



NNHF Programmes: selected updates on activities in the 2nd half year 2017 (1 July – 31 December 2017)

Overview

Novo Nordisk Haemophilia Foundation H2 2017 update	By end H1 2017
Number of projects approved by NNHF Council since 2005 (new projects since last half year)	156 (8)
- 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)	16 (0)
HCPs trained since 2005	36'000
Patients and family members educated & patient leaders trained since 2005	38'150
People with haemophilia retested and newly diagnosed since 2005	22'750
NNHF engaged in number of countries (new countries since last half year)	69 (1)

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
Africa	Egypt 2 - EG2	Improving musculoskeletal (MSK) care in Egypt and establishing a MSK-registry to collect outcome data	Project	Execution	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.	- ESH received the 2nd shock wave machine and Dr Adly Sabour started to treat the complicated haemophilia cases with deformative joints. - For better joint evaluation, ESH purchased ultrasound machine and physiotherapists were trained on using it. - Very impressive results achieved by using the shock wave to treat hemophilia patients, helping to correct the deformities of the large joints especially flexion contractures of the knee joints. Many patients are able to move and improved their motion range after mobility loss.	1.5 years Q1 2016
Africa	Ethiopia 1 - ET1	Improve haemophilia care in Ethiopia by decentralisation of care and empowerment of haemophilia community	Project	Formalisation	Ethiopian Hemophilia Society, Addis Ababa - Samson Hallemariam	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.	- Sign project partnership agreement.	2 years Q1 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.	- Three patient meetings were held in Accra and Kumasi, attended by 175 patients and 70 parents. Participants were educated about basic haemophilia knowledge and agreed on creation of new patient association chapters. The selected locations are Komfo Anokye Teaching Hospital, Eastern Regional Hospital and Tamale Teaching Hospital. - The Society's website was re-designed and updated with the relevant information. - The medical outreach started with training of HCPs in the regional hospitals as following: • 34 lab scientists trained on basic coagulation methods. • A total of 23 doctors, 21 physiotherapists and 97 nurses trained on how to identify PwH and provide basic care. • The training was followed by screenings of 92 patients in Tamale region.	2 years Q1 2017
Africa	Kenya - KE3	Enhancement of capacity for comprehensive haemophilia management	Project	Execution	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.	- Taking a step forward to provide comprehensive care at Coast General Hospital in Mombasa, the project supported the purchase of a semi-automated coagulometer and facilitation of lab training. - 27 youth attended a youth leadership camp as a first step of succession planning. - After completing all the project objectives, KHA board meeting was organised to review the results of KE3 project and plan for a new project application. - All project activities have been completed and waiting for the final project report to be submitted.	2 years Q2 2015
Africa	Malawi 1 - MW1	Establish haemophilia care in Malawi	Fundraised project	Execution	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.	- Outreach visits were conducted to regional health centres to identify more patients. 21 potential patients were identified and they will be diagnosed at Kamuzu Central Hospital. - The reagents were purchased to continue with patients' diagnosis. - Dr Christine Chilinga attended the 2017 ASH meeting and presented a poster about the project. The poster was received positively from the audience and the collaborative approach was highly appreciated.	9 months Q1 2016 prolonged until Q4 2017
Africa	Mali 1 - ML1	Improve haemophilia care in Mali by capacity building and awareness creation	Project	Execution	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.	- Organised training for traditional practitioners who are strongly involved with the health system. 126 traditional practitioners attended the training and a link between PwH and traditional practitioners was created. 7 new patients were identified as a result of the training. So far, the project helped to increase diagnosed PwH from 42 in 2016 to 103 patients. - 51 HCPs were trained from 4 health district hospitals. The training included general knowledge about haemophilia, identification of PwH and providing basic care.	2 years Q1 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, Mauritius - 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.	- The medical bleeding disorder registry was implemented. The registry includes demographic and medical data as well as the required factor concentrates dose for each patient. So far 25% of patients are registered. - The selected orthopaedic surgeon by the MoH was trained at CMC Vellore, India for one month. - One nurse was trained at Maxeke Hospital, Johannesburg for one month.	2 years Q3 2015
