## NNHF Programs: Selected Updates on Activities in the 1st Half Year 2017 (1 January – 30 June 2017)

### Overview

<table>
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<tr>
<th>Novo Nordisk Haemophilia Foundation H1 2017 Update</th>
<th>By end H1 2017</th>
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<tbody>
<tr>
<td>Number of projects approved by NNHF Council since 2005 (new projects since last half year)</td>
<td>148 (6)</td>
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<tr>
<td>-Thereof number of fundraised projects (new projects since last half year)</td>
<td>14 (0)</td>
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<td>Number of fellowships (new fellowships since last half year)</td>
<td>74 (0)</td>
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<td>Number of awards (new awards since last half year)</td>
<td>16 (2)</td>
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<tr>
<td>HCPs trained since 2005</td>
<td>31'290</td>
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<td>Patients and family members educated &amp; patient leaders trained since 2005</td>
<td>35'500</td>
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<td>People with haemophilia retested and newly diagnosed since 2005</td>
<td>22'430</td>
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<tr>
<td>NNHF engaged in number of countries (new countries since last half)</td>
<td>68 (0)</td>
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<tr>
<td>Region</td>
<td>Programme type</td>
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</table>
| Africa | Egypt 2 - GS4 | Improving haemophilia care in Egypt | Project | Execution | Ihab Shalash, General Hospital for Haemophilia, Cairo | • Training in managing haemostasis and physical therapy for staff.
• Conducting an audit of the existing system in the hospital.
| 1.5 years / Q1 2017 |
| Africa | Ghana 2 - GHA | Improve access to and care for haemophilia in Ghana | Project | Execution | Ghana Haemophilia Society, Accra | • Improve patient awareness.
• Establish a multidisciplinary care team and improving haemophilia care in Ghana.
| 2 years / Q1 2017 |
| Africa | Kenya - KE3 | Strengthen the patient association and build capacity for comprehensive haemophilia management | Project | Execution | Kenya Haemophilia Association, Nairobi | • Improve access to care for haemophilia patients.
• Strengthen the patient association and build capacity for comprehensive haemophilia management.
| 2 years / Q1 2015 |
| Africa | Malawi - MW | Establish haemophilia care in Malawi | Fundraising project | Execution | Malawi Haemophilia and Allied Bleeding Disorders Association | • Establish haemophilia care in Malawi.
• Improve access to care for haemophilia patients.
| 1 year / Q1 2016 |
| Africa | Malawi - MW | Established a haemophilia care team and improving haemophilia care in Malawi | Fellowship | Closing | Blessing Malemo, Dr David Livingstone Memorial, Lilongwe | • Establish a multidisciplinary care team and improving haemophilia care in Malawi.
• Improve access to care for haemophilia patients.
| 1 year / Q1 2016 |
| Africa | Mali - ML | Improve haemophilia care in Mali | Project | Execution | Association Malienne de Lutte contre l’Hémophilie, Bamako | • Improve haemophilia care in Mali.
• Improve access to care for haemophilia patients.
| 2 years / Q1 2016 |
| Africa | Mauritius - MO | Establish a multidisciplinary care team and improving haemophilia care in Mauritius | Project | Execution | Haemophilia Association of Mauritius, Mauritius, Quatre Bornes, Mauritius | • Establish a multidisciplinary care team.
• Improve access to care for haemophilia patients.
• Improve the physical therapy care provided to PwH.
| 2 years / Q1 2015 |
**Region** | **Programme type** | **Programme title** | **Phase** | **Partner** | **NNHF contact** | **Objectives** | **Status** | **Programme duration / Start date** |
--- | --- | --- | --- | --- | --- | --- | --- | --- |
Africa | Nigeria 2 - NG 2 | Attract and strengthen the medical and patients community in Nigeria | Project | Execution | Haemophilia Foundation of Nigeria, Ibadan - Megan Bucy Adeyinde | nnnrf@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 organizing two world haemophilia day celebrations and develop awareness publications Establish regional haemophilia care service in the South West Region. | - | 2 years Q1 2015 |
Africa | South Africa 3 - ZA3 | Bringing better haemophilia care closer to the patients and strengthening the community | Project | Closing | ski Foundation - Charmaine Groothuisen | nnnrf@nnhf.org | Improve services provided at district level Increase responsibility and compliance of patients Implement updated electronic registry Raise teaching & organizing capabilities. | - All project activities have been completed. Waiting for the final audit report. | 2 years Q1 2016 |
Africa | South Africa 4 - ZA4 | Strengthen South African haemophilia federation capacity through youth development and strengthening of health care providers | Project | Execution | South African Haemophilia Foundation (SAHF) and its Medical and Scientific Advisory Council (HASCAC) - Johan Noltes | nnnrf@nnhf.org | Establish a national web-based registry Improve capacity and acceleration planning of SAHF Improve haemophilia care through multidisciplinary training. | - Project partnership agreement was signed. | 3 years Q1 2017 |
