 2 project	Expanding diagnosis and registry of haemophilia in Dominican Republic	Execution	Fundación 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	- Completed formalisation phase (agreement and dedicated bank account).	2 years	Q1 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	- Organisation in Merida of the fourth regional training (5-6 October 2018) with a total of 78 participants. This training tackled several disciplines including haematology, rehabilitation, orthopaedics, nursing and social work. - Initiation of the development of the national online registry.	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 patients and family members	- Laboratory training with Marion Echenagucia from 1 to 4 August at ISSEMyM hospital in Toluca in conjunction with NNHF Mexico 7 project and different hospitals from the State of Mexico. 14 participants attended this theoretical and practical training. - Organisation of annual camp with 40 children with haemophilia. - Development of educational material on dental health.	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 Agustín 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 patients and their families to take a bigger role in self-care	- Organisation of 6 self-infusion training for PwH and family members. - Participation in Mayan radio programme explaining generalities about haemophilia. - Development and printing of educational material in Mayan language and reprinting of material in Spanish. - Training session given to 15 physicians who serve rural communities in the State of Yucatán. - Organisation on 4 October of the final project event in Merida with participation of approximately 50 PwH and family members. A self-infusion workshop was also part of this festive event.	1 year	Q3 2017

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
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	<ul style="list-style-type: none"> <li>- Initiate diagnosis at the hospital's laboratory</li> <li>- Improve the knowledge of the multidisciplinary team and standardise care delivery in the HTC</li> <li>- Empower PwH and relatives to achieve a better quality of life</li> <li>- Create awareness on haemophilia and coagulation disorders to promote timely diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>- 4-day laboratory training given by Marion Echenagucia in Toluca. This training, organised in conjunction with the NNHF Mexico 5 project, counted with the participation of 4 members of the haematology laboratory staff from Hospital de Occidente.</li> <li>- Initiation of Factor VIII and Factor IX testing within Hospital de Occidente.</li> <li>- Establishment of the haemophilia clinic goals and initiation of the definition of the roles for each member of the multidisciplinary team.</li> <li>- First phase of the analysis of the current processes in the clinic and identification of areas of opportunity.</li> </ul>	2.5 years	Q3 2018
North and Middle America	Nicaragua 2 project	Haemophilia care outreach in Nicaragua	Formalisation	Asociación Nicaragüense de Hemofilia - Mr Engels Rolando Reyes Sánchez and Dr René Berrios Cruz from Banco de Sangre, Ministerio de Salud	sdtm@nnhf.org	<ul style="list-style-type: none"> <li>- Decentralise diagnosis to the hospital Escuela César Amador Molina and improve the diagnosis rate in the Central region from 25% to 40%</li> <li>- Develop and implement national diagnosis guidelines in collaboration with the Ministry of Health</li> <li>- Improve healthcare professionals' knowledge on haemophilia in Managua, Matagalpa, Bluefields and Puerto Cabezas</li> <li>- Empower 80 PwH from Matagalpa and Managua through 7 training sessions</li> <li>- Strengthen patient organisations from Nicaragua, Guatemala, Honduras and El Salvador through a 3-day training in Managua</li> </ul>	<ul style="list-style-type: none"> <li>- Complete formalisation phase (agreement and dedicated bank account).</li> <li>- Activities to start in Q1 2019.</li> </ul>	2 years	Q1 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	<ul style="list-style-type: none"> <li>- Initiate MSK care and occupational therapy in Salta</li> <li>- Create a network of HCPs and patients trained in MSK care and occupational therapy across the province of Salta</li> <li>- Strengthen MSK care and occupational therapy across Argentina building a national network</li> </ul>	<ul style="list-style-type: none"> <li>- Organisation from 6 to 9 November in Salta of an aquatic therapy, MSK and occupational therapy training with HCPs from all around the country as well as both national and international speakers (Brazil and Mexico).</li> <li>- Development of protocols for aquatic rehabilitation, work in gym for hemarthrosis, synovitis and muscular bruises.</li> <li>- Continuation of the evaluation of patients and use of the rehabilitation pool.</li> <li>- Development of educational material on home exercising for PwH and vWD.</li> </ul>	2 years	Q3 2017