Africa	Nigeria 2 - NG 2	Activate and strengthen the medical and patients community in Nigeria	Project	Closing	Haemophilia Foundation of Nigeria, Kaduna - Megan Buckie Aderin	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 and waiting for the final reports to be submitted.	2 year 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.	2 years Q1 2018
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) - Johan Potgieter	sysd@nnhf.org	Establish a national web-based registry Improve capacity and succession planning of SAHF Improve haemophilia care through multidisciplinary training.	- Organised a leadership programme for 15 youth in Cape Town. Participants were selected from various regions around South Africa based on their motivation. Programme was designed to suit all participants as they came from different backgrounds. As part of the training, the young leaders were divided into 4 groups selecting strategic goals which they will lead. - Drafted requirements, specification and functions for the national online registry. So far, phase 1 developed which includes 70% of the needed functionality. - 10 key opinion leader doctors from the CCCs across South Africa had a meeting in Johannesburg to agree on the national haemophilia training programme for HCPs. In addition, they agreed on the curriculum, printed materials and presentations. - A national nurses training was organised for 21 nurses. All the trained nurses achieved over 80% of the post-training test.	3 years Q2 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.	- Engaged in advocacy discussions and meetings with the non-communicable diseases department. As a result, the team was invited to attend the meeting with the authorities to review the 2018 National Health Policy. For the first time, haemophilia was included as well.	1 year Q1 2017

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
Africa	Uganda 2 - UG2	Create awareness and HCPs training in Uganda	Project	Execution	Haemophilia Foundation of Uganda, Kampala - Agnes Kisakyee, 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.	- Three medical workshops were organised in the Eastern, Central and Northern regions to raise awareness among HCPs. - Four workshops for Village health teams were successfully organised in the Eastern, North and Central regions. Village Health teams were equipped with the basic knowledge about haemophilia. A team coordinator was identified for better follow-up and mobilisation. - Representatives from NGOs for disabled people attended workshops which were organised in the Eastern, North and Central regions. More than 80 participants were trained. - Muslim leaders/workshops were organised at Kibuli Muslim mosque in Lira District. This attracted sheikhs and circumcisers. Much emphasis was put on ensuring safe circumcision and immediate referral in case of prolonged bleeding. - The Haemophilia patient's camp was successfully organised on the 16th December 2017 with the theme "Youth and Women through vibrant sensitisation". The camp empowered the youth and the parent's support groups, intended to create a united advocacy voice. The following sessions were included in the camp: o Introduction about haemophilia, signs and symptoms, management and home therapy. o Psychosocial session. o Youth empowerment session with focus on how to live a normal life, raise awareness and leadership. The session was followed by an election of regional coordinators who accepted the challenge to identify 20 new cases by December 2018 and proactively involved in the organisational activities. - One press release was published with Daily Monitor newspaper. It covered the patient's camp and captured patients' stories.	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.	- A circumciser training was held on 30th September 2017 for 31 participants. Taking in consideration that haemophilia is highly undiagnosed in Zambia, the workshop built the capacity of the participants in understanding bleeding disorders. The training addressed the issues related to identification, diagnosis and management of bleeding disorders during the circumcision procedure. In addition, the participants were provided with training materials namely "Haemophilia: Training for Circumcision Practitioners". The workshop was covered by journalists from 9 media houses including radio and TV. - In the preparation for the awareness campaign, ZACCAF created awareness materials and trained the volunteer team. The team chose to start with Copper Belt region where most of the patients come from. To gain credibility, the team had a meeting with Arthur Davidson Children's Hospital superintendent. It was agreed with him to establish a haemophilia clinic at the hospital and endorse a partnership for the awareness campaign in the region.	1.5 years Q2 2017
East Asia	Cambodia 2 - KH2	Establish multidisciplinary care and strengthen awareness in Cambodia	Project	Formalisation	Cambodia Hemophilia Association (CHA), Phnom Penh - Sokpanha Sem	smqy@nnhf.org	Establish multidisciplinary care teams in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap Decentralise basic care to 5 provincial hospitals Strengthen advanced diagnosis in the National Pediatric Hospital in Phnom Penh and in Angkor Hospital for Children in Siem Reap Increase patients' and families' self-management ability Strengthen the patient association by having more active members Create awareness about haemophilia.	- Project approved with full grant.	3 years Q1 2018
