



NNHF Programmes: selected updates on activities in quarter 2, 2016 (1 April – 30 June 2016)

Overview

Novo Nordisk Haemophilia Foundation Q2 2016 update	By end Q2 2016
Number of projects approved by NNHF Council since 2005 (new projects since last quarter)	127 (0)
- Number of fundraised projects (new projects since last quarter)	13 (0)
Number of fellowships (new fellowships since last quarter)	70 (0)
Number of awards (new awards since last quarter)	14 (0)
HCPs trained since 2005	26,350
Patients and family members educated & patient leaders trained since 2005	31,000
People with haemophilia retested and newly diagnosed since 2005	19,300
NNHF engaged in number of countries (new countries since last quarter)	68 (0)

NNHF quarterly programmes update - quarter 2, 2016

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	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-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.	- The required equipment to strengthen the dental clinic were purchased. - The HCPs educational materials which will be used during the training were prepared and will be reviewed and printed in the next quarter.	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 KNH and MOI.	- The final draft of the five year KHA strategic plan was developed. It was circulated to all stakeholders for their input. - KHA team officially opened the Kenyatta National Hospital Haemophilia Comprehensive Care centre (HCC) the opening lead by the Kenyatta National Hospital CEO, Ms. Lily Koros and representatives from MoH, University of Nairobi, Moi Teaching and Referral, NNHF representatives and Jose memorial Haemophilia Society. - One day training for HCPs from the regions around Nairobi.	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 - 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.	- On 13th April the Haemophilia Association of Mauritius launched the haemophilia week by lighting the Municipal Council building of Quatres Bornes in red, in the presence of the President of the Republic of Mauritius, NNHF programme Manager and further guests. This event was covered nationally by television, radio as well as newspaper. - Amongst other activities, highlights were the lighting of the Municipal Council building in red again on 17 April, WHD as well as the live body painting event at the Trianon Shopping Mall prior the WHD. 8 new patients have been diagnosed during the WHD celebration. - 2 day training was organised at Reunion Island to start the haemophilia care in the island.	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 reprinted and distributed.	2 year Q1 2013
Africa	South Africa 3 - ZA3	Bringing better haemophilia care closer to the patients and strengthening the community	Project	Execution	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 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.	- Project partnership agreement was signed.	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.	- Project partnership agreement was signed.	Q1 2016 9 months
Africa	Uganda - UG	Setting up diagnosis, basic care and education in Uganda	Fundraised project	Closing	Haemophilia Foundation of Uganda, Kampala Agnes Kisakye, executive secretary	sysd@nnhf.org	Establish coagulation laboratory facilities Launch a country-wide awareness campaign Organise a patient education camp for 150 participants from all regions Provide diagnosis, consultation and an opportunity to gather patient data.	- The project will be closed in the Council Meeting in September.	6 months Q3 2015

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Africa	Malawi - MW	Specialised training in haemophilia care and management	Fellowship	Formalisation	Dr Yohannie Billy Mlombe, 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; Johnny Mahlangu.	- Training will start in September 2016.	Q1 2016 2 months
Africa	Nigeria 2 - NG2	Specialised training in the diagnosis and management of haemophilia	Fellowship	Formalisation	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. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; Johnny Mahlangu.	- Organisation of the training logistics started. The training will start in September.	6 months Q3 2016
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. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; Johnny Mahlangu.	- Organisation of the training logistics started.	1.5 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. Christina Medical College, Vellore, India under supervision of Dr Alok Srivastava	- 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	Ghana - GH	Improve lab capacity in Kumasi, Ghana	Fellowship	Closing	David Ofoosu, Komfo Anokye Teaching Hospital, Kumasi, Ghana Biomedical Scientist	sysd@nnhf.org	Learn more technical details for diagnosis either manual or by machine for haemophilia A, B and VWD especially factor assay and inhibitors Perform quality audits for testing of all coagulation assays Learn how to teach other lab technicians all the required skills Perform quality assurance procedures for coagulation tests. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; Johnny Mahlangu.	- Training took place in Q1 2016 - Fellowship final report was submitted - Fellowship to be closed during the Council Meeting.	2 months Q1 2016
Africa	Kenya 4 - KE4	First haemophilia nurse in Mombasa	Fellowship	Closing	Betty Mbogho, nurse Coast General Hospital, Mombasa, Kenya	sysd@nnhf.org	Gain knowledge on identification, diagnoses and treatment of haemophilia patients Learn about the comprehensive care approach and nurse role in multidisciplinary team Recognise the storage, indications, safe administration and handling of blood components and factor Learn how to create awareness. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; Johnny Mahlangu.	- Training took place in Q2 2016 - Fellowship final report was submitted - Fellowship to be closed during the Council Meeting.	3 months Q1 2016