South America	Brazil 4 project	Strengthening the care and education network for haemophilia in the state of Pará in Brazil	Closing	FBH – Federação Brasileira de Hemofilia - Mrs Christianne Maria Oliveira Costa	sdtm@nnhf.org	<ul style="list-style-type: none"> <li>- Prepare and deliver training activities for health care professionals of primary health care and municipal hospitals</li> <li>- Prepare and deliver training activities for patients and their families</li> <li>- Reproduction and distribution of educational materials, posters and infusion diaries for patients</li> <li>- Draw the psychosocial profile of patients and their situation to promote the appropriate treatment</li> <li>- Publicise the results in a national meeting and at the Haemophilia Journal</li> </ul>	<ul style="list-style-type: none"> <li>- Outreach training in Altamira (818km away from State capital city of Belem) on 19-20 December where no care network currently exists for haemophilia.</li> <li>- Finalisation of patient research study on adherence to treatment considering socio-economic aspects.</li> <li>- Participation at the HEMO 2018 congress in Sao Paulo in November and presentation of the haemophilia treatment barriers and adherence of people with haemophilia in the State of Pará.</li> </ul>	2.5 years	Q2 2016
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	<ul style="list-style-type: none"> <li>- Advance level of diagnosis in 8 pre-selected Haemophilia Treatment Centres at national level</li> <li>- Achieve diagnosis sustainability by training local patient association members and HTCs on advocacy and communication</li> <li>- Analyse and improve vWD subtype classification</li> </ul>	<ul style="list-style-type: none"> <li>- Finalisation of survey for 26 diagnosis centres across the country.</li> <li>- Evaluation of survey results and selection of 8 laboratories in Brazil (States of: Amapá, Alagoas, Bahia, Goias, Mato Grosso, Piaui, Rondonia and Sergipe) for diagnosis improvement.</li> <li>- Development of testing protocol.</li> </ul>	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	<ul style="list-style-type: none"> <li>- Improve the diagnosis of congenital coagulopathies in the national reference centre</li> <li>- Improve the outcome in patients with orthopaedic maintained flexo disease and who require knee replacement</li> <li>- Introduce MSK diagnosis and training</li> <li>- Have an updated track record of patients with congenital coagulopathies</li> </ul>	<ul style="list-style-type: none"> <li>- Completion of a 2-week laboratory training in Valencia of Dr Lamas.</li> <li>- Development of online clinical registry platform.</li> <li>- Initiation of the development of a mobile application for Hemophilia Joint Health Score (HJHS) evaluation and balance exercises.</li> </ul>	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	<ul style="list-style-type: none"> <li>- Improve awareness and care given to patients with bleeding disorders in the main public and private healthcare centres in Santander</li> <li>- Educate patients on bleeding disorders' prevention, care and rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>- Organisation of 10 HCP training in 5 different hospitals from Bucaramanga (Clínica Bucaramanga, Hospital Militar, Clínica la Merced, Hospital Piedecuesta and Hospital Universitario de Santander) with the aim to familiarise medical teams with haemophilia.</li> <li>- On 13 July, organisation at the Foscal Clinic of a training session for PwH and families on haemophilia carriers. This event was attended by more than 100 participants.</li> <li>- Purchase of prosthetic infusion arm for training sessions with PwH and families.</li> </ul>	2 years	Q2 2018
South America	Colombia 3 project	Strengthening our life skills	Formalisation	Liga Antioqueña de Hemofílicos - Mr David Andrés Cuartas Bolivar	sdtm@nnhf.org	<ul style="list-style-type: none"> <li>- 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</li> <li>- Sensitise 50 HCPs from 10 hospitals in the department on humanised and comprehensive care that promotes psychosocial accompaniment and education within the care models</li> <li>- Improve knowledge of teachers from 20 educational institutions in the department to promote better integration and performance of children with haemophilia</li> <li>- 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</li> </ul>	<ul style="list-style-type: none"> <li>- Opened dedicated bank account.</li> </ul>	2 years	Q1 2019
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"> <li>- Organise care on a national level strengthening and creating multidisciplinary care teams</li> <li>- Achieve quality diagnosis in the reference centres and create basic diagnosis hubs in other regions of the country</li> <li>- Reflect the national epidemiological picture of haemophilia and allied bleeding disorders in a web-based registry</li> </ul>	<ul style="list-style-type: none"> <li>- Sharing at a haematology congress in September of the results from the national survey initiated during the first semester.</li> <li>- Development of educational material (brochures and posters) to be distributed to the different centres at national level.</li> <li>- Preparation of patient identification cards.</li> <li>- Planning of treatment centres' visits in 7 regions of Peru.</li> </ul>	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"> <li>- Strengthen the haemostasis laboratory in Tacuarembó for patients living in the northern part of Uruguay</li> <li>- Improve the expertise of HCPs caring for PwH in Tacuarembó and Paysandú</li> <li>- Educate patient community in Tacuarembó and Paysandú on disease knowledge</li> </ul>	<ul style="list-style-type: none"> <li>- On 12 October, a training for psychologists and social workers was held in Tacuarembó with a total of 27 participants.</li> <li>- A training for gynaecologists and obstetricians on carrier pregnant women and Von Willebrand disease was held on 19 December in Tacuarembó. This training was attended by 15 participants.</li> <li>- Purchase of tube centrifuge for laboratory in Tacuarembó Hospital.</li> <li>- Diagnosis of 15 new cases of haemophilia and vWD as well as retesting of 15 samples.</li> </ul>	2 years	Q4 2017