East Asia	China 5 - CNS	Set up and consolidate five comprehensive treatment centres for haemophilia and von Willebrand disease in Jiangsu Province China	Project	Execution	The First Affiliated Hospital of Suzhou University, Suzhou - Prof Ziqiang YU	smqy@nnhf.org	Set up multidisciplinary care and train the teams in Suzhou, Nanjing, Yangzhou, Huai'an 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.	- 46 physiatrists and nurses trained on ultrasound and joint assessments in Jiangsu province. - 49 healthcare professionals, including 27 physiotherapists trained about joint health and HHHS in Xuzhou city. - 21 local patient association leaders of Jiangsu province educated on prophylactic treatment and joint health in order for them to cascade their new knowledge locally. - Meeting between the Jiangsu Hemophilia Expert Team and an official in the department of health of Jiangsu province, reporting on NNHF project achievements and discussing next steps in haemophilia care.	3 years Q1 2016
East Asia	China 6 - CN6	Decentralisation of multidisciplinary care in four city level haemophilia centres in Sichuan Province China/ Sichuan Province	Project	Execution	Sichuan Center of Haemophilia Diagnosis and Treatment - Prof Xiaojing LI	smqy@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.	- HCP training of trainers session carried out about joint assessments. - 5 training sessions carried out in Nanchong Sub-center for doctors, nurses, laboratory technicians and physiotherapists. - Meeting between medical insurance authorities and several national haemophilia experts hosted in Chengdu New Century Women's and Children's Hospital. - 300 copies of educational materials for HCPs and people with haemophilia distributed.	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 - Dr Xinsheng Zhang	smqy@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.	- Training session of HCPs from Tibet People's Hospital and Tibet Blood Center in Lhasa. The training was done by leading national experts travelling to Lhasa. - Computer purchased for Tibet People's Hospital to update patient registry. - Consultations of people with haemophilia carried out.	1 year Q1 2017
East Asia	China 8	Establishing and strengthening quality haemophilia care in the northeast region of China.	Project	Execution	Institute of Haematology and Hospital of Blood Diseases, Chinese Academy of Medical Sciences, Tianjin - Prof Renchi Yang	smqy@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.	- Project launch on 1 of July with the directors from the 7 involved provincial HTCs. - One week in-depth training of the 7 multidisciplinary care teams carried out by HTC/CNC expert team in Tianjin. 40 healthcare professionals received specialised training, including haematologists, nurses, physiotherapists, laboratory technicians and ultrasound doctors. - One full-time haemophilia nurse in each of the 7 centres was made responsible for data entry in the national registry. - Five provinces; Hebei, Henan, Jilin, Heilongjiang and Shanxi, launched the project locally. - Education needs identified for people with haemophilia and educational materials printed. - In total 184 people with haemophilia and 249 family members educated during eight workshops in Henan province, Shanxi province and Heilongjiang province. - 221 new people with haemophilia diagnosed and 174 re-tested. - 415 patients registered in the national registry.	3 years Q2 2017
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	smqy@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.	- Multidisciplinary haemophilia care introduced in the new HTC in Samarinda. - Emergency management in multidisciplinary haemophilia care strengthened in the HTCs in Jakarta and Manado. - Haemophilia awareness training of in total 451 HCPs from primary and secondary health care centres in Jakarta, Samarinda and Manado. - Self-management and self-infusion education of in total 259 people with haemophilia and/or their family members in Jakarta, Samarinda and Manado. - Educational materials such as leaflets, posters, a "Haemophilia in pictures"-booklet, the "Indonesian guidelines of diagnosis and management of haemophilia", and a diary book recording bleeds were printed and distributed.	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 Natesirinnikul - Prof Ampaiwan Chuansumrit	smqy@nnhf.org	Validate the HHS 2.1, FISH, PEDI/HAAL, CHOKLAT and HEMOQpL-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.	- MSK training carried out ensuring an equal knowledge level of Thai HCPs before an expert visit from Sick Kids Hospital in Canada. Training done by Thai trainers. 13 HCPs representing 5 centres in the North of Thailand attended the training. - MSK follow-up visit from Sick Kids Hospital in Canada to IHTC Ramathibodi Hospital Bangkok and Chiang Mai Hospital. A total of 24 HCPs trained. - Haemophilia education day for people with haemophilia held in Chiang Mai Hospital. - Haemophilia awareness day carried out for HCPs in Northern Thailand. - Translation of the NNHF "Stretch Out for Haemophilia and Exercise" booklet to Thai. - MSK assessment continued. - Monthly operation committee conference calls organised between IHTC Ramathibodi Hospital Bangkok, Chiang Mai Hospital and Sick Kids Hospital in Canada.	3 years Q4 2015