Africa | Tanzania 2 - TZ2 | Empower the patient association to organize successful awareness campaigns and advocacy | Project | Execution | Haemophilia Society of Tanzania, Dar es Salaam - Richard Ninja | nnnrf@nnhf.org | Empower the haemophilia community Organise media engagement training Create awareness in the region of Dar es Salaam Advocacy meetings with authority. | - Strategic Media Engagement training was organised by NNHF. The training was attended by 9 haemophilia leaders - Following the Strategic Media Engagement training, a training for 36 media reports from 17 media organisations including radio, TV and newspapers. The training covered the aspects of haemophilia and how media can help to identify PWH and decrease stigmatisation. Not supported the training and the Minister was guest of honor. - 3 TV talks (TSC TV, Clouds and Star TV) and 2 radio talks (TSC Radio) and 6 newspapers reported about haemophilia. New PWH were identified as a result of the awareness campaign - Youth trained on how to use social media to create awareness about the society - Leadership training was organised for 18 young leaders on how to be active with the society. - Organised stand alone training for 33 traditional healers from Dar es Salaam region. The training was attended by 7 patients and covered by 12 media reporters. | 3 years Q1 2017 |
Africa | Tanzania 2 - TZ2 | Start haemophilia care in Southern Tanzania | Fellowship | Closing | Arthur Lupembwe, Nurse, Mbeya Referral Hospital, Mbeya, Tanzania | nnnrf@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 Muhumbili National Hospital Acquire the knowledge to train the other Hospital Staff. - Christian Medical College, Victoria, India; responsible person(s): Dr Alok Sinhatha. | - The training was completed in May 2017. - Positive feedback received from the participants. | 3 months Q1 2017 |
Africa | Uganda 2 - UG2 | Create awareness and IHC training in Uganda | Project | Execution | Haemophilia Foundation of Uganda, Lusaka - Agnes Ikasye, executive secretary | nnnrf@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 Advocacy for better care for haemophilia patients. | - During the health camp organised by the office of the vice president at Lambu Landings, HPU team created awareness for over 1,400 people - A haemophilia symposium was organised during 90th with focus on patient identification, referral and management. It was attended by 46 doctors, 27 nurses, 2 physiotherapists and 29 other HCPs - An Muslimcircumcisors’ workshop was conducted. Much emphasis was put on safe circumcision and guidelines developed for the process. The training was attended by 100 Muslim circumcisors which will increase safe circumcision and help in new patient identification. - 10 Village Health Team (VHT) coordinators were identified and they supported the training of 236 VHT at Dimo Landin site and 45 youth VHT at Kubu Muslim mosque - 23 media houses covered the haemophilia activities, featured live in the day’s news bulletin and live interviews were conducted on different radio stations. - A haemophilia motion advocating for a comprehensive policy on haemophilia care was presented by the chairperson on the floor of parliament to get government support to develop a comprehensive policy on haemophilia care - Haemophilia team participated at the three day parliamentary health week. This led to a new partnership between HVU and the office of the vice president and strengthened the advocacy strategy with government officials. - Three healthcare practitioners’ workshops were successfully organized. | 2 years Q1 2016 |
Africa | Zambia 1 - ZM1 | Haemophilia awareness campaigns and outreach across Zambia | Project | Execution | Haemophilia Foundation of Zambia, Lusaka - Chikuya Hiku, Founding member | nnnrf@nnhf.org | Create awareness through documentaries and materials Organise outreach programme by training community health workers, village health team and other health workers Improve self-care of people living with haemophilia through education Establish first haemophilia treatment centre. | - The project partnership agreement was signed. | 1.5 years Q1 2017 |
East Asia | Cambodia - KR | Raising awareness, support, diagnosis and treatment for people with haemophilia living in Cambodia | Project | Execution | Cambodia Haemophilia Association - Si Soth Hong | enqy@nnhf.org | Develop national guidelines for diagnosis, treatment and management of patients with haemophilia and other bleeding disorders Improve diagnosis, treatment and management of haemophilia and other bleeding disorders in five provincial hospitals Empower patients and family members to better cope with their condition and engage in the patient society Conduct awareness activities engaging health authorities to secure their support. | - WHO was consulted with an awareness raising event and the project team succeeded in engaging with several media channels. The event was for example broadcasted at PNN and articles were written to raise awareness about haemophilia - Final project report received. | 2.5 years Q1 2014 |
### Region