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Africa	Kenya 5 - KE5	Specialised training for Mombasa physician	Fellowship	Closing	Tima Ali, general practitioner Coast General Hospital, Mombasa, Kenya	sysd@nnhf.org	Develop skills in management of haemophilia and other bleeding disorders Gain experience in the diagnosis and evaluation of PwH Recognise the indications, safe administration and handling of the blood components and factor replacement therapy Obtain skills in training in order to train other HCPs Learn about the multidisciplinary care approach and the role of Physiotherapy for PwH. - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; Johnny Mahlangu.	-Training took place in Q2 2016 - Fellowship final report was submitted - Fellowship to be closed during the Council Meeting.	4 months Q1 2016
Africa	Tanzania 1 - TZ1	Training in general haemophilia care	Fellowship	Closing	Neema Marandu, Nurse Kilimanjaro Christian Medical Center, Moshi, Tanzania	sysd@nnhf.org	Acquire knowledge and skills about treatment and care of people with hemophilia at all stages of their life Have the capacity to identify symptoms of hemophilia Learn how to educate patients and to develop patient educational materials Start the haemophilia care in KCMC instead of relying on Muhimbili Referral hospital in Dar el Salaam. Christina Medical College, Vellore, India Dr Alak Sivasubramanian	-Training took place in Q4 2015 - Fellowship final report was submitted - Fellowship to be closed during the Council Meeting.	3 months Q3 2015
Africa	Uganda - UG	Management of haemophilia and rare bleeding disorders	Fellowship	Closing	Dr Kasirye Gitta Phillip, Paediatrician Haemophilia Foundation of Uganda, Kampala kasiryep@yahoo.com Replacment candidate Hilda Tumwebaze	sysd@nnhf.org	Get equipped with knowledge regarding The identification, diagnosis and various treatment plans for patients with haemophilia Share and learn from experts who actively participated in The management of patients with haemophilia with focus on multidisciplinary approach learn about The role of The Patient association and collaboration between The medical and Patient community learn how to advocate for rights of patients with haemophilia in Uganda Importance of quality data and how to reach this goal through the establishment of a national registry Understand The global statistics of haemophilia. Great Ormond Street Hospital, London, UK Dr Kate Khair	-Training took place in Q2 2016 - Fellowship final report was submitted - Fellowship to be closed during the Council Meeting.	3 months Q3 2015
Africa	Libya 1 - LY1	Improve lab capacity and learn how to efficiently set up a coagulation laboratory upon return	Fellowship	Cancellation	Safa Naser Abdelgader, laboratory technician Benghazi children hospital, Benghazi	sysd@nnhf.org	Learn how to perform quality diagnosis for haemophilia A, B and VWD with a focus on factor assays and inhibitor diagnosis Learn technical details for different diagnosis techniques – from manual to using a semi-automated or automated coulometer Support the new haemophilia association to learn about how to build up a haemophilia registry Get familiar with the conceptualisation for and necessary steps to ensure the establishment of a laboratory for bleeding disorders with enhanced diagnostic processes for retesting of known patients as well as new cases Assist doctors in planning of the care approach including treatment according to the given diagnostic information. - Ampang Hospital, Malaysia; responsible person: Dr Jameela Sathar.	- The fellow was not able to travel due to the situation in Libya. The fellowship will be cancelled.	1 month Q3 2015
Africa	Sudan - SD	Providing physiotherapy for haemophilia patients in Sudan	Fellowship	Cancellation	Omer Khatem, physiotherapist Ribat University Hospital, Khartoum	sysd@nnhf.org	Learn how to reduce pain by improving the joint functionality and muscle strength Receive skilful training in using accessories, devices and support items Coordinate with orthopaedic in treating the chronic complications Use of the various scoring systems to assess and follow up patients. - Shibravishi Hospital, Cairo, Egypt; responsible person: Prof Magdy Elekiaby, Head of Haemophilia Center.	- The fellow was not able to travel due to the master study. The fellowship will be cancelled.	2 months Q1 2015