South and Central Asia	Armenia 2 project	Establish rehabilitation capacity and decentralise haemophilia care in Armenia	Formalisation	Haematology Center after Prof. R.H.Yeolyan - Prof Samvel Danielyan and Dr Heghine Khachatryan	smqy@nnhf.org	<ul style="list-style-type: none"> <li>- Strengthen haemophilia team capacity across Armenia</li> <li>- Bring care closer to the patients by setting up 2 satellite centres and organising 6 outreach</li> <li>- Establish rehabilitation capacity and care in the haemophilia centre in Yerevan</li> <li>- Increase disease knowledge of 160 PwH and family members to live better lives</li> <li>- Gain health authority support for the haemophilia programme</li> </ul>	<ul style="list-style-type: none"> <li>- The project was approved in November 2018 and the project partnership agreement will be prepared for signature.</li> </ul>	2 years	Q1 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"> <li>- Establish haemophilia care in Nakhchivan</li> <li>- Advocate for better care in Nakhchivan</li> <li>- Improve physiotherapy care</li> <li>- Raise awareness of patients and families</li> </ul>	<ul style="list-style-type: none"> <li>- Project planning meeting between Azerbaijan Republic Association of Hemophilia and the Central Hospital of Nakhchivan Autonomous Republic.</li> <li>- All diagnosed people with haemophilia living in Nakhchivan Autonomous Republic was included in the national registry.</li> <li>- In September, the haematology and physiotherapy department of the Central Hospital of Nakhchivan Autonomous Republic was examined.</li> <li>- New medical equipment was purchased for the Central Hospital of Nakhchivan Autonomous Republic.</li> <li>- In November and December, physiotherapy workshops were held for a total of 54 people with haemophilia and their families.</li> </ul>	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"> <li>- Increase capacity of the multidisciplinary teams in Dhaka, Rajshahi and Rangpur</li> <li>- Develop diagnostic facilities for coagulation studies</li> <li>- Educate patients and families and encourage them to attend the newly trained centres</li> <li>- Engage authorities and the public for more support to bleeding disorders</li> </ul>	<ul style="list-style-type: none"> <li>- No activity in H2 2018.</li> </ul>	1 year	Q4 2015

Region	Programme name	Programme title	Phase	Partner	NNHF contact	Objectives	Status	Duration	Start date of activities
South and Central Asia	India 7 project	Preventing and Decreasing Musculoskeletal Morbidities among People with Hemophilia in Southern India	Execution	Haemophilia Federation India - Dr Pamela Narayan	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Map the musculoskeletal morbidities and physiotherapy practices prevalent in factor limited settings, particularly India</li> <li>- Delineate and implement a clinical pathway of MSK care for PWH</li> <li>- Increase awareness and access to physical therapy in the management of MSK morbidities amongst PWH</li> </ul>	<ul style="list-style-type: none"> <li>- Data Analysis of phase 3 trial was completed, measuring the efficacy of the physiotherapy protocols.</li> <li>- In September, the physiotherapists involved in phase 3 clinical trial had a meeting for 2 days in Kerala. The results of the trial were presented and all the logistics for the train the trainer workshops were finalised.</li> <li>- Four train the trainer workshops were organised in Durgapur, Kolhapur, Kunnamkulam and Lucknow. 111 local physiotherapists attended the workshops. They were given the opportunity to present and contribute to the training.</li> <li>- On December 1st, the first national haemophilia MSK meeting was organised in Delhi. 71 physiotherapists, 1 occupational therapist and 4 orthopaedic surgeons attended the meeting. The workshop focused on: <ul style="list-style-type: none"> <li>• Advocate for physiotherapy in governmental hospitals</li> <li>• Address various aspects of MSK care by exposing the trainees to in-depth knowledge by a panel of speakers including one foreign expert</li> <li>• Include orthopaedic surgeons as part of the MSK network</li> <li>• Hands on training with focus on MSK assessment</li> </ul> </li> <li>- MSK clinics in Agra, Surat, Kolhapur, Berhampur, Rajkote, Jamshedpur, Vizag, Cuddapah, Kannur, Tirunelveli and Hyderabad run regularly by the trained physiotherapists</li> <li>- The MSK registry is regularly updated and currently includes 316 patients.</li> <li>- 3 short films were made to increase awareness and highlight the importance of physiotherapy in haemophilia.</li> </ul>	3 years	Q3 2015
