



NNHF Programmes: selected updates on activities in the 1st half year 2017 (1 January – 30 June 2017)

Overview

| Novo Nordisk Haemophilia Foundation H1 2017 update | By end H1 2017 |
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| Number of projects approved by NNHF Council since 2005 (new projects since last half year) | 148 (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 (2) |
| HCPs trained since 2005 | 31'290 |
| Patients and family members educated & patient leaders trained since 2005 | 35'500 |
| People with haemophilia retested and newly diagnosed since 2005 | 22'430 |
| NNHF engaged in number of countries (new countries since last half) | 68 (0) |

| 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 | Gamaeet 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- | 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. | - A shockwave medical device was purchased to strengthen the physiotherapy clinic in Cairo. | 1.5 years Q1 2016 |
| 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. | - Project partnership agreement was signed. | 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. | - A team from KHA visited the Coast General Hospital and held discussions with the hospital management and the regional health administration. As a result, a clinic was allocated to establish a haemophilia care clinic - During the visit to the Coastal Region, the team held a patient support meeting and a patient training on home therapy and self-infusion - On April 15, the Kenya Haemophilia Association organised for one day sensitisation forum for clinical team from the coast region on management of haemophilia - On April 16, KHA organised a walk to celebrate WHD. The event was flagged off by the County Director of Health - On May 12, KHA opened the haemophilia clinic in Mombasa - On May 13 and June 10, the KHA board and executive committee met to review the strategic plan and agree on priorities until 2019. | 2 years Q2 2015 |
| Africa | Malawi - MW | 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. | - 11 new PwH were diagnosed - As a result of the availability of proper diagnosis, the society started to receive factor concentrates (Factor VIII) from the WFH Humanitarian Aid programme. This has made tremendous impact in the care provided to PwH in Malawi - On WHD 2017, a patient camp was held to train patients on self-infusion. | 9 months Q1 2016 |
| Africa | Malawi - MW | Specialised training in haemophilia care and management | Fellowship | Closing | Christine Chilinga, haematologist Kamuzu Central Hospital, Lilongwe, Malawi | sysd@nnhf.org | Learn how haemophilia treatment centre operates in terms of clinical care and laboratory diagnosis Get equipped with knowledge regarding identification, diagnosis and management of haemophilia and bleeding disorders Gain experience on management of complications of haemophilia as well as management of treatment complications Understand the concept of prophylaxis treatment. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; responsible person(s): Prof Johnny Mahlangu. | - Training was completed in May 2017. | 2 months Q1 2016 |
| Africa | Malawi 2 - MW 2 | Build diagnosis capacity in Malawi | Fellowship | Closing | Blessing Mwangomba, Dr David Livingstone Memorial, Lilongwe | sysd@nnhf.org | Acquire knowledge on how to handle manual and automated diagnosis of haemophilia and other bleeding disorders Learn about the quality scheme for coagulation tests Gain skills on organising training in Coagulation procedures. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; responsible person(s): Prof Johnny Mahlangu. | - Training was completed in March 2017. | 1.5 months Q1 2017 |
| Africa | Mali - ML | 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. | - To create awareness, a short movie called "the daily life of hemophilia patient in Mali" was created and broadcasted in collaboration with the national television. The movie was re-broadcasted by two other television stations - On radio, an awareness emissions was continuously broadcasted on three private radio stations (Radio Espoir, Radio Kunandi and Radio Aw Kodi) - During WHD celebration, the team organised a meeting with health authorities and national haemophilia society. The ceremony was attended by Mr Moussa Mara, former Minister of Health, Dr Bakary Diarra, the general secretary of the Ministry of Health, Mr Abdoulaye Diabate haemophilia ambassador of Malian hemophilia society. - A press conference was organised and attended by 50 journalists and press workers. The conference was covered by three TV channels - In the last 6 months, 48 samples were collected and 24 new patients were diagnosed. | 2 years Q1 2016 |
| Africa | Mauritius - MU | 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. | - HAM organised a week celebration around the WHD including: o A short video on the reality of haemophilia in Mauritius was developed and published on Facebook o Lit up the Bagatelle Bridge in red o HAM held an official ceremony at Mauritius Council of Social Services Regional Leadership Centre in Reduit, attended by over 120 patients and their families. The event was attended and supported by Her Excellency, Mrs. Ameenah Gurib Faqueem, the President of the Republic of Mauritius - MoH in process of nominating a physician and a paediatrician to receive 3 months training at CMC Vellore starting in September 2017 - A nurse, a bone surgeon were assigned for 1 month training at CMC Vellore starting in September 2017 - The development of the online registry started. | 2 years Q3 2015 |

| Region | Programme name | Programme title | Programme type | Phase | Partner | NNHF contact | Objectives | Status | Programme duration / Start date |
|-----------|----------------------|---|----------------|-----------|---|---------------|---|---|---------------------------------|
| Africa | Nigeria 2 - NG 2 | Activate and strengthen the medical and patients community in Nigeria | Project | Execution | Haemophilia Foundation of Nigeria, Kaduna - Megan Buckie Adediran | sysd@nnhf.org | Establish a reference laboratory at the Lagos University Teaching Hospital (LUTH) Create an electronic medical registry and complete the identified patient profiling Empower patients through four educational camps Create awareness by organising two world haemophilia day celebrations and develop awareness publications Establish regional haemophilia care service in the South West Region. | - Empowerment patient camp was organised for 13 participants in age group 26-53. Topics discussed included other health issues to consider, joint management, physiotherapy and exercise - A total of 6,000 educational handbills as well as 1,000 posters were printed. | 2 year Q1 2015 |
| Africa | South Africa 3 - ZA3 | Bringing better haemophilia care closer to the patients and strengthening the community | Project | Closing | Igazi Foundation - Charmaine Oosthuizen | sysd@nnhf.org | Improve services provided at district level Increase responsibility and compliance of patients Implement updated electronic registry Raise teaching & organising capacities. | - All project activities have been completed. Waiting for the final audit report. | 2 years Q1 2014 |
| 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. | - Project partnership agreement was signed. | 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. | - Strategic Media Engagement training was organised by NNHF. The training was attended by 9 haemophilia leaders - Following the Strategic Media Engagement training, a training for 36 media reports from 17 media organisations including radio, TV and newspapers. The training covered the aspects of haemophilia and how media can help to identify PwH and decrease stigmatisation. MoH supported the training and the Minister was guest of honour - 3 TV talks (TBC TV, Clouds and Star TV) and 2 radio talks (TBC Radio) and 6 newspapers reported about haemophilia. New PwH were identified as a result of the awareness campaign - 6 youth trained on how to use social media to create awareness about the society - Leadership training was organised for 18 young leaders on how to be active with the society and lead activities - Organised stand alone training for 33 traditional healers from Dar es Salaam region. The training was attended by 7 patients and covered by 12 media reporters. | 1 year Q1 2017 |
| Africa | Tanzania 2 - TZ2 | Start haemophilia care in Southern Tanzania | Fellowship | Closing | Goreth Lupembe, Nurse, Mbeya Referral Hospital, Mbeya, Tanzania | sysd@nnhf.org | Have the basic knowledge to identify the patients with haemophilia Learn how to provide the basic care to PwH; instead of referring them to Muhimbili National Hospital Acquire the knowledge to train the other Hospital Staff. - Christian Medical College, Vellore, India; responsible person(s): Dr Alok Srivastava. | - The training was completed in May 2017. | 3 months Q3 2015 |
| Africa | Uganda 2 - UG2 | Create awareness and HCPs training in Uganda | Project | Execution | Haemophilia Foundation of Uganda, Kampala - Agnes Kisakye, executive secretary | sysd@nnhf.org | Increase public awareness about haemophilia Organise outreach visits to Eastern, Central and Northern Uganda to identify new haemophilia patients Increase patients knowledge about haemophilia Advocate for better care for haemophilia patients. | - During the health camp organised by the office of the vice president at Lambu Landing, HFU team created awareness for over 1,400 people - A haemophilia symposium was organised during WHD with focus on patient identification, referral and management. It was attended by 46 doctors, 27 nurses, 2 physiotherapists and 19 other HCPs - A Muslim circumcisers' workshop was conducted. Much emphasis was put on safe practice for PwH and preparation needed for the process. The training was attended by 100 Muslim circumcisers which will increase safe circumcision and help in new patient identification - 10 Village Health Team (VHT) coordinators were identified and they supported the training of 238 VHT at Dimo Landing site and 45 youth VHT at Kibuli Muslim mosque - 23 media houses covered the haemophilia activities, featured live in the day's news bulletin and live interviews were conducted on different radio stations. - A haemophilia motion advocating for a comprehensive policy on haemophilia care was presented by the chairperson on the floor of parliament to get government support to develop a comprehensive policy on haemophilia care - Haemophilia team participated at the three day parliamentary health week. This led to a new partnership between HFU and the office of the vice president and strengthened the advocacy strategy with government officials. - Three health care practitioner's workshops were successfully organised. | 2 years Q2 2016 |