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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.	- Laboratories where previous training have been done are continuing to perform coagulation testing on patients as required by the medical practitioners. - Building self-esteem training workshop for patients were held 30 April 2016.	2.5 years Q4 2014
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.	- To celebrate World Haemophilia Day with haemophilia patients, their families and Health Care Professionals, the event "Bring happiness to haemophilia patients" took place in Weifang City (Shandong Province, China) during 14 April to 15 April. - In April, Health and Family Planning Commission of Shandong Province started a project "targeted measures to help people lift themselves out of poverty" to help haemophilia patients. In May, there was a haemophilia patients training lecture about haemophilia care and treatment. - 50 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.	- Project implementation recently started.	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	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.	- Project implementation recently started.	3 years Q2 2016
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 has been no activities in Q2 2016 besides meetings planning the second workshop in 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.	- Medical training activity planned in collaboration with the Mary Gooley Care Center (Rochester, NY) has been postponed to later this year.	6 months Q1 2015
East Asia	Thailand - TH	Improving haemophilia care in Thailand through the Chronic Care Model	Project	Execution	National Health Security Office (NHSO) and IHTC Bangkok - Hathaiwit 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 integration, 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. - Waiting for the final project reports.	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 JHTC Bangkok - Dr Rungrote Natesirinilkul - 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.	- Ethics approval by the Institutional Research Ethics Board/ Ethics Committee at the Faculty of Medicine, Chiang Mai University - Identification of healthcare professionals and the budget for MSK training in September - Thai version of the instructional video Hemophilia Joint Health Score 2.1 is in development - Three monthly operations committee conference calls has been held between Bangkok, Chiang Mai and the team at the Hospital for Sick Children.	2 years 10 months 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.	- 42 new patients diagnosed - Three group meetings with overall 96 patients and families were held at the Hemophilia Center, National Institute of Hematology and Blood Transfusion. - Three conferences with overall 540 patients and families were organised for patients and families; in Ho Chi Minh city, Hue and Hanoi. The organisation of World Hemophilia Day was paralleled with the conference in Hanoi. - Press conference organized to create awareness about hemophilia in regards to the World Hemophilia Day, participation of delegates from Ministry of Health of Vietnam and 200 journalists.	3 years Q2 2013
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 (EQA) 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 bleeding disorders registry.	-Finalising activities.	2 years Q2 2012
East Asia	Philippines - PH	National Registry of Haemophilia and Allied Bleeding Disorders Philippines	Project	Closing	Philippine Haemophilia Foundation INC. - Dr Flerida 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.	- Outreach was conducted last December 19, 2015 at the Perpetual Succour Hospital in coordination with HAPLOS Cebu and Dr Lynda Mae Lepatan. 24 suspected patients were tested. - PHF participated in the booth exhibit during the Paediatric Postgraduate Course of the University of Santo Tomas Hospital last November 9 to 10, 2015. Over 300 paediatricians from Metro Manila and Southern Tagalog area (Laguna, Cavite and Batangas provinces) attended the postgraduate course and were given hemophilia flyers and posters. - Continuous coordination with partner IT Company to revise registry application process and integrate the different issues rose during the launching of the website and potential issues that may be encountered when the Institutional Review Board of UST Hospital inspects the e-registry site. - Revisions are in process to improve confidentiality of information while encouraging medical centres involvement in the registry.	3 years Q3 2012
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.	- Kick off meeting with haematologists, patient organisation, authorities and IT-developers took place in the end of June 2016. - The project partnership agreement was signed at this occasion.	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.	- Educational camp for 25 parents and 8 children with haemophilia was held - Parent Section within Serbian Haemophilia Society is being established - The Youth Section, founded in Q4 2015, is now actively and independently operating.	2 years Q1 2015