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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 - Hathaiwit Lamthean - Prof Ampaiwan Chuansumrit - Dr Rungrote Natesirinnikul - Mr Ekawat Suwanartaj	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.	- Two day follow-up conference call and 'virtual multidisciplinary care training' by CCC trainer team from Bangkok to Songkhla and Narathiwat (due to safety issues). - Youth leadership development workshop with representatives from the four patient clubs; Northern, Southern, Western and North-Eastern, carried out. - First follow-up meeting in the four established patient association youth groups held. - Follow-up visit by the National Health Security Office to Songkhla and Narathiwat province.	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	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 approved with full grant.	3 years Q1 2018
Europe	Latvia 2 - LV2	Set up of a web-based bleeding disorders registry in Latvia	Project	Execution	Latvia Hemophilia Society, Riga - Baiba Ziemele	smqy@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.	No activities carried out in H2 2017.	1 year Q2 2016 prolonged until Q1 2019
Near and Middle East	Jordan 3 - JO3	Creation of a medical and social network to support haemophilia care across Jordan	Project	Closing	Princess Sumaya University for Technology (PSUT), Amman - Dr Ararat Awajan	sysd@nnhf.org	Organise a comprehensive national training programme for healthcare professionals Conduct educational sessions and awareness campaigns for people with haemophilia Create educational materials for PwH and their family in Arabic Develop an Arabic website with educational material for both HCP and PwH. The website will serve as a communication channel for PwH and the different stockholders in the Arabic speaking countries.	- All project activities have been completed and waiting for the final reports to be submitted.	2 years Q2 2014 prolonged until Q3 2017
Near and Middle East	Palestine 1 - PS 1	Improve the quality of health care provided for patients with Haemophilia in Palestine	Project	Closing	Palestine Ministry of Health, Foreign Relation department, Ramallah. - Huda Lahham and Dr Hussein Elyan	sysd@nnhf.org	Design and apply a comprehensive national training programme for healthcare professionals Create guidelines for treatment of haemophilia Produce educational material for healthcare professionals and patients Improve the laboratory facilities Screen and (re-)diagnose of 1680 people with haemophilia Six educational sessions for people with haemophilia will be conducted. Set up a national medical registry.	- All project activities have been completed and waiting for the final reports to be submitted.	1.5 years Q1 2014 prolonged until Q2 2017
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 Hematología e Inmunología (IHI), Habana - Prof. José M. Ballester Santovenia and Dr Dunia Castillo	sdm@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.	- Completion of HCP training in the provinces of Holguin and Santiago de Cuba. - Preparation of digital documents for the registry. - Selection of provincial coordinators for Santiago de Cuba and Holguin on HCP and patient side.	2 years Q3 2016
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	sdm@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.	- Medical training at the XXII National Mexican Haemophilia Congress which took place on 27-29 July 2017 with 728 participants attending (524 PwH and family members and 204 HCPs). - Organisation of regional training at the University Hospital of Monterrey, Nuevo León on 22-23 September 2017. The event had the participation of 30 HCPs - First contact and discussions on the development of the national online 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	sdm@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 bank account has now been opened and the PPA signed.	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	sdm@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.	- Acquisition of an infusion arm for patients to practice venepuncture. - A multidisciplinary team was trained in Monterrey in August 2017. - Outreach visits to patients outside of the city.	1 year Q3 2017