South and Central Asia	India 8 project	Empowering parents in South and West India	Execution	Haemophilia Federation India and Empowering Minds Society for Research & Development - Dr Richa Mohan	smqy@nnhf.org	<ul style="list-style-type: none"> <li>- Customise and update the Parents Empowering Parents (PEP) programme and materials with the international PEP</li> <li>- Train the trainers programme on PEP for 150 parents from 8 states in South and West India</li> </ul>	<ul style="list-style-type: none"> <li>- Two three-day Parents Empowering Parents workshops carried out in the state of Karnataka. 41 parents trained to understand haemophilia as well as the physical and emotional needs of children growing up with a bleeding disorder.</li> </ul>	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"> <li>- Build care capacity in 12 medical colleges and 17 district hospitals</li> <li>- Create awareness to identify undiagnosed PwH</li> <li>- Organise diagnosis campaign</li> <li>- Empower newly diagnosed PwH</li> </ul>	<ul style="list-style-type: none"> <li>- Psychosocial counselling training organised for HCPs at Bishnupur District Hospital.</li> <li>- Awareness about haemophilia training organised for HCPs at The Mission Hospital, Durgapur.</li> <li>- Annual patient association chapter meeting organised by the women and youth group.</li> </ul>	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"> <li>- Establish a haemophilia treatment centre in Northern Myanmar</li> <li>- Decentralise basic care to two regions</li> <li>- Strengthen the patient association chapter and empower patients and families living with haemophilia</li> <li>- Strengthen the communication skills of the patient association chapter and raise awareness about haemophilia</li> </ul>	<ul style="list-style-type: none"> <li>- Haemophilia nurse training organised with the support of volunteer expert nurse Jennifer Maahs from Indiana Hemophilia &amp; Thrombosis Center, US. 14 nurses trained; from Yangon, Mandalay, Lashio and Nay Pyi Taw.</li> <li>- Laboratory equipment purchased for Mandalay General Hospital.</li> <li>- "Walkathon" organised with 80 participants including people with haemophilia, health care professionals, social workers, volunteers and family members. A TV-interview done with the president of Myanmar Haemophilia Patient Association, Mandalay Chapter raising awareness about haemophilia.</li> <li>- A patient association office was established for Myanmar Haemophilia Patient Association, Mandalay Chapter.</li> </ul>	3 years	Q2 2018
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"> <li>- Empower the community through capacity building</li> <li>- Identify new patients with bleeding disorders through awareness raising activities</li> <li>- Improve access to care in the regions through advocacy activities in partnership with the provincial and national authority</li> <li>- Improve diagnosis rate and update national patient registry</li> </ul>	<ul style="list-style-type: none"> <li>- A consultant is developing the Standard Operating Procedures (SOPs) for Hemophilia Federation of Pakistan (HFP). The consultant is working on different types of policies to improve and align the daily operations.</li> <li>- National Medical Advisory Board was formulated to establish national diagnosis and treatment guidelines.</li> <li>- Fundraising materials were created and distributed to all the chapters.</li> <li>- HFP-Karachi Chapter organised a psychosocial workshop for 100 PwH and their family members from Sindh region. The participants were sensitised on how to deal with the psychosocial issues.</li> <li>- Haemophilia awareness seminar was organised by HFP-Karachi Chapter engaging local HCPs and local media.</li> <li>- HFP board representatives visited the province of Sindh and had meetings with Fatmid Foundation, Husaini Blood Bank, Indus Hospital and Aga Khan University Hospital with the objective to align all the efforts in the province and have a contentious collaboration.</li> </ul>	2 years	Q3 2017
South and Central Asia	Sri Lanka 1 project	Improve physiotherapy and musculoskeletal training and awareness for HCPs and haemophilia community	Closing	Haemophilia Association of Sri Lanka - Mr Pinsiri B. Godamunna, president	sysd@nnhf.org	<ul style="list-style-type: none"> <li>- Publish the national treatment guidelines for adult and children and general guideline about physiotherapy care of haemophilia</li> <li>- Improve physiotherapy and MSK care in the five main centres</li> <li>- Strengthen the Sri Lanka Haemophilia Association through education and awareness sessions</li> <li>- Empower carriers and women with bleeding disorders</li> </ul>	<ul style="list-style-type: none"> <li>- 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.</li> <li>- All project activities have been completed and waiting for the final reports to be submitted.</li> </ul>	2 years	Q2 2015
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"> <li>- Improve diagnosis capacity and quality in Kurunegala, Batticaloa, Galle and Anuradhapura regional hospitals</li> <li>- Increase diagnosis rate by 10% through awareness creation</li> <li>- Improve multidisciplinary care of haemophilia treatment centres in Kurunegala, Batticaloa, Galle and Anuradhapura</li> <li>- Empower 250 people with haemophilia and their families through 4 workshops and 2 patient camps</li> </ul>	<ul style="list-style-type: none"> <li>- The project was approved in November 2018 and the project partnership agreement will be prepared for signature.</li> </ul>	2 years	Q1 2019