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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.	1 year Q1 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
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 Bisano	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 in September 2016.	1.5 years Q1 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 (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.	- Project partnership agreement was signed and project activities are starting in Q3 2016.	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 Gilian 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.	- A group of medical technologists, nurse, haematologists as well as physiotherapists went to Montego Bay to assess and test patients. - 15 additional patients were diagnosed, achieving a total of 45 until today. 39 patients have been evaluated with the joint scores. - Jamaican lab technicians physiotherapists continue close collaboration with team at Sick Kids in Canada to improve their testing. - An abstract was submitted and accepted for the WFH Congress showcasing the work done by the team in the project. - Preparations are ongoing for an educational camp for patients and families in September with support by the Canadian team.	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	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.	- 3 sessions were organised for 40 patients and 60 family members at Hospital Infantil de México Federico Gómez (HIMFG) about 1) management of orthopaedic complications, 2) workshop with bandages, 3) family support - World Haemophilia Day was celebrated with an event at the HIMFG and participation in the 4th Walk organised by the Mexican Federation of Haemophilia. - An educational booklet for paediatric patients was created and 1,000 copies printed for the HIMFG and National Paediatric Institute (INP). They were also distributed at a talk by Dr Io Castillo at the Mexican Federation of Haemophilia. - MSK evaluations on patients have started and the needed equipment has been purchased.	1.5 years Q4 2015

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
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.	- The required equipment for the laboratory has been purchased. - The arrangements have been done to train 2 laboratory technicians from Nicaragua in Panama in the next quarter.	2 years Q1 2016
North and Middle America	Mexico 2 - MX2	Establishing a regional multidisciplinary haemophilia healthcare centre in Monterrey, Mexico	Project	Closing	Hospital Universitario "Dr. José Eleuterio González", Monterrey - Dr Laura Villarreal Martínez	deni@nnhf.org	Provide education, guidance and psychological support to patients Train healthcare professionals to establish a multidisciplinary care team Formalise a complete patient database Raise awareness amongst the general public including school children and teachers.	- The project results were presented to the NNHF Council in the end of March 2016 and a final project article will soon be published. - The multidisciplinary team continues to organise monthly educational sessions for patients and their families, e.g. about home treatment, self-infusion, rehabilitation and inviting Dr Misael Herrejón from Morelia to share his experience. - A team from the ISSEMyM from the State of Mexico visited the University Hospital in Monterrey to learn about how the multidisciplinary care team is working. - On WHD, the project team organised a public 5km walk in Monterrey to raise awareness of haemophilia. 1,200 persons participated. This was done without financial support of NNHF, making the activities sustainable that were started through the NNHF project. - The MSK registry created through the NNHF Brazil II project was installed in Monterrey.	2 years Q1 2014
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	- Increase knowledge about haemophilia in general - get training on different processes and techniques for MSK - learn how to do rehabilitation treatment for people with haemophilia. - Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible persons: Dr Santiago Bonadad, haematologist.	- Organisation of the training logistics have started.	1 month Q2 2016
North and Middle America	Panama 2 - PA2	Use of ultrasound in the diagnosis of haematomas and haemarthrosis	Fellowship	Closing	Dr Benilda González Lao, haematologist Hospital del Niño, Panama City, Panama	deni@nnhf.org	Specialise in haemophilia care Get tools to work with haemophilia patients and their families Establish new programmes to improve patients' quality of life. - Complejo Asistencial Dr. Sótero del Río, Santiago de Chile, Chile; responsible person: Dr José Luis Lamas Castellanos, haematologist.	- Training took place in April in Santiago de Chile.	1 month Q2 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.	- 60 patients and families participated in an awareness meeting organised by the Jordan Hemophilia Society - The hardware required for creating the website were purchased.	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.	- The national registry was finalised and training workshop was conducted to train the HCPs on using the registry. - An order was made to purchase the required reagents to test more patients. - On 16 April, one education session was conducted in Hebron for patients from Hebron and Beit Lahem.	1.5 years Q1 2014
South America	Argentina 3 (Jujuy) - AR3	Outreach to patients with haemophilia in the province of Jujuy	Project	Formalisation	Fundación Jueña de Hemofilia, San Salvador de Jujuy - Dr Susana Gastaldo	deni@nnhf.org	Identify new patients and improve diagnosis infrastructure Improve access to care for people with haemophilia in the province of Jujuy Improve patients' quality of life by establishing self-treatment processes and educating the social environment.	Project partnership agreement to be signed and activities to start in Q3 2016.	1 year Q3 2016