<table>
<thead>
<tr>
<th>Region</th>
<th>Programme title</th>
<th>Programme type</th>
<th>Phase</th>
<th>Partner</th>
<th>NNHF contact</th>
<th>Objectives</th>
<th>Status</th>
<th>Programme duration / Start dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Asia</td>
<td>Cambodia 2 - NN5</td>
<td>Advanced training in rare bleeding disorders diagnosis</td>
<td>Fellowship</td>
<td>Closing</td>
<td>Dr. Samany, Laboratory technician, National Pediatric Hospital (NPH), Phnom Penh</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Increase capacity of diagnosis regarding; Detection of inhibitors Diagnosis of von Willebrand disease Diagnosis of Rare Blood Function Disorders Testing for antiplatelet antibodies.</td>
<td>Fellowship completed and final report received.</td>
</tr>
<tr>
<td>East Asia</td>
<td>China 3 - CN3</td>
<td>Further improve reliability of diagnosis and comprehensive care in China by setting up a National Quality Assurance Programme</td>
<td>Project</td>
<td>Closing</td>
<td>Hematology department, Rohan Hospital affiliated to Medicine School of Shanghai Jiaotong University, Shanghai - Prof Hongli Wang</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Further improve reliability of diagnosis and comprehensive care in China by setting up a National External Quality Assurance (EQA) programme. Improve the Quality Assurance in Haemophilia laboratories in China with a standardisation of knowledge of haemophilia in rural areas of selected less privileged provinces. Final and Diagnostic Lab new patients - Maintain and update the established national web-based bleeding disorders registry.</td>
<td>Final audit report received.</td>
</tr>
<tr>
<td>East Asia</td>
<td>China 4 - CN4</td>
<td>Identity and improve five city level comprehensive haemophilia treatment centres in Shandong province</td>
<td>Project</td>
<td>Closing</td>
<td>Standing Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Identity 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, press engagement and a documentary film. Diagnose and register 200 new cases identified through the proposed awareness activities.</td>
<td>- Development of project summary kit - 116 new patients diagnosed and registered - Final audit report received.</td>
</tr>
<tr>
<td>East Asia</td>
<td>China 5 - CNS</td>
<td>Set up and consolidate five comprehensive care treatment centres for haemophilia and von Willebrand disease in Jiangsu Province China</td>
<td>Project</td>
<td>Execution</td>
<td>The First Affiliated Hospital of Suhu University, Suhu - Prof Ziqiang Yu</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Set up multidisciplinary care and train the teams in Suhu, hangjing, Qinzhou, Fuzheu and Suhu. 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.</td>
<td>- Education sessions for healthcare professionals held in Suhu and Fuzheu. 75 doctors and 21 nurses trained about haemophilia care. The healthcare professionals were from Haematology department, Orthopedics department, Supersonic department, Emergency department, Pediatrics department and Physiotherapy department - WHO celebrated in all five cities involved in the project. Education meetings for patients and their families carried out. More than 200 patients and family members attended the events.</td>
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<tr>
<td>East Asia</td>
<td>China 6 - CN6</td>
<td>Decentralisation of multidisciplinary care in four city level haemophilia centres in Sichuan Province China/ Sichuan Province</td>
<td>Project</td>
<td>Execution</td>
<td>Shunhui Centre of Haemophilia Diagnosis and Treatment - Prof Xiaoling Li</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Select four city-level haemophilia centres in Nanchang, Lushu, Kaifu and Lianhu. 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.</td>
<td>- First train-the-trainer-workshops held for the provincial HCP expert team focusing on haemophilia diagnosis and treatment. - Trainings of health care professionals carried out in Chengdu and in Mianyang in order to further improve the knowledge of haemophilia care - Education about haemophilia and treatment options of patients and family members done in Chengdu. - WHO celebrated to support patients, improve social awareness about haemophilia and to promote the strengthening of haemophilia care in Sichuan. Healthcare professionals, volunteers, patients and families from more than 18 hospitals and organizations united. - Educational materials developed and printed for both healthcare professionals and patients - 21 new haemophilia patients diagnosed and registered.</td>
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<tr>
<td>East Asia</td>
<td>China 7 (Tibet)</td>
<td>Development of comprehensive care in Tibet Autonomous Region</td>
<td>Project</td>
<td>Execution</td>
<td>Standing Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>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 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.</td>
<td>- Trip to these planning and preparing for the training session of HCPs. - Capacity needs assessment of the 7 involved HCPs. Training needs of each HCPs and appropriate clustering determined - Laboratory needs assessments of the 7 involved HCPs and secondary centres to be included in the National Quality Assurance Scheme. - The train-the-trainer-programme package developed and printed, including national treatment guidelines and a book about comprehensive care - Launch of the NNHF-CNS program at a workshop in Tianjin - One week in-depth training of the 7 multidisciplinary care teams carried out by HTCONC expert team in Tianjin. 30 healthcare professionals were in-depth trained - Provincial awareness and advocacy need assessments done. Advocacy objectives and goals defined. Causes for lack of supportive policies, legislation and coverage limitations and delivery of care deficiencies analysed.</td>
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<tr>
<td>East Asia</td>
<td>East Asia Indonesia 2 - NN8</td>
<td>Establishing and strengthening quality haemophilia care in the southeast region of China</td>
<td>Project</td>
<td>Formalisation</td>
<td>Institute of Haematology and Blood Diseases, Chinese Academy of Medical Sciences, Tianjin - Professor Chench Yang</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Establish and strengthen haemophilia care in 7 provinces in China. Increase quality diagnosis across 7 provinces - Consolidate patient data in national online patient registry, including medical data - Empower patients and families to enjoy better quality of life and becoming an active partner within the haemophilia community - Increase understanding and recognition about haemophilia amongst general public, HCPs and authorities - Improve legislation and reimbursement for haemophilia care by introducing haemophilia within provincial health care agendas.</td>