North and Middle America	Nicaragua 1 - NI1	Establish comprehensive care of haemophilia in Nicaragua	Project	Execution	Nicaraguan Association of Hemophilia - Javier Antonio Rivas Ojeda and Red Cross Nicaragua - Dr Rene Berríos	sdm@nnhf.org	Improve coagulation laboratory and train the staff to do diagnosis Create national treatment guidelines Train professionals in nursing, physiotherapy, dental care and medical training of patients with haemophilia Provide educational sessions to patients and families on haemophilia Strengthen the haemophilia care centre and the patient association.	- 2 professionals from the diagnostic laboratory received training from the experience of Marisol Soza in her course in Panama. - Invitations through mass media to PwH to get diagnosed. - A web application was developed for the online registry. - Development of two types of conferences to be replicated in the future, one for university students and another one for HCPs. - Organisation of the final project event on 2 December 2017.	2 years Q1 2016
South America	Argentina 2 (South of Buenos Aires province) - AR2	Creation of a cross-institutional and multidisciplinary care network to offer a comprehensive approach in the South of Buenos Aires province	Project	Execution	CARDHE - patient association and healthcare centre in Bahía Blanca, - Dr Susana Garbiero	deni@nnhf.org	Establish a working agenda with all relevant health institutions in the region and create a network Evaluate the patients' situation and empower them and their families through education Strengthen the healthcare institutions in the region through training.	- A self-infusion workshop for 36 patients and parents took place. - As part of the education of the patients' social environment and the efforts to decrease stigmatisation, a group of HCPs trained the director, administrative personnel, teachers and parents at a kindergarten and a school in Tres Arroyos. - Educational material for HCPs, schools and patients is being created. The website of CARDHE is in the process of being finalised and will provide information on haemophilia and allied bleeding disorders for various target groups.	1.5 years Q2 2016
South America	Argentina 3 (Jujuy) - AR3	Outreach to patients with haemophilia in the province of Jujuy	Project	Execution	Fundación Jueña de Hemofilia, San Salvador de Jujuy - Dr Susana Gastaldo	deni@nnhf.org	Identify new patients and improve diagnosis infrastructure Improve access to care for people with haemophilia in the province of Jujuy Improve patients' quality of life by establishing self-treatment processes and educating the social environment.	- In total, through the outreach visits, 24 training and awareness sessions were performed in different parts of the province of Jujuy since the beginning of the project in October 2016, reaching 55 HCPs, 45 patients, 180 family members and 170 students. The sessions included training for HCPs, self-infusion workshops for patients and parents and informational sessions for schools. - Educational material was created and distributed in the training sessions. - 40 patients have been re-diagnosed and 12 new patients diagnosed. All have been registered.	1 year Q4 2016
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	sdm@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.	- A rehabilitation pool was built and swirling baths were improved. - Training in Campinas, Brazil (Hemocamp) of Maria Helena Martínez, occupational therapist. - A booklet on home exercises for PwH and vWD was developed. - Multidisciplinary evaluation of 57 patients done.	2 years Q3 2017

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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 - Christianne Maria Oliveira Costa	sdm@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.	- A training in Marabá on 30 November 2017 brought together 45 HCPs and 31 PwH and family members. - Preparation of the 2018 training sessions in Santarem and Belem. - Advocacy activities were completed with the State Ministry of Health and the HEMOPA association.	2.5 years Q3 2015
South America	Brazil 5 - BR5	Training of haemostasis laboratories and patient associations as strategy for sustainable diagnosis	Project	Formalisation	Brazilian Federation of Hemophilia, Sao Paulo - Francisco de Paula Careta	sdm@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 HTC's on advocacy and communication Analyse and improve VWD subtype classification.	- Formalisation of project ongoing.	2.5 years Q1 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	sdm@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	- A physiotherapist (Carlos Cruz) received a physiotherapy training in Spain during 4 weeks in November 2017 and now provides training to different rehabilitation teams in Santiago. - Acquisition of an ultrasound for the MSK evaluation and ELISA device for diagnosis.	1.5 years Q4 2017
South America	Colombia 2 - CO2	Knowledge and skills for better lives	Project	Formalisation	FAHES Colombia, Bucaramanga - Nurse Gina Patricia Bolaño Suarez	sdm@nnhf.org	Improve awareness and care given to PwH and other bleeding disorders in the main public and private health care centres in Santander Educate PwH on bleeding disorders' prevention, care and rehabilitation.	- Formalisation of project ongoing.	2 years Q1 2018
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	sdm@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.	- Meetings with authorities to plan for project activities. - Needs assessment of the centres in the regions of the country. - Plan national HCP training in Lima.	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	sdm@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	- Organisation and planning of a multi-disciplinary training to be run during the Haemophilia week (17-21 April 2018). - Training of a nutritionist completed. - A haemophilia educator's training was initiated to increase patients' adherence to treatment. - Tromboelastogram and coagulometer ordered for laboratory. - A database was developed with the patients from the departments in the north of the Rio Negro.	2 years Q3 2017
South and Central Asia	Armenia - AM	Building the national haemophilia care network in Armenia	Project	Execution	Haematology Center of Armenia, Yerevan - Prof Smbat Daghabashyan	sysd@nnhf.org	Strengthen the local haemophilia care team Establish haemophilia treatment guidelines Establish a web based national haemophilia registry Raise awareness to increase the quality of life of PwH Improvement of diagnostic facilities Outreach visits to improve haemophilia awareness in the regions.	- All project activities have been completed and waiting for the final reports to be submitted.	2 years Q1 2015
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 November, the project team had a meeting with representatives from the MoH and Nakhchivan region to agree on next steps and responsibilities. - Translated, edited and printed the physiotherapy care educational materials. - A study was conducted and patients' joints evaluated across the country. The study included patients aged 12-35 years using laboratory examination, ultrasound and X-ray examination. The study results were submitted to MoH. Among the 225 patients studied, 107 patients have disability. The patients will receive regular physiotherapy care during the project.	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 - Prof Salma Afrose	smqy@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 activities carried out in H2 2017.	1 year Q2 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 - 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.	- Organised a master trainers workshop in Bangalore to finalise the physiotherapy treatment protocols. - Designed the data portal and started to collect the MSK data, testing the physiotherapy protocol. So far, 293 patients were registered. - Obtained permission from 14 centres to participate in the study. - Organised 4 MSK camps training PwH on relevant exercises as following: o At Hyderabad, attended by 86 PwH. o At Vizag, attended by 21 PwH. o At Surat attended by 40 PwH. o At Cuddapah attended by 11 PwH. - As a policy impact, the health authority and HFI are unconditionally committed to improve MSK health care of PwH across India.	3 years Q2 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 - 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.	- The team organised the third PEP workshop in Kerala in December 2017. Kunnankulam chapter in Kerala as part of HFI together with Empowering Minds organised the workshop with focus on psychosocial training for parents, HCPs and professionals working with children. - The workshop was a platform for the parents to open up with their queries and concerns. Valuable information was shared on the types of care and support required by children with haemophilia on a daily basis.	2 years Q4 2016
South and Central Asia	India 9 (West Bengal)- IN9	Identify, diagnose and empower people with haemophilia in West Bengal	Project	Formalisation	Hemophilia Society Durgapur, Durgapur - Roy Ajay 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.	- Sign project partnership agreement.	3 years Q1 2018
South and Central Asia	Myanmar 3 - MM3	Strengthening haemophilia care and diagnosis in Northern Myanmar	Project	Formalisation	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.	- Project approved with full grant.	3 years Q2 2018

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
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.	- PHPWS organised a workshop to create a Women Group, in order to give the females with bleeding disorders a platform to share their experience, to discuss their issues freely and to highlight the female population of bleeders in Pakistan. - A workshop was successfully organised to address the psychosocial issues facing PwH and their families. More than 100 PwH and their family members from Punjab attended this event. The workshop was designed in such an interactive way that patients and their parents were sensitised and briefed about the way to cope with the psychosocial issues, motivational lecture, panel group discussion and networking exercise were part of the agenda. - A Memorandum of Understanding was signed between PHPWS-Peshawar Chapter and Frontier Foundation to ensure smooth cooperation between both organisations. The signing ceremony was held during a provincial advocacy visit.	2 years Q2 2017
South and Central Asia	Sri Lanka 1 - LK1	Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community	Project	Execution	Haemophilia Association of Sri Lanka - Pinsiiri 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.	- Project has been prolonged until Q2 2018 to organise training of nurses and doctors.	2 years Q2 2015 prolonged until Q1 2018