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
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 Q1 2016, the project was presented to the authorities of the Hospital Interzonal General Dr José Penna, of the Sanitary Region I and to the representatives of the health areas of the subregions of the Sanitary Region I. The main objective is to create a cross-institutional and multidisciplinary care network to offer a comprehensive approach in the South of Buenos Aires province. - In the end of April 2016, the first meeting and training took place in Tres Arroyos in the Eastern area. The topics were: General haemophilia knowledge, psycho-social aspects of haemophilia, infusion of factors, orthopaedical and rehabilitation aspects.	1.5 years Q2 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	Execution	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 software has been evaluated by members of the Intenational Prophylaxis Study Group. Their feedback is being incorporated to the software. - Meeting at WFH congress will serve as platform to decide how different parties will support the improvement and rollout in different countries.	3 years Q3 2011
South America	Brazil 4 - BR4	Strenthening the care and education network for haemophilia in the sate of Pará in Brazil	Project	Execution	FBH – Federação Brasileira de Hemofilia - Christianne Maria Oliveira Costa	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.	- Adaptation and printing of educational materials is taking place. - First regional training for HCPs on haemophilia planned in April 2016 however delays in scheduling may delay the start of trainings.	2.5 years Q3 2015
South America	Chile 2 - CL2	Improvement of care with a focus on home therapy and MSK through empowerment of medical and patient community	Project	Execution	Complejo Asistencial Dr Sotero del Río, Santiago de Chile - Dr José Luis Lamas Castellanos	deni@nnhf.org	Develop and perform an educational programme for patients and their families – focus: home therapy and importance of MSK/physiotherapy care Train healthcare personnel in primary healthcare centres Educate school staff and pupils on the condition Train healthcare teams in two satellite centres in strategic parts of the country to become trainers of the modules created for patients, their families, healthcare centres and schools Strengthen the patient association to become an active partner collaborating with the medical community and the authorities.	- No activities took place in Q2 2016 due to illness and leaves in the project team. - The project will be closed in the Council Meeting in September.	2 years Q2 2014
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 project was kicked off with a meeting between the Patient Organisation, the National Blood Programme and healthcare professionals from National Hospital of Itagua and Regional Hospital of Encarnación to define the roles, responsibilities and key next steps to start the activities. - A healthcare professional training is planned for September 2016 and a lab training for November 2016 with experts from abroad.	1.5 years Q4 2015
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 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.	1 year Q1 2016

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
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, Vitoria - 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	Bolivia - BO	Setting up diagnosis, basic care and education in Bolivia	Fundraised project	Closing	Fundación Nacional de Hemofilia Bolivia, Santa Cruz - Victor Manuel Ponce Rojas	deni@nnhf.org	Establish coagulation laboratory facilities and skills Organise a national educational event for 200 participants Raise awareness through a campaign engaging media.	- The project will be closed in the Council Meeting in September.	1 year Q2 2014
South America	Chile 5 - CL5	The role of a social worker in haemophilia	Fellowship	Formalisation	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 Cláudio 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.	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.	- Organisation of the logistics of the training have started.	1 month Q3 2016
South America	Chile 4 - CL4	MSK care to achieve joint function in people with haemophilia	Fellowship	Closing	Antonio Enrique Ibarra, physiotherapist, Complejo Hospitalario Sóterio del Río, Santiago, Chile	deni@nnhf.org	Specialise in haemophilia care Get knowledge about how an advanced haemophilia care centre is working and functioning Share experience and knowledge gained adapting it to the local circumstances Provide better care to the patients. - Hemocentro "IHTC Cláudio Luis Pizzigatti Correa", Hematology Center of University of Campinas (UNICAMP), Campinas, Brazil; responsible person: Dr Margareth Ozelo, Head of the Centre.	- Antonio Ibarra's fellowship was approved by the NNHF Council in March 2016. - His training took place in May in Campinas, Brazil, during 1 month.	1 month Q2 2016
South America	Colombia 5 - COS	Training in physiotherapy to improve care for people with haemophilia	Fellowship	Closing	Lina Teresa Mateus Díaz, physiotherapist IPS Especializada, Bogota	deni@nnhf.org	- Increase knowledge in providing better physiotherapy care for people with haemophilia - Learn how to use ultrasound in physical rehabilitation - Get knowledge on other physiotherapy techniques and tools to improve the daily treatment for patients - Share experience and knowledge gained adapting it to the local circumstances. - Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible persons: Dr Santiago Bonadad, haematologist.	- Training of Lina Teresa Mateus Díaz in Valencia, Spain, took place in April 2016 during 1 month.	1 month Q2 2016
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.	- On April 15, in advance to WHD Hematology Center in cooperation with Armenian Hematology Association and Armenian Society of Hemophilia patients organised an awareness seminar on "New prospects in diagnosis and treatment of haemophilia patients in Armenia". It was attended by 80 participants including haematologists, nurses, haemophilia patients, family members and foreign speakers.	2 years Q1 2015

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
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	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.	- Delhi Government's Haemophilia Centre (HDCC) at MAMC & LN Hospital celebrated the World Haemophilia Day on Wednesday 13th April 2016, in New Delhi with intense enthusiasm and active support from the haemophilic community and the haemophilia care staff. The event was attended by 698 PwH and family members. This haemophilia convention was named as "Haemo-Utsav" implying the celebration of life with haemophilia with focus on the following activities: o Highlight the success achieved under the "ONE COUNTRY, ONE TREATMENT" programme during the last year 2015-2016 o Release of "Manual for Haemophilia- 2nd Edition" o Highlight "What makes a Haemophilic self-reliant".	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 September 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	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.	- Regional MSK workshops were ran as following: West Regional Workshop Surat, April 9 and 10, 2016 North Regional Workshop Lucknow, May 14 and 15, 2016 East Regional Workshop Kolkatta, June 18 and 19, 2016 -The Regional Council Chairperson for the East, EC member, HFI used the opportunity to to advocate to the local state government for better care and coverage. -Including the South regional Workshop, the total number of physiotherapists and Occupational Therapists trained in the use of the MSK Registry is 88 in all.	3 years Q2 2015