<td>- Capacity needs assessment of the 7 involved HCPs. Training needs of each HCP and appropriate clustering determined - Laboratory needs assessments of the 7 involved HCPs and secondary centres to be included in the National Quality Assurance Scheme. - The train-the-trainer-programme package developed and printed, including national treatment guidelines and a book about comprehensive care - Launch of the NNHF-CNS program at a workshop in Tianjin - One week in-depth training of the 7 multidisciplinary care teams carried out by HTCONC expert team in Tianjin. 30 healthcare professionals were in-depth trained - Provincial awareness and advocacy need assessments done. Advocacy objectives and goals defined. Causes for lack of supportive policies, legislation and coverage limitations and delivery of care deficiencies analysed.</td>
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<tr>
<td>East Asia</td>
<td>Indonesia 2 - NN10</td>
<td>Improve access to care through strengthened multidisciplinary care teams in regional care centres and 10 provinces by education and training of healthcare professionals in 10 selected provinces about self-infusion and better self-management</td>
<td>Project</td>
<td>Execution</td>
<td>Indonesian Society of Haematology &amp; Blood Transfusion (ISIBT), Jakarta - Dr/Consultant Haematologist Dr Henry S. Sathemalaman, South East Asia Centre; Ridwan Hadi - Indonesia - Dr/Consultant Haematologist, National Children's Hospital, Jakarta</td>
<td><a href="mailto:smqy@nnhf.org">smqy@nnhf.org</a></td>
<td>Establish and strengthen multidisciplinary haemophilia care and emergency management in 9 regional HTCs and 10 CCC. Improve haemophilia care and emergency management in 10 provinces by educating primary and secondary health care providers about haemophilia care and appropriate cluster identified - Establish and strengthen multidisciplinary care in 10 selected provinces about self-infusion and better self-management.</td>
<td>- Needs assessment of the 10 involved haemophilia treatment centres done - Kick-off meeting held in Jakarta. The focus of the meeting was to ensure an aligned project team, to discuss the training concept and tailor it to specific needs - Establishing the National materials developed, a booklet on self-infusion for patients and a leaflet and a poster for HCPs about emergency care for haemophilia patients.</td>
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<tr>
<td>Region</td>
<td>Programme title</td>
<td>Programme duration / start date</td>
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<tr>
<td>East Asia</td>
<td>Malayasia - NY3 Improving Haemophilia Care in Thailand - through education, quality measurement and the enhancement of two training centres in Bangkok and Chiang Mai</td>
<td>1,5 years</td>
<td></td>
<td>Project Execution</td>
<td>Faculty of Medicine/Chiang Mai University and IHTC Bangkok - Dr Rungrote Natesirinilkul- Prof Ampaiwan Chuansumrit</td>
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<td>Project Execution</td>
<td>Faculty of Medicine/Chiang Mai University and IHTC Bangkok - Dr Rungrote Natesirinilkul- Prof Ampaiwan Chuansumrit</td>
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<tr>
<td>East Asia</td>
<td>Thailand - TH4 Improving Haemophilia Care in Thailand through the Chronic Care Model, strengthening of comprehensive care teams and development of leadership talents</td>
<td>2 years</td>
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<td>Project Execution</td>
<td>East Asia Thailand - TH4 - improve the chronic care model, strengthening of comprehensive care teams and development of leadership talents</td>
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<td>Project Execution</td>
<td>East Asia Thailand - TH4 - improve the chronic care model, strengthening of comprehensive care teams and development of leadership talents</td>
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<tr>
<td>East Asia</td>
<td>Vietnam - V2 Improving Haemophilia Care in Vietnam - through education, outcome measurement and the enhancement of the care provided in two training centres in Ho Chi Minh city and Can Tho</td>
<td>1 year</td>
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<td>Project Execution</td>
<td>Altinh Society of Congenital Bleeding Disorder, Hanoi - Prof Nguyen Anh Tri</td>
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<td>Project Execution</td>
<td>Altinh Society of Congenital Bleeding Disorder, Hanoi - Prof Nguyen Anh Tri</td>
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<tr>
<td>Europe</td>
<td>Latvia - LV2 Setting up of a web-based bleeding disorders registry in Latvia</td>
<td>1 year</td>
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<td>Project Execution</td>
<td>Latvia Hemophilia Society, Riga - Saba Ziemele</td>
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<td>Project Execution</td>
<td>Latvia Hemophilia Society, Riga - Saba Ziemele</td>
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<tr>
<td>Europe</td>
<td>Serbia - RS2 Empowering the patient community to be active and compliant</td>
<td>1 year</td>
<td></td>
<td>Project Execution</td>
<td>Serbian Haemophilia Society, Belgrade - Tatjana Markovski</td>
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<td>Project Execution</td>
<td>Serbian Haemophilia Society, Belgrade - Tatjana Markovski</td>
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<tr>
<td>UNIF Lab Module</td>
<td>Module 2016 Strengthening the education and awareness of healthcare professionals and patients in Palestine</td>
<td>1 year</td>
<td></td>
<td>Project Execution</td>
<td>Palestinian Ministry of Health, Foreign Rotation department, Ramallah - Huda Lahham and Dr Hussen Elyan</td>
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<td>Project Execution</td>
<td>Palestinian Ministry of Health, Foreign Rotation department, Ramallah - Huda Lahham and Dr Hussen Elyan</td>
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**Notes:**
- The Projects listed above are part of a broader initiative focusing on improving healthcare delivery and education in various regions around the world.
- Each project has specific objectives, such as improving patient care, enhancing awareness, and strengthening healthcare systems.
- The status of each project is indicated by the year and whether activities were completed or if the project was extended.
- Projects often involve partnerships with various organizations, adding to the comprehensive approach.
**Programme Title**

**Objectives**

**Phase**

**Partner**

**Contact**

**Programme description**

**Programme duration / Start Date**

**Region**

**Programme title**

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**Phase**

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<th>Phase</th>
<th>Partner</th>
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<th>Status</th>
<th>Programme duration / Start date</th>
</tr>
</thead>
</table>
| North and Middle America| Nicaragua - NI| Establish comprehensive care of haemophilia in Nicaragua                        | Project | Execution | Nicaraguan Association of Haemophila  
- Javier Antonio Rivero Ojeda  
- Dr. Rafael Barrios  
- Red Cross Nicaragua
- Dr. Raúl Barriga | deni@nnhf.org | Improve coagulation laboratory and train the staff to do diagnostic tests        | Q4 2015 | Improve quality of diagnosis in the reference centres and create basic diagnosis hubs in other regions of the country Reflect the national epidemiological picture of haemophilia and allied bleeding disorders in a web-based registry. | Improve quality of diagnosis in Nicaragua. Improve haemophilia care network and create a network to promote the appropriate treatment. | 2 years Q2 2016 |
## NNHF half yearly programmes update - H1, 2017

### Region: South and Central Asia

<table>
<thead>
<tr>
<th>Country</th>
<th>Programme type</th>
<th>Programme title</th>
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</table>
| Armenia - AM     | Building the national haemophilia care network in Armenia                      | Project                 | Execution                | Haematology Center of Armenia, Yerevan - Prof Simbal Dagbashyan | sysd@nnhf.org                    | - Outreach visits organized in Tashkent, Tashkent, Nukus, Khiva, Buxoro, Tashkent, Andijan, Aravan and Lyab-i Hauz provinces. The outreach visits included the following activities:  
  - Educational seminars for local doctors in providing first aid to PHN  
  - Educational seminars for PHