



NNHF Programmes: selected updates on activities in quarter 3, 2016 (1 July – 30 September 2016)

Overview

Novo Nordisk Haemophilia Foundation Q3 2016 update	By end Q3 2016
Number of projects approved by NNHF Council since 2005 (new projects since last quarter)	134 (7)
- Thereof number of fundraised projects (new projects since last quarter)	14 (1)
Number of fellowships (new fellowships since last quarter)	74 (4)
Number of awards (new awards since last quarter)	14 (0)
HCPs trained since 2005	28,700
Patients and family members educated & patient leaders trained since 2005	32,100
People with haemophilia retested and newly diagnosed since 2005	19,500
NNHF engaged in number of countries (new countries since last quarter)	68 (0)

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q3 2016	Programme duration / Start date
Africa	Egypt 2 - EG2	Improving musculoskeletal (MSK) care in Egypt and es-tablishing 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.	- Follow up meeting on the improvement of the dental care service at the Red Crescent blood bank dental clinic - Dr Adly Sabbour prepared all the essential educational materials for the physiotherapy for PwH and all the assessment tools of MSK in haemophilia. 500 copies of the educational materials were printed and will be distributed during the planned trainings - The preparations for training session for physiotherapists from the participating centres from HIO were made. The training will be organised on October 2nd.	1.5 years Q1 2016
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 KMH and MCH	- Organised an outreach visit to Meru. During the visit HCPs training was organised and was attended by 16 participants from the county hospital and sub county hospitals. After the training, one of the participants explained how he had admitted a young boy in the ward. The team visited the child and performed complete diagnosis. It was confirmed that the boy has haemophilia A.	2 years Q2 2015
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.	- Organised a WHD celebration to identify new haemophilia patients.	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.	- No major activities were carried during this quarter due to lack of personal and bureaucratic obstacle when dealing with public institution.	2 years Q3 2015
Africa	Nigeria 2 - NG2	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.	- In collaboration with, Dr Fatal Bello and Miss Okereke Jennifer from Lagos University Hospital, 83 samples were collected at Aminu Kano Teaching Hospital, Kano. The diagnosis campaign started by an explanation about the importance of accurate diagnosis by Dr Dalhat Gwarzo. - The second patient camp was organised with focus on how the patients can take the challenge and live a normal life. The camp was attended by 10 patients who are older than 27. - More copies of educational materials about what is Haemophilia, Diagnosis were reported and distributed	2 year Q1 2015
Africa	South Africa 3 - ZA3	Bringing better haemophilia care closer to the patients and strengthening the	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 and Final Project report.	2 years Q1 2014
Africa	Uganda 2 - UG2	Create awareness and HCPs training in Uganda	Project	Execution	Haemophilia Foundation of Uganda, Kampala - Agnes Kisakyie, 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.	- Two health workers and VHT workshops were successfully conducted - A total of 497 traditional surgeons were trained before the launch of the circumcision ceremony in the Eastern region, Mbale district. The training provided them with the knowledge to identify bleeding disorder patients and know where to refer them - HFU participated in the "IMBALU" a traditional circumcision ceremony in the Eastern Region and disseminated educational and awareness materials about Haemophilia and other bleeding disorders - Two radio talkshows were held in Northern and Central Regions. The radio talkshows attracted many people calling in to learn more about haemophilia and where to go in case of bleeding - Contacts were established with NGOs working with the disability in Central and North regions. The NGOs will help HFU identify and refer haemophilia cases who may wrongly identified as disabled patients - 16 new haemophilia patients have been identified and scheduled for diagnosis - New contacts were identified with Regional hospitals to provide care and follow up on haemophilia cases.	2 years Q2 2016
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.	- Lab equipment were delivered with the following remaining items: freezer, computer and citrate tubes - The haemophilia centre was painted and tiles were fixed - Organised training for 10 doctors, 10 nurses and 16 clinical officers from 10 district hospitals.	9 months Q1 2016

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q3 2016	Programme duration / Start date
Africa	Malawi - MW	Specialised training in haemophilia care and management	Fellowship	Execution	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.	- Training will start in January 2016.	2 months Q1 2016
Africa	Malawi 2 - MW 2	Build diagnosis capacity in Malawi	Fellowship	Formalisation	Blessing Mwangomba, Dr David Livingstone Memorial, Lilongwe	sysd@nnhf.org	Acquire knowledge on how to handle manual and automated diagnose 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; Johnny Mahlangu.	- Approved in the NNHF Council Meeting in September 2016.	1.5 months Q1 2017
Africa	Nigeria 2 - NG2	Specialised training in the diagnosis and management of haemophilia	Fellowship	Execution	Dr Livingstone Dogara, Kaduna State University, Kaduna	sysd@nnhf.org	Gain knowledge on diagnosis and consultation of people with haemophilia Develop skills in the management of haemophilia people Learn how to advocate for better care.	- The training started in August 2016.	6 months Q3 2016
Africa	Tanzania 2 - TZ2	Start haemophilia care in Southern Tanzania	Fellowship	Execution	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.	- Fellowship started in November 2015. The fellow had a medical condition and had to return back before completing the fellowship.	3 months Q3 2015
Africa	Zambia - ZM	Training in diagnosis and care management of haemophilia	Fellowship	Formalisation	Dr Silweya David, Chinsali District Hospital, Chinsali	sysd@nnhf.org	Optimise medical knowledge in diagnosis and management of people with haemophilia and other bleeding disorders Learn about multidisciplinary care approach Learn how to establish treatment guidelines.	- Organisation of the training logistics started.	1.5 months Q1 2017
Europe	Latvia 2 - LV2	Set up of a web-based bleeding disorders registry in Latvia	Project	Execution	Latvia Hemophilia Society, Riga - Baiba Ziemele	deni@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.	- Development of the software for the registry has started and the software is being tested.	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.	- Development of a publication about three successfully completed psychosocial workshops organised for youth, adults and parents of children with haemophilia. - Planning of advocacy training workshop in Q4. All interested members of the patient association had to write an application and 20 participants are being selected.	2 years Q1 2015
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.	- The website was created and will be launched after the final review of the content by the medical committee - Organise patients training on Self infusion which was attended by 12 patients.	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 dr_elyan@hotmail.com	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.	- The guidelines were finalised and were sent to purchasing department to choose the company that will print it. The launch of the guidelines is planned to take place during a regular physicians meeting with MoH to save money for purchasing the deep freezer and refrigerator - 15 patients were tested and registered in the national registry - The saved grant from the different activities will be used to purchase a deep freezer and refrigerator for haemophilia.	1.5 years Q1 2014
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.	- A physiotherapy manual namely "The effectiveness of physical therapy in haemophilia care" was developed and 200 copies were printed. It is planned to disrepute the manual PwH and their families during the planned regional visits and awareness seminars.	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

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South and Central Asia	Bangladesh - BD	Improving quality of care for hemophilia in three centres in Bangladesh	Project	Execution	Dhaka Medical College - Prof Salma Afrose	smqy@nnhf.org	Increase capacity of multidisciplinary team in Dhaka, Chittagong and Rangpur Development of 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.	- Planning of two capacity building programmes in Rangpur medical college Hospital and Chittagong Medical College Hospital is ongoing. - Planning of three patient education training programmes in Dhaka, Rangpur and Chittagong are ongoing.	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 Makhdadiani	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 2 - IN2	IDEEA - Identification, Diagnosis, Education and Empowerment for Action of people with bleeding disorders in South India	Project	Closed	Katsurba Hospital, Manipal University , Manipal - Dr Annamma Kurien	rbgs@nnhf.org	Create awareness and identify new patients with haemophilia and allied bleeding disorders in 4 districts (Udupi, Dakshina Kannada, Chickamangaluru and Shimoga) of Karnataka, India Diagnose improvement (Haemophilia, von Willebrand disease, platelet function).	-Final project report received and audit report to be received end within Q4.	3 years Q1 2012
South and Central Asia	India 3 - IN3	Spread awareness, building capacity, and diagnostics spectrum in haemophilia- (Spread ABCD Spectrum project) in northern India	Project	Execution	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.	- A meeting of the Self-Help Group for Haemophilia (SHGH) and HDCC staff was held on 26th Sep and participated by 16 participants. The primary objective was to get an update on the functioning of the Self-Help Group for Haemophilia and to plan accordingly for future role and objectives. The following topics were covered in the meeting: o Empowerment of Self- Help Group for Haemophilia o Government support for Haemophilia community o Psycho-social challenges for PwH o Status of PwH and their position in society o Behaviour of other peoples towards PwH o Financial problems of PwH o Volunteer participation and support of other peoples to Self-help Group o Treatment options available for haemophilia other than AHF o Role of mother and hurdles & bleeding episode management o Planning for PwH for day to day activities o Effect of patient to patient communication - After the discussions an event was planned for the Self-Help Group for Haemophilia along with the patients from Self-infusion programme with the support and help of HDCC staff members. It was decided to hold a Haemophilia Programme in MAMC/LNH under the theme of "Life with haemophilia" on 12th Nov 2014.	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	Execution	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.	- Final lab training will happen in October 2016.	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.	- During this period individualized training were carried out on use of the MSK web-based registry at different locations including Bangalore and Delhi with HCPs and key stakeholders including HFI. - A total of 23 patients were assessed and relevant details were included at the MSK Registry. Productive discussions around both clinical issues of the MSK aspects of Hemophilia as well as practical issues around the Registry were discussed. Additionally MSK surveys were also sent to all participating centers.	3 years Q2 2015
South and Central Asia	India 8 - IN8	Empowering parents in South and West India	Project	Formalisation	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.	- Project partnership agreement to be signed.	2 years Q4 2016
South and Central Asia	Pakistan 5 - PK5	Bringing change by improving access to care and awareness: Ca-pacity building and leadership initiative	Project	Execution	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.	- The development of the scripts for 2 documentaries has successfully finalised. The 2 short documentaries are about the lives of male and female with haemophilia. The shooting will start in the coming week - The content for the e-newsletter has been finalised and will be published in Q4.	2 years Q2 2014

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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 - Pinsiri B. Godamunna, president	sysd@nnhf.org	Publish the national treatment guidelines for adult and children and general guideline about physiotherapy care of haemophilia. Improve physiotherapy and MSK care in the five main centres Strengthen the Sri Lanka Haemophilia Association through education and awareness sessions Empower carriers and women with bleeding disorders.	- All project activities have been completed. Waiting for the final Audit report and Final Project 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	Execution	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.	- 2 day seminar organised in Khorezm region about "Carrying out medical preventive and rehabilitation measures to reduce disability and improve the quality of life of PwH". The training was attended by 12 haematologists, 15 physiotherapists, 6 surgeons, 29 nurses and 18 patients. The training build the capacity in the region to provide care to patients who are unable to come to Tashkent Hemophilia centre and reduce time, efforts and cost for the patient to receive the required care. One of the training objectives was to build the network and trust between doctors & patients and between the patients themselves. After the training the positive change was noticed by all the participants. - 7 days training was organised for the doctors from Karakalpakstan, Nukus at Tashkent Hemophilia centre on providing rehabilitation care for patients. Training focused not only on medical and surgical procedures but also psychological aspects. - Due to the holiday period, training for the doctors from Namangan and Ferghana were rescheduled to October.	1.5 years Q1 2016
South and Central Asia	Myanmar - WHD 2013	Empowering of patients and capacity building of HCP by focusing on physiotherapy in Mandalay	Fundraised project	Execution	Myanmar Haemophilia Patient Association - Mr Arkar Htun Hlaing	smqy@nnhf.org	Strengthen patient community and capacity building of HCP by organising regional training sessions with a focus on physiotherapy in Mandalay.	- Awaiting the final project plan.	1 year Q1 2017
South and Central Asia	Myanmar 2 - MM2	Fellowship in Haemostasis Laboratory	Fellowship	Formalisation	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.	- Fellowship started.	6 months Q1 2016
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 the diagnosis, treatment and management of patients with haemophilia and other bleeding disorders Improve the 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.	- There has been no activities in Q3 2016 besides planning of final project activities for Q4.	2.5 years Q4 2014
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	rbgs@nnhf.org	Further improve reliability of diagnosis and comprehensive care in China by setting up a National External Quality Assessment (EOA) programme: - 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	- A meeting took place at the WFH - HTCNC national meeting between HTCNC and NNHF to discuss current needs and further opportunities for collaboration	2 years Q2 2012
East Asia	China 4 - CN4	Identify and improve five city level comprehensive haemophilia centres in Shandong province	Project	Execution	Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang	rbgs@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.	- Dr. Zhang Xinsheng, Dr. Fang Yunhai and Nurse Chen Yan lead different site inspections to Linyi City haemophilia center, Taian City Central Hospital where a hemophilia comprehensive care training ward was set up. - 62 new patients were diagnosed and registered	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	rbgs@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.	- Professor Yu hosted the first hemophilia care expert meeting in Yangzhou which was attended by all leaders from five Haemophilia Treatment Centers. At the meeting the project was kicked off for the next 3 years. A subsequent meeting was held on Sept 27 in Suzhou with more than 90 HCPs and 15 hemophilia patient leaders from the Jiangsu province. Seven experts gave trainings for doctors, nurses, and local health officers. This meeting received very positive feedback from the attendees. More training and educational sessions will be held in 5 HTCs.	3 years Q1 2016

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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	rbgs@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.	- Since June 2016 Professor Li and team developed relevant educational material for HCPs and patients. In total it was carried out 11 workshops with medical staff (86) and patients (69) In order to guarantee the standardization of haemophilia centres, the training was enhanced and HCPs participated in several training sessions in Beijing at Children's Hospital and The Hospital for Sick Children in Canada. - During the month of September 58 new patients were diagnosed and many other haemophilia patients were attended at New Century hospital receiving appropriate comprehensive care and follow up.	3 years Q2 2016
East Asia	China 7 (Tibet) - CN7	Development of haemophilia care in Tibet Autonomous Region	Project	Formalisation	Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang	rbgs@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.	- Project approved with a grant of CHF 50'000. Activities will start shortly.	1 year Q1 2017
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 the 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.	- There have been no activities in Q3 2016 besides 3 meetings planning the second workshop of the women's group in October 2016.	1.5 years Q1 2016
East Asia	Nepal - NP	Strengthening the local chapters of Nepal Hemophilia Society to achieve better care through advocacy	Project	Execution	Nepal Hemophilia Society (NHS), Kathmandu - Beda Raj Dhungana	rbgs@nnhf.org	Increase NHS local chapters knowledge on haemophilia and provide a structured approach to advocacy. Support haemophilia care training for two doctors (one paediatrician and one general physician) from rural areas of each chapter. Raise awareness amongst local government officials.	- Planning for medical training in collaboration with Mary Gooley Care Center is underway and will take place this November.	6 months Q1 2015
East Asia	Philippines - PH	National Registry of Haemophilia and Allied Bleeding Disorders Philippines	Project	Closing	Philippine Haemophilia Foundation INC. - Dr Florida G. Hernandez	rbgs@nnhf.org	Create a National Registry of Haemophilia and other Bleeding disorders. Educate the medical, paramedical practitioners and general population about haemophilia and allied bleeding disorders Gather data essential for lobbying support from the National Government. Encourage haemophilia advocacy in the countryside Empower haemophilia support group. Strengthen partnership with stakeholders.	- A research protocol on registry was approved for the on-line registry. An haemophilia screening program was carried out resulting on 18 new hemophilia patients identified. Parents of PwH were trained on how to address bleeding episodes and infuse clotting factor concentrates. Awareness and Information Dissemination Campaign: - Flyers and posters were distributed in some barangays and health departments in Quezon City and in the province of Cavite (south of Metro Manila). - Hemophilia care was presented by Dr. Hernandez during the 2016 PSHBT National Convention which was attended by 235 healthcare professionals from the different regions of the country. HAPLOS, the patient organization, was as well introduced to healthcare professionals to improve engagement, and cross-collaboration such as in advocacy work which is carried out by different patients groups and associations across the Philippines.	3 years Q3 2012
East Asia	Thailand 3 - TH3	Improving haemophilia care through the Chronic Care Model	Project	Formalisation	National Health Security Office (NHSO), IHTC Bangkok and Faculty of Medicine/Chiang Mai University - Hathaiwut Lamthean - Prof Ampaiwan Chuansumrit	smqy@nnhf.org	Identify final, tailored HCP training needs and strategic confirmation of involved provinces in project	- Approved in the NNHF Council Meeting in September 2016.	3 months Q4 2016
East Asia	Thailand -TH	Improving haemophilia care in Thailand through the Chronic Care Model	Project	Execution	National Health Security Office (NHSO) and IHTC Bangkok - Hathaiwut Lamthean - Prof Ampaiwan Chuansumrit	deni@nnhf.org	Improve capacity of HCPs at Haemophilia Treatment Centres, Community and District hospitals in 14 Provinces in order to improve care of Haemophilia and patient's quality of life Educate the community and create a network among patients and volunteers resulting in improved adherence to treatment and Chronic Care Model Empower patients by building skills in self-care, psychological and social intergration, and informing them about their rights and obligations in relation to their treatment.	- The project results were presented to the NNHF Council in March 2016. - The project will be closed at the NNHF Council Meeting in December 2016.	1.5 years Q4 2013

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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 HEMOQoL-A into Thai language Perform a Training of Trainers session on MSK evaluations for the team in Chiang Mai and Bangkok Delineate the MSK status of patients in Chiang Mai and Bangkok Provide training to patients about the importance of MSK evaluation and physical activity Share results at local and international journals and at one international conference.	- A three days Training of Trainers session on musculoskeletal care was organised in Bangkok in collaboration with the Sick Kids hospital in Canada. Haematologists, nurses, physiatrists, physiotherapists and radiologists from Chiang Mai University and Ramathibodi Hospital (IHTC) participated in the training with the objective of developing a Thai multidisciplinary national trainer team. - A Thai version of HJHS 2.1 and HJHS 2.1 Instructional video are now available on IPSPG website.	3 years Q4 2015
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.	- Two Summer Camps were organised for a total of 230 patients in Northern and Southern part of Vietnam. Different activities were arranged for the different age groups with a particular focus on how to have an active life with haemophilia; amongst other activities like swimming and quizzes on haemophilia. - Guidelines for diagnosis and treatment of haemophilia were developed and printed. - 37 new patients have been diagnosed: 22 in Hanoi and 15 in Ho Chi Minh. - Medical specialists - haematologists, nurses, physiotherapists and dentists - came from Melbourne and Thailand to train a total of 220 doctors and medical staffs in first Hue and then Ho Chi Minh city. - Two training courses were organised for 300 medical students in Hai Phong Medical University and Thai Binh Medical University in order to bring haemophilia into the education program of medical students.	1
East Asia	Cambodia 2 - KH2	Advanced training in rare bleeding disorders diagnosis	Fellowship	Formalisation	Sam Samey, Laboratory technician, National Pediatric Hospital (NPH), Phnom Penh	smqy@nnhf.org	Increase capacity of diagnosis regarding: - Detection of inhibitors - Diagnosis of von Willebrand disease - Diagnosis of Platelet Function Disorders - Testing for antiphospholipid antibodies. Hospital Ampang, Malaysia; responsible person: Jameela Sathar,	- Approved in the NNHF Council Meeting in September 2016.	2 months Q1 2017
North and Middle America	Central America, Caribbean and Venezuela	Empowering and developing future community leaders to advocate and create awareness in their countries and in the region of Central America, the Caribbean and Venezuela	Project	Execution	Fundación Apoyo al Hemofílico, Santo Domingo - Fendi Valez Bisono	deni@nnhf.org	Plan and coordinate activities for the patient associations to identify and form new leaders Empower and develop 18 young leaders in the region Start creating micro-projects by the new leaders to integrate them to their patient associations and raise funds to implement the projects and advocate for their cause Replication of acquired knowledge and skills by the new leaders to other members of their associations.	- All activities planned in the project were finalised. - The Final Project Report was written and handed in to NNHF. - With the remaining funds, the project team is creating a manual including useful hands-on tools learned during the project, so that the patient associations have them at hand. Therefore, the project is planned to finish soon and the results will be presented in the December Council Meeting.	1.5 years Q2 2014 - prolonged until Q3 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 (IH), 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.	- Project partnership agreement was signed and project activities are starting in Q3 2016.	2 years Q3 2016
North and Middle America	Guatemala - GT	Advancing integrated care management of people with haemophilia in Guatemala	Project	Formalisation	Hospital Roosevelt and Hospital San Juan de Dios, Guatemala City - Dr Marta Julia López Ruano	deni@nnhf.org	Train the healthcare professionals from both public hospitals and social security hospital in Guatemala City as well as hospital in Quetzaltenango Improve the hospital infrastructure and quality of care of PwH Educate patients and their families by the multidisciplinary care team Create a national technical committee for haemophilia and institutionalise it Create national haemophilia treatment guidelines.	- Project partnership agreement has not yet been signed because the project responsible person left the hospital. During the WFH Congress in Orlando some options were discussed and NNHF is currently looking into a possible solution.	2 years Q1 2017

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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 Gilian Wharfe	deni@nnhf.org	<p>Improve the diagnosis accuracy in haemophilia</p> <p>Train healthcare professionals on haemophilia</p> <p>Organise educational workshops for patients and family members</p> <p>Create a national registry and treatment guidelines</p> <p>Raise awareness of bleeding disorders amongst the authorities and the general public.</p>	<p>- Meetings took place in Kingston including the team from Sick Kids Hospital in Canada as well as from the University of the West Indies (UWI) in Jamaica, who were involved in the project. The focus of the discussions was: 1) To establish UWI laboratory as the only specialist coagulation lab in Jamaica. This was agreed upon by the MOH attendee. 2) To get final approval from MOH to proceed with the TTI testing for the project participants. This was agreed upon. 3) To get a commitment from all involved in the project to continue collecting registry data and testing of new cases and to continue being part of a follow up project. All agreed to continue to participate.</p> <p>- In preparation of the patient educational event, the following breakout sessions took place: 1) Laboratory: Dr Lillcrap and Dr Rand met with the laboratory staff to have the inhibitor testing done. 2) Physiotherapy: Dr Hilliard met with local physiotherapists to discuss once more the various tools for assessment and management of joint problems in PwH. 3) Nursing: Nurse Bouskill met with Sister Watson to assess the impact of the project and they also had a very meeting with the dental surgeons.</p> <p>- Patient educational event took place on 17 September 2016 with 23 PwH, 26 family members and 40 HCPs: Focus was on discussing strategies to protect joints and to facilitate their care when they go to emergency room to get urgent management to prevent long term complications. The development of a patient group was encouraged and plans have started to get this group to meet and advance their cause.</p>	2 years Q3 2014
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	<p>Train healthcare professionals on MSK care</p> <p>Identify children with haemophilia with haemarthrosis and at risk of developing functional limitations</p> <p>Establish a rehabilitation programme and anchor it in the regional care approach</p> <p>Raise awareness amongst the haemophilia community of the importance of MSK care and prevention.</p>	<p>- 3 sessions were organised for 20 patients and 20 parents at Hospital Infantil de México Federico Gómez (HIMFG) about 1) dental care, 2) psychological support, 3) self-infusion</p> <p>- HIMFG and the National Paediatric Institute (INP) are running 2 rehabilitation programmes with 30 paediatric patients: one at home with weights, rods and rings and another one in the hospital with balance and coordination devices and with the kinect xbox.</p> <p>- A manual including exercises to be done at home is being created.</p>	1.5 years Q4 2015
North and Middle America	Mexico 4 - MX4	National alliance for a cross-sectorial haemophilia programme	Project	Formalisation	Mexican Haemophilia Federation (FHRM), Mexico City - Miguel Izquierdo Zarco	deni@nnhf.org	<p>Create or strengthen multidisciplinary care teams across hospitals and healthcare institutions in Mexico by increasing the capabilities and haemophilia knowledge of healthcare professionals</p> <p>Consolidate data in national online patient registry and expand registry to include medical data</p> <p>Reach better levels of care and treatment for all patients through advocacy initiatives.</p>	- Approved in the NNHF Council Meeting in September 2016.	3 years Q1 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	<p>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</p> <p>Provide education, guidance and psychological support to patients and their families</p> <p>Formalise a complete haemophilia patient database for the hospital</p> <p>Improve the quality of diagnosis in the hospital laboratory and beyond.</p>	- Approved in the NNHF Council Meeting in September 2016.	1.5 years Q1 2017
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	<p>Improve coagulation laboratory and train the staff to do diagnosis</p> <p>Create national treatment guidelines</p> <p>Train professionals in nursing, physiotherapy, dental care and medical training of patients with haemophilia</p> <p>Provide educational sessions to patients and families on haemophilia</p> <p>Strengthen the haemophilia care centre and the patient association.</p>	<p>- The required equipment for the laboratory has been purchased.</p> <p>- One laboratory technician from Nicaragua was trained in Panama with Guadalupe Vivero in the end of August.</p>	2 years Q1 2016
North and Middle America	Costa Rica - CR	Conduct advanced musculoskeletal evaluation through EMG	Fundraised project	Execution	Hospital Nacional de Niños "Dr. Carlos Sáenz Herrera" - Dr Marta Navarrete	deni@nnhf.org	<p>Purchase of a computer, printer and an EMG evaluation machine</p> <p>Organise one monitoring visit from Dr Seuser and his team members.</p>	- Planning of visit by German team to Costa Rica for 2017 ongoing.	2 years Q2 2016
North and Middle America	Cuba 2 - CU2	MSK training in haemophilia	Fellowship	Formalisation	Armando Javier Tejera Valdés Hospital General Docente Dr. Antonio Luaces Iraola	deni@nnhf.org	<p>Increase knowledge about haemophilia in general</p> <p>Get training on different processes and techniques for MSK learn how to do rehabilitation treatment for people with haemophilia.</p> <p>- Hospital Universitario y Politécnico La Fe, Valencia, Spain: responsible persons: Dr Santiago Bonadad, haematologist.</p>	- Delays in the administration of the host institute and therefore the fellow was not able to start the process of getting the needed documentation to be trained in Spain. The training will take place in Q2 2017.	1 month Q2 2017

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North and Middle America	Mexico 5 - MX5	Rehabilitation in haemophilia care	Fellowship	Formalisation	Dr Mariela Colin Marin, 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.	1 month Q3 2017
North and Middle America	Mexico 6 - MX6	Advanced rehabilitation training	Fellowship	Formalisation	Dr Aíde 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.	1 month Q1 2017
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.	- In the 3rd quarter of 2016, 2 training sessions took place in Coronel Suárez and Bahía Blanca. The topics in Coronel Suárez were: General haemophilia knowledge, psycho-social aspects of haemophilia, infusion of factors, orthopaedic and rehabilitation aspects. In Bahía Blanca, the odontologist Dr Miryam Parreira from Buenos Aires led the session with 12 HCPs, 18 patients and 10 family members. - The project was also presented in a medical meeting organised by the Argentinian Haemophilia Foundation in Buenos Aires.	1.5 years Q2 2016
South America	Argentina 3 (Jujuy) - AR3	Outreach to patients with haemophilia in the province of Jujuy	Project	Execution	Fundación Jujena 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.	- Project partnership agreement signed and activities started in Q4 2016.	1 year Q4 2016
South America	Brazil 2 - BR2	Improve MSK status of PWH in Brazil by Measuring, Analysing, Disseminating and Educating – the way to correct, prevent and optimise the treatment	Project	Closing	IHTC "Luiz Cláudio Pizzigatti Correa", Hemocentro UNICAMP (State University of Campinas), Campinas - Dr Margareth Castro Ozelo	rbgs@nnhf.org	Establish guidelines for MSK evaluation and treatment Develop educative materials for PWH, their families and for healthcare professionals. Improve Quality of Life (QoL) of PWH through improvements in their physical, mental and social well-being.	- MSK web-based registry tool is being rolled-out in Mexico, India and Egypt.	3 years Q3 2011
South America	Brazil 3 - BR3	Impact of training health care professionals and patients with inherited bleeding disorders on quality of treatment	Project	Closing	Hemocentro do Estado do Espírito Santo-HEMOES, Vitória - Dr Alessandra Nunes Loureiro Prezotti, M.D., Ph.D	rbgs@nnhf.org	Develop practical guidelines customised for professionals who work in primary health care Produce an educative material for professionals and patients with inherited bleeding disorders and their families Develop a treatment guiding poster to be placed in emergency rooms Devise an educative and monitoring diary for patients with inherited bleeding disorders Prepare and deliver training activities for patients and their families Organize scientific meetings and training programs to expand and apply the outcomes generated by this project Publicise the results in a national meeting and the Haemophilia journal	- Waiting for final project audit report.	2 years Q3 2013
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	rbgs@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 Physiotherapy/MSK training was held at the University of Campinas. Thereafter physiotherapists were able to apply learnings in their respective care centers. Additionally a follow up meeting coordinated by Dr. Idea was held in Ponta de Pedras to align overall project implementation and training schedule. - Authorities from the Ponta de Pedras and the Secretary of Health were informed about the project and decided to support the screening activities leading to the identification of 9 patients. - In September 2016, the physical therapist Shirley Farias Fontinele from the HEMOPA Foundation together with physiotherapist Janaina Bosso delivered an MSK training at UNICAMP. Feedback about the training received at UNICAMP was quite positive. Training highlights can be summarized as follows: expertise knowledge-sharing, increased capacity building for appropriate MSK assessment and on the importance of multidisciplinary teams to deliver comprehensive care. In the future the MSK online assessment tool will be available for other physiotherapists at HEMOPA.	2.5 years Q3 2015
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.	- The laboratory equipment, reagents and consumables have been purchased to equip the laboratories in the National Hospital in Itagua and the Regional Hospital in Encarnación. - Lab training is being organised to take place on 7-11 November in Paraguay by expert trainer Marión Echenagucia from Venezuela. - Several meetings took place between the patient organisation (FUNDAHEMO), the National Blood Programme and the involved hospitals.	1.5 years Q4 2015

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South America	Peru 2 - PE2	Training of social workers in haemophilia in Peru	Project	Execution	Peruvian Haemophilia Association, Lima - Carmen Emperatriz Castro Abad	deni@nnhf.org	Improve knowledge and awareness of haemophilia of social workers on a national basis Facilitate patients' access to health infrastructure and proper management of their condition.	- A total of 6 one-day intensive training sessions about haemophilia for a total of 257 social workers were organised in the 2nd quarter of 2016 in Lima, Cajamarca, Chiclayo, Trujillo and Arequipa including theoretical and practical sessions. The training had academic value endorsed by three universities and ACAES (the national accrediting institution). The sessions were conducted by social workers, haematologists, other healthcare professionals and representatives from the health authorities (ESSALUD and MINSA). Educational material created through the project was distributed in all sessions. - In the 3rd quarter of 2016, the project team compiled the evaluation and results of the training sessions and published the final project report. Only the final audit report is now outstanding in order for the project to be closed at the NNHF Council Meeting in December 2016.	1 year Q1 2016
South America	Chile 5 - CL5	The role of a social worker in haemophilia	Fellowship	Execution	Pamela Andrea Suazo Navarro, social worker, Santiago, Chile	deni@nnhf.org	Specialise in haemophilia care Learn about the role of a social worker in haemophilia Increase knowledge about self-management and social re-integration for people with haemophilia. - Hemocentro "IHTC Claudio Luis Pizzigatti Correa", Hematology Center of University of Campinas (UNICAMP), Campinas, Brazil: responsible person: Dr Margareth Ozelo, Head of the Centre.	- Organisation of the logistics of the training have started to take place in November 2016 in Campinas, Brazil.	2 weeks Q4 2016
South America	Chile 6 - CL6	Comprehensive care training with a focus on diagnosis	Fellowship	Formalisation	José Luis Lamas Castellanos, haematologist, Santiago, Chile	deni@nnhf.org	Optimise medical knowledge in haemophilia care Improve interpretation skills of diagnosis test results Share experiences and knowledge gained adapting it to the local circumstances. - Hospital Universitario y Politécnico La Fe, Valencia, Spain: responsible persons: Dr Santiago Bonadad, haematologist.	- Delays in the administration of the host institute and therefore the fellow was not able to start the process of getting the needed documentation to be trained in Spain. The training will take place in Q2 2017.	1 month Q2 2017
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	deni@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.	- The Basic Coagulation Course for English speaking Africa for 9 participants took place from 11 to 15 April 2016 and was facilitated by Dr Angus McCraw, in collaboration with the team of Dr Mahlangu at the National Health Laboratory Service, Charlotte Maxeke Johannesburg Academic Hospital, South Africa. - The Basic Coagulation Course for Latin America for 10 participants took place from 5 to 8 July 2016 and was facilitated by Lic. Marión Echenagucia, in collaboration with the team of Dr Bélgica Moreno at the National Children's Hospital in Panama City. - NNHF is currently planning the courses for Southeast Asia in Thailand and for French speaking countries in Morocco. Both will take place in November 2016.	1 year Q1 2016