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
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 idea of having a national level youth group was shared with the all chapters of Pakistan Hemophilia Patients Welfare Society, on which the executive boards of the chapters have agreed. A consensus has been reached that each chapter will nominate two youth candidates for this national level youth group. - Many corporate trainers and professional consultants working in the non-profit sector were contacted to train the newly elected national executive board. A short listed trainers that will facilitate this national level visioning exercise session. The members of the national Ex. Board is having regular brainstorming sessions to generate ideas in order to develop a strategic plan which would ultimately achieve the vision to the organization. Furthermore, the executive boards of the chapters have also been contacted to get ideas and inputs regarding the development of this strategic plan. It has been done with the rationale that it's the chapters that ultimately provide treatment to the patients, thus, they are the one that are aware of the ground realities that exists and effects the various operation of the organization. They have provided many ideas and highlighted various issues along with solution that need immediate attention; which all would be made a part of the strategic plan - Positive Diaries is a collection of testimonials of people living with inherited bleeding disorders in Pakistan. After the designing phase, a printer was hired to print this booklet. Finally, this product is now ready to be disseminated. - Funds were issued to the Rawalpindi/Islamabad chapter of PHPWS-NMO for outreach seminar, which took place at a medical college. It was an awareness seminar in which future doctors and nurses were sensitized about Hemophilia and other bleeding disorders. It is an attempt to reduce the gap between the number of identified and estimated number of patients.	2 years Q2 2014
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.	- A telephone meeting with the regions chief physicians held to agree on the project steps and the final training participant list. - A 7-day training programme was developed and all the educational materials were developed. - On 19 – 20 May, a haematologists international conference in Tashkent was held and an update about the project was presented to the doctors from Tashkent haemophilia centre and chief haematologist of Dzhizah, Fergana, Namangan, Karakapakistan, Kashkadarya, Navoi, Syrdarya regions. - Training was organised for the doctors from the regions in rehabilitation and small operations as following: Syrdarya (Elmuratova R., Numanov H., Mutazakulova M.A), from Samarkand region (Tolibayeva D., Sho-muradov K.), from Navoi (Karimov U. Musaeva), from the remote areas 15 haematologists, 10 medical laboratory assistants and 23 nurses were trained. All physicians participating in the training.	1.5 years Q1 2016
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 and Final Project report.	2 years Q1 2013

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Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status Q2 2016	Programme duration / Start date
South and Central Asia	India 2 - IN2	IDEA - Identification, Diagnosis, Education and Empowerment for Action of people with bleeding disorders in South India	Project	Closing	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.	- Education material, poster & pamphlet to create awareness among general public, primary health centres and district hospitals has been delivered. - Project closing meeting took place at the Manipal University on 30 January. Dr Annamma Kurien and the university directors praised the work provided to the haemophilia and bleeding disorders community through the IDEEA project. - NNHF is working with Dr Annamma to extend the activities to the entire state of Karnataka through a second project.	3 years Q1 2012
South and Central Asia	Myanmar - MM	Institution of the Myanmar Haemophilia Patients' association and establishment of its collaboration network	Project	Closing	Yangon Children's Hospital, Yangon - Dr Khin Nwe Oo	deni@nnhf.org	Plan and execute the establishment of the Myanmar Haemophilia Patients' Association Adapt and translate key training materials on haemophilia into Myanmar version Educate HCPs on haemophilia in key centres and inform about the association and its role Create awareness amongst patients and society about the association, haemophilia and provide guidance Prepare and execute application to become a WFH National Member Organisation.	- Patient association registration done - WFH recognised the patient association as an associate National Member Organisation - Project results were presented in the Council Meeting in March 2016. The missing documentation to close the project will be presented in the September meeting.	1.5 years Q4 2013
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 and Final Project report.	2 years Q2 2015
South and Central Asia	Myanmar - WHD 2013	Empowering of patients and capacity building of HCP by focusing on physiotherapy in	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. Project is to start in Q3 2016.	1 year
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 to start in Q3 2016.	6 months Q1 2016