| Africa | Zambia 1 - ZM1 | Haemophilia awareness campaign and outreach across Zambia | Project | Execution | Haemophilia Foundation of Zambia, Lusaka Chilufya Pikiti, Founding member | sysd@nnhf.org | Create awareness through documentaries and materials Organise outreach programme by training community health workers, traditional and non-medical circumcisers Improve self-care of people living with haemophilia through education Establish first haemophilia treatment centre. | - The project partnership agreement was signed. | 1.5 years Q2 2017 |
| East Asia | Cambodia - KH | Raising awareness, support, diagnosis and treatment for people with haemophilia living in Cambodia | Project | Execution | Cambodia Haemophilia Association - Mr Sithan Kong | smqy@nnhf.org | Develop national guidelines for diagnosis, treatment and management of patients with haemophilia and other bleeding disorders Improve diagnosis, treatment and management of haemophilia and other bleeding disorders in five provincial hospitals Empower patients and family members to better cope with their condition and engage in the patient society Conduct awareness activities engaging health authorities to secure their support. | - WHD was celebrated with an awareness raising event and the project team succeeded in engaging with several media channels. The event was for example broadcasted at PNN and articles were written to raise awareness about haemophilia - Final project report received. | 2.5 years Q4 2014 |

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|-----------|-----------------------|--|----------------|---------------|---|---------------|--|---|---------------------------------|
| East Asia | Cambodia 2 - KH2 | Advanced training in rare bleeding disorders diagnosis | Fellowship | Closing | Sam Samey, Laboratory technician, National Pediatric Hospital (NPH), Phnom Penh | smqy@nnhf.org | Increase capacity of diagnosis regarding; <ul style="list-style-type: none"> - Detection of inhibitors - Diagnosis of von Willebrand disease - Diagnosis of Platelet Function Disorders - Testing for antiphospholipid antibodies. - Hospital Ampang, Kuala Lumpur, Malaysia; responsible person: Jameela Sathar, Dr/Consultant Haematologist. | - Fellowship completed and final report received. | 2 months Q1 2017 |
| East Asia | China 3 - CN3 | Further improve reliability of diagnosis and comprehensive care in China by setting up a National Quality Assessment Programme | Project | Closing | Haematology Department, Ruijin Hospital affiliated to Medicine School of Shanghai Jiaotong University, Shanghai - Prof Hongli Wang | smqy@nnhf.org | Further improve reliability of diagnosis and comprehensive care in China by setting up a National External Quality Assessment (EQA) programme: <ul style="list-style-type: none"> - Improve the Quality Assessment in Haemophilia laboratories in China - Improve the awareness and knowledge of haemophilia in rural areas of selected less privileged provinces - Find and diagnose 1,000 new patients - Maintain and update the established national web-based bleeding disorders registry. | - Final audit report received. | 2 years Q2 2012 |
| East Asia | China 4 - CN4 | Identify and improve five city level comprehensive haemophilia centres in Shandong province | Project | Closing | Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang | smqy@nnhf.org | Identify five city level haemophilia centres from urban and rural areas who meet the established criteria to be developed into comprehensive care centres. Conduct a tailored training program on these centres and assist them in developing cooperation with local government Foster knowledge of patients and families and give them tools to improve their quality of life. Raise awareness through education materials, press engagement and a documentary film. Diagnose and register 200 new cases identified through the proposed awareness activities. | - Development of project summary film - 116 new patients diagnosed and registered - Final audit report received. | 2.5 years Q3 2014 |
| East Asia | China 5 - CN5 | 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, Huaian and Xuzhou. Advance the capacity in the selected centres on factor activity and VWD detection, and the usage of the registry system. Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities. | - Education sessions for healthcare professionals held in Xuzhou and Huaian. 75 doctors and 21 nurses trained about haemophilia care. The healthcare professionals were from Haematology department, Orthopaedics department, Supersonic department, Emergency department, Paediatrics department and Physiotherapy department - WHD celebrated in all five cities involved in the project. Education meetings for patients and their families carried out. More than 200 patients and family members attended the events. | 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. | - Five train-the-trainer-workshops held for the provincial HCP expert team focusing on haemophilia diagnosis and treatment - Trainings of health care professionals carried out in Chengdu and in Mianyang in order to further improve the knowledge of haemophilia care - Education about haemophilia and treatment options of patients and family members done in Chengdu - WHD celebrated to support patients, improve social awareness about haemophilia and to promote the strengthening of haemophilia care in Sichuan. Healthcare professionals, volunteers, patients and families from more than 18 hospitals and organisations united - Educational materials developed and printed for both healthcare professionals and patients - 21 new haemophilia patients diagnosed and registered. | 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. | - Trip to Lhasa planning and preparing for the training session of HCPs. | 1 year Q1 2017 |
| East Asia | China 8 | Establishing and strengthening quality haemophilia care in the northeast region of China. | Project | Formalisation | Institute of Haematology and Hospital of Blood Diseases, Chinese Academy of Medical Sciences, Tianjin - Professor 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. | - Capacity needs assessment of the 7 involved HTCs. Training needs of each HTC and appropriate clustering determined - Laboratory needs assessments of the 7 involved HTCs and secondary centres to be included in the National Quality Assurance Scheme - The train-the-trainer programme package developed and printed, including national treatment guidelines and a book about comprehensive care - Launch of the NNF-CN8 program at a workshop in Tianjin - One week in-depth training of the 7 multidisciplinary care teams carried out by HTCCNC expert team in Tianjin. 38 healthcare professionals were in-depth trained - Provincial awareness and advocacy need assessments done. Advocacy objectives and goals defined. Causes for lack of supportive policies, legislation and coverage limitations and delivery of care deficiencies analysed. | 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 Choie, 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. | - Needs assessment of the 10 involved haemophilia treatment centres done - Kick-off meeting held in Sanur, Bali. The focus of the meeting was to ensure an aligned project team, to discuss the training concept and tailor it to specific centre needs - Educational materials developed; a booklet on self-infusion for patients and a leaflet and a poster for HCPs about emergency care for haemophilia patients. | 3 years Q2 2017 |

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|----------------------|------------------------|--|----------------|-----------|---|---------------|--|--|---------------------------------|
| East Asia | Malaysia 3 - MY3 | Identifying and empowering women leaders to activate regional chapters within the Malaysian Haemophilia Society | Project | Execution | Ampang hospital, Kuala Lumpur - Dr Jameela Sathar | smqy@nnhf.org | Raise awareness among healthcare professionals on diagnosis and treatment of women with bleeding and clotting disorders Create a women's support group at a national level Devise a leadership manual for the women's group in Malaysia Engage media to support improvement of care in Malaysia Set up a National Haemophilia and Coagulation Disorders Standards Board. | - A leadership training manual has been developed - The Women Haemostatic Club (KHWAN) and Hemophilia Society of Malaysia (HSM) organised a two day WHD event; 124 people with haemophilia or families participated in the activities being educated about exercise, a hiking trip and self-infusion training - Collaboration with the Ministry of Health has started regarding setting up a National haemophilia standards board. | 1,5 years Q1 2016 |
| East Asia | Thailand2 - 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 Natesirinikul - Prof Ampaiwan Chuansumrit | smqy@nnhf.org | Validate the HJHS 2.1, FISH, PedHAL/HAL, CHOKLAT and HEMOQQL-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. | - Monthly operation committee conference calls organised between IHTC Ramathibodi Hospital Bangkok, Chiang Mai Hospital and Sick Kids Hospital in Canada - Planning of MSK follow-up visit from the team from Sick Kids Hospital in Canada to IHTC Ramathibodi Hospital Bangkok and Chiang Mai Hospital in September - MSK assessment continued. | 3 years Q4 2015 |
| 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 Natesirinikul - 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. | - Comprehensive care management workshop carried out in Bangkok for CCC teams from 8 selected, regional hospitals (Chantaburi, Ubonrajtani, Ratchaburi, Krabi, Chiang Rai, Phitsanulok, Narathivas and Songkhla) - 24 doctors and 169 nurses were trained from regional and provincial hospitals in Songkhla, Narathivas, Krabi and Chantaburi provinces ensuring awareness and basic knowledge about haemophilia - Printing and distribution of a booklet for HCPs regarding care and treatment of haemophilia patients - 2 day follow-up visit and 'in action multidisciplinary care training by CCC trainer team from Bangkok or Chiang Mai to Chiang Rai, Phitsanulok and Ubon Ratchathani. | 2 years Q1 2017 |
| East Asia | Vietnam 2 - VN2 | Join efforts to improve quality of haemophilia care across Vietnam | Project | Execution | Vietnam Society of Congenital Bleeding disorder, Hanoi - Prof Nguyen Anh Tri | smqy@nnhf.org | Improve quality of haemophilia care in the four main regions: Hanoi, Hue, HoChiMinh city (HCMC) and Can Tho Improve medical staff knowledge about haemophilia Improve knowledge of patients and families Diagnose 200 new patients through an outreach program Create awareness about haemophilia. | - Meeting in the National Haemophilia Committee with representatives from NNHF, WFH and IHS - Printing of 6 publications about haemophilia: Haemophilia and school, Haemophilia and Dental care, General information about haemophilia, Haemophilia and sport, Mild Haemophilia, Women and bleeding disorders - Peer group meetings. | 3 years Q2 2013 |
| 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. | 1 year Q2 2016 |
| Europe | Serbia 2 - RS2 | Empowering the patient community to be active and compliant | Project | Execution | Serbian Haemophilia Society, Belgrade - Tatjana Marković | smqy@nnhf.org | Empower and engage patients through psychological workshops and materials targeted by age group Strengthen SHS through empowerment of regional educators who will drive the educational/empowerment activities of the Society Create awareness about the activities of the Society and the insufficient and irregular supply of factor concentrates and its consequences. | - Start-up meetings in the newly established educator groups in Belgrade, Kragujevac and Novi Sad - Workshop for psychologists from secondary clinical centres - Final audit report received. | 2 years Q1 2015 |
| Global | Laboratory Module 2016 | NNHF Laboratory Module 2016 | Project | Execution | NNHF Lab training module in cooperation with the Royal Free Hospital (UK) - Dr Angus McCraw - Haemophilia centre service manager & principal biomedical scientist - Marion Echenagucia, Head of Haematology Lab, Banco de Sangre de Caracas, Venezuela - Dr Christophe Nougier Edouard Herriot Hospital, Lyon, France | sysd@nnhf.org | Improve expertise in quality diagnoses tailored to the working conditions of developing countries Give continuity to the basic module performing five basic courses in 2016 Develop and engage regional lab expert trainers Build an international network of trainees. | - All the project activities were completed. - An instructors meeting was held in July 2017 to discuss the future of the lab courses. | 1 year Q1 2016 |
| Near and Middle East | Jordan 3 - JO3 | Creation of a medical and social network to support haemophilia care across Jordan | Project | Execution | Princess Sumaya University for Technology (PSUT), Amman Dr Arafat 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. | - Patients and volunteers training organised on using and updating the an Arabic haemophilia website and its contents - HCPs training was re-scheduled for August 2017. | 2 years Q2 2014 |
| Near and Middle East | Palestine 1 - PS1 | Improve the quality of health care provided for patients with Haemophilia in Palestine | Project | Execution | 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. | - Continue strengthening the labs at the regional hospitals by purchasing 2 freezers. | 1,5 years Q1 2014 |

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|--------------------------|----------------------------------|--|--------------------|---------------|--|---------------|--|---|---|
| North and Middle America | Costa Rica 1 - CR1 | Conduct advanced musculoskeletal evaluation through EMG | Fundraised project | Execution | Hospital Nacional de Niños "Dr. Carlos Sáenz Herrera" - Dr Marta Navarrete | deni@nnhf.org | Purchase of a computer, printer and an EMG evaluation machine Organise one monitoring visit from Dr Seuser and his team members. | - Planning of visit by German team to Costa Rica for 2017. | 2 years Q2 2016 |
| 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 | deni@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. | - All contractual preparations for the procurement of the laboratory and IT equipment have been done and will soon be delivered to the respective hospitals. - The national treatment guidelines are in revision and need to be edited. - The national registry has been upgraded and will be online soon. | 2 years Q3 2016 |
| North and Middle America | Jamaica - JM | Establishing quality diagnosis, comprehensive care and expertise in bleeding disorders | Project | Execution | University of the West Indies, Kingston - Dr Gillian Wharfe | deni@nnhf.org | Improve the diagnosis accuracy in haemophilia Train healthcare professionals on haemophilia Organise educational workshops for patients and family members Create a national registry and treatment guidelines Raise awareness of bleeding disorders amongst the authorities and the general public. | - The diagnosis of patients was continued, mainly doing inhibitor testing in H1 2017. - Several meetings took place to form the patient association, agreeing on a new name, electing a new board, developing the constitution. The next steps will be registration of the association, preparation of the office at UHWI and formally launch the association in October 2017. | 2 years Q3 2014 - prolonged until Q2 2017 |
| North and Middle America | Mexico 3 - MX3 | Set up paediatric rehabilitation to prevent functional limitations in children in two hospitals in Mexico City | Project | Execution | Hospital Infantil de México Federico Gómez (HIMFG), Mexico City - Dr Io Daiela Castillo | deni@nnhf.org | Train healthcare professionals on MSK care Identify children with haemophilia with haemarthrosis and at risk of developing functional limitations Establish a rehabilitation programme and anchor it in the regional care approach Raise awareness amongst the haemophilia community of the importance of MSK care and prevention. | - A manual was developed for patients to take to their schools including a letter from the psychologist to the parents. - World Haemophilia Day celebration with 50 children and their families from Hospital Infantil de México Federico Gómez (HIMFG) and National Paediatric Institute (INP) presenting the results of the project, in which the collaboration of the medical teams, the patients and their families has been crucial for its success. - 5 monthly educational sessions were carried out with topics such as psychosocial development in haemophilia, ABC of haemophilia, basic care, orthopaedic treatment. - An app is being finalised including all the educational material created in this project, focussing on exercise for people with haemophilia. It will be available in English and Spanish. - Patient diaries and ID cards are being finalised. | 1.5 years Q4 2015 |
| North and Middle America | Mexico 4 - MX4 | National alliance for a cross-sectorial haemophilia programme | Project | Execution | Mexican Haemophilia Federation (FHRM), Mexico City - Miguel Izquierdo Zarco | deni@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. | - A Haemophilia Expert Board was created with 6 haematologists from different key hospitals of Mexico to elaborate the HCP training concept. - National training at the XXII National Mexican Haemophilia Congress took place on 27-29 July. - The indicators of the national registry are being reviewed by the health authorities. - Several meetings took place with the health authorities to increase the coverage of people with haemophilia under Seguro Popular. | 3 years Q1 2017 |
| North and Middle America | Mexico 5 - MX5 | Rehabilitation in haemophilia care | Fellowship | Execution | Dr Mariela Colín Marín, Physiatrist, IMSS Hospital, Pachuca, Hidalgo | deni@nnhf.org | Learn more about general haemophilia care and the multidisciplinary approach Get more acquainted with the rehabilitation tools for haemophilia care Share experiences and knowledge gained adapting it to the local circumstances. Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible person: Dr Santiago Bonanad, Haematologist. | - Approved in the NNHF Council Meeting in September 2016. - Organisation of fellowship logistics done. | 1 month Q3 2017 |
| North and Middle America | Mexico 5 (State of Mexico) - MX5 | Creation of comprehensive haemophilia clinic of ISSEMyM | Project | Formalisation | Haemophilia clinic of Maternal-Infant Hospital ISSEMyM, Toluca, State of Mexico - Dr Cecilia Rodríguez Castillejos | deni@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. | - Formalisation phase in process. | 1.5 years Q1 2017 |
| North and Middle America | Mexico 6 - MX6 | Advanced rehabilitation training | Fellowship | Execution | Dr Aidee Gibraltar Conde, Physiatrist, Medical Unit of High Specialty, Unit of Physical Medicine and Rehabilitation North, IMSS, Mexico City | deni@nnhf.org | Learn more about new diagnosis and treatment methods for MSK complications Focus on prevention of damage in joints Share experiences and knowledge gained adapting it to the local circumstances. Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible person: Dr Santiago Bonanad, Haematologist. | - Approved in the NNHF Council Meeting in September 2016. - Organisation of fellowship logistics done. | 1 month Q1 2017 |
| 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, State of Yucatan - Dr Eric Gutierrez | deni@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. | - Project activities started in July 2017 (H2 2017). | 1 year Q3 2017 |

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|--------------------------|--|--|----------------|---------------|--|---------------|---|--|---------------------------------|
| North and Middle America | Nicaragua - NI | Establish comprehensive care of haemophilia in Nicaragua | Project | Execution | Nicaraguan Association of Hemophilia - Javier Antonio Rivas Ojeda and Red Cross Nicaragua - Dr Rene Berrios | deni@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. | - 105 samples were taken for PT and aPTT. The next step is to define the factor levels. - The registry is being created and will be launched towards the end of 2017. 84 persons from the patient organisation were trained on the importance and use of the registry. - 44 HCPs were trained during 2 days by experts from abroad on various aspects of bleeding disorders reaching 8 states and 12 hospitals in Nicaragua. - Awareness training was organised for 118 medicine students. - The patient organisation's activity plan for 2017 was created. - An awareness and media campaign was organised achieving participation of 70% of the invited media representatives. - Collaboration with the American University is being pursued in order to train HCPs. - Monthly meetings with the National Blood Bank and the Ministry of Health to advocate for improved care for bleeding disorders. | 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. | - The first patient camp for the patients and relatives associated to CARDHE took place with various educational, group and recreational activities. - WHD activities took place with the patient community, offering the opportunity to focus on the female community, especially the carriers. - Two very successful visits were made to schools in the city of Bahía Blanca to raise awareness of the condition amongst teachers and pupils. - A video showcasing a patient story was produced. | 1.5 years Q2 2016 |
| South America | Argentina 3 (Jujuy) - AR3 | Outreach to patients with haemophilia in the province of Jujuy | Project | Execution | Fundación Jujueña 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, 16 training and awareness sessions were performed in different parts of the province of Jujuy since the beginning of the project in October 2016, reaching 27 HCPs, 45 patients, 120 family members and 170 students. - Educational material was created and distributed in the training sessions. - 45 patients have been re-diagnosed and 7 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 | deni@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 | - The project activities started in July 2017 (H2 2017). | 2 years Q3 2017 |
| South America | Brazil 4 - BR4 | Strengthening the care and education network for haemophilia in the state of Pará in Brazil | Project | Execution | FBH - Federação Brasileira de Hemofilia - Christianne Maria Oliveira Costa crisbyoc@yahoo.com.br | deni@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 for 50 HCPs was conducted in Belém, State of Pará, in the end of June. The training team consisted of a medical doctor, a physiotherapist, a nurse and representatives of the patient organisation. | 2.5 years Q3 2015 |
| South America | Chile 3 - CL3 | Consolidating care and treatment for haemophilia and allied bleeding disorders across Chile | Project | Formalisation | Hospital Roberto del Río, Santiago - Dr Veronica Soto Arellano | deni@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. | - In the process of formalising the project by opening the project dedicated bank account. | 1.5 years Q2 2017 |
| South America | Paraguay - PY | Consolidating haemophilia care in Paraguay through diagnosis, registry and training of healthcare professionals and patients | Project | Execution | Fundación de Ayuda al Hemofílico (Fundahemo) - Mayda Tamara Yasychyn | deni@nnhf.org | Train staff to improve care offered to patients with haemophilia Improve quality of diagnosis in Paraguay by strengthening coagulation laboratory facilities at Hospital Nacional de Itagua and Hospital Regional de Encarnación Execute a nationwide census to diagnose and register patients Provide educational sessions to patients and families on haemophilia. | - More than 100 HCPs attended a training organised in Hospital Nacional de Itagua with 4 experts in haemophilia from Monterrey, Mexico. The key topic was multidisciplinary care. - On WHD 2017, a walk was organised with more than 100 participants in Encarnación to raise awareness of the condition and strengthen the haemophilia network. Haemophilia care and diagnosis has recently been established in this city and both the patient as well as the medical community is very engaged in haemophilia care and awareness raising activities. | 1.5 years Q4 2015 |
| South America | Peru 3 - PE3 | Strengthen and expand network and structure of haemophilia care across sectors in Peru | Project | Formalisation | Peruvian Haematology Society, Lima - Dr Juan Navarro Cabrera and Dr Nancy Loayza | deni@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. | - Project dedicated bank account opened. Final signature of contract pending. | 2 years Q2 2017 |
| South America | Uruguay 3 - UY3 | Decentralising care and diagnosis network in Uruguay | Project | Formalisation | Hospital Tacuarembó, Tacuarembó - Dr Maria Teresa Faguaga González | deni@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 | - Opening of project dedicated bank account is ongoing. | 2 years Q3 2017 |

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|------------------------|--------------------|---|----------------|---------------|--|---------------|---|--|---------------------------------|
| South and Central Asia | Armenia - AM | Building the national haemophilia care network in Armenia | Project | Execution | Haematology Center of Armenia, Yerevan - Prof Smbat Daghbashyan | 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. | - Regional outreach visits organised to Gegharkunik, Lori, Tavush, Syunik, Kotayk, Ararat, Armavir and Vayots Dzor provinces. The outreach visits included the following activities: o An awareness session was conducted in each of the visited centres to create awareness about haemophilia o Educational seminars for regional doctors in providing first medical aid to PwH o Educational sessions for PwH and their families o Consultations by trained haemophilia doctor in all 6 regions with the support of the Yerevan haemophilia team o Psychological support was given to individuals and more sessions were scheduled o Consultations by the trained physiotherapist. | 2 years Q1 2015 |
| South and Central Asia | Azerbaijan 2 - AZ2 | Establish haemophilia care in Nakhchivan region and improve physiotherapy care across Azerbaijan | Project | Formalisation | 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. | - Project partnership agreement to be signed. | 2 years Q1 2017 |
| South and Central Asia | Bangladesh - BD | 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. | - Training session of healthcare professionals at Rajshahi Medical College, a large Medical Centre outside the capital Dhaka - Education of patients and families and encouraging them to attend the newly trained centre in Rajshahi Medical College. | 1 year Q2 2015 |
| South and Central Asia | Georgia - GE | Spreading knowledge about haemophilia and improving quality of diagnosis and treatment in Georgia | Project | Closing | Georgian Society of Thrombosis and Haemostasis - Dr Levani Makhaldiani | sysd@nnhf.org | Improve the laboratory facilities Update current guidelines for treatment of haemophilia and allied bleeding disorders Produce educational material for healthcare professionals and patients Perform comprehensive national training programme for healthcare professionals Reach out to offer better care and education to patients and family members Raise awareness of bleeding disorders amongst the general public and the authorities. | - All project activities have been completed. Waiting for the final audit report. | 2 years Q1 2013 |
| South and Central Asia | India 3 - IN3 | Spread awareness, building capacity, and diagnostics spectrum in haemophilia-(Spread ABCD Spectrum project) in northern India | Project | Closing | Maulana Azad Medical College, New Delhi - Prof Naresh Gupta | sysd@nnhf.org | Capacity Building in the National Capital Region Increase public awareness and IEC activities Widening Diagnostic Base Publications and Haemophilia Newsletter Website based regional electronic medical record system and patient forum. | - All project activities have been completed. | 2 years Q2 2013 |
| South and Central Asia | India 6 - IN6 | Capacity Building and Empowerment program for care givers and parents involved in the Hemophilia Care in North East and North India | Project | Closing | Haemophilia Federation India - Mr Mukesh Garodia & Dr Richa Mohan | sysd@nnhf.org | Improve skills of haematologists, lab technicians, physiotherapists and nurses of 8 states comprising the North East region Customise the Parents Empowering Parents programme according to local language and culture to enhance parents' communications and capacity to manage their child's condition Train 40 parents in the suggested states using the adapted PEP programme in order to have them replicate the training to other parents in their chapters. | - All project activities have been completed. | 2 years Q4 2014 |
| 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 pamelanarayan@yahoo.co.in | 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. | - The collected data from the sent survey to physiotherapy facilities was analysed and presented at the MSK congress in Seoul - A national MSK meeting was organised to agree on national MSK guidelines for India. The meeting was the first of its kind and the guidelines were signed off. | 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 train the trainer PEP workshop was held in Bangalore, Karnataka on 17 February for 3 days. 22 participants including a nurse, a social worker, parents, care givers and professionals representing different chapters of the south region attended the training workshop - The newly revised and updated PEP manual was published. | 2 years Q4 2016 |
| South and Central Asia | Myanmar 2 - MM2 | Fellowship in Haemostasis Laboratory | Fellowship | Closing | Yan Naing, pathologist General Hospital, Mandalay, Myanmar | smqy@nnhf.org | Improve expertise in diagnose techniques of inherited and acquired bleeding and clotting disorders Learn to implement good laboratory practices and the importance of pre-analytical variables in haemostasis investigations Acquire in depth knowledge about quality control and the use of appropriate instrumentation and reagents. - Katharine Dormandy Haemophilia and Thrombosis Centre, Royal Free Hospital, London, UK; responsible person: Dr Thynn Thynn Yee, Haematologist. | - Fellowship completed and final report received. | 6 months Q1 2016 |
| South and Central Asia | Pakistan 5 - PK5 | Bringing change by improving access to care and awareness: Ca-pacity building and leadership initiative | Project | Closing | Pakistan Haemophilia Patients Welfare Society (PHPWS) - Masood Fareed Malik | sysd@nnhf.org | Strengthen the Pakistan Haemophilia Patients Welfare Society and its chapters to excel in their role Increase the public and the patients awareness Outreach for identification of new patients Develop centralized web-based national patients registry. | - All the project activities were completed and the final report was submitted. | 2 years Q2 2014 |

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|------------------------|--------------------|---|----------------|-----------|---|---------------|--|---|---------------------------------|
| 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. | - Project partnership agreement was signed. | 2 years Q2 2017 |
| South and Central Asia | Sri Lanka - LK | Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community | Project | Closing | 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. | - All project activities have been completed. Waiting for the final Audit report. | 2 years Q2 2015 |
| South and Central Asia | Uzbekistan 4 - UZ4 | Improving the quality of life of haemophilia patients by establishing rehabilitation care in Uzbekistan | Project | Closing | Scientific Research Institution of Haematology and Blood Transfusion - Dr Aziza Makhmudova | sysd@nnhf.org | Strengthen the rehabilitation care in the haematology Centre in Tashkent Start the rehabilitation care in 12 regions by training of HCPs. | - All project activities have been completed. | 1.5 years Q1 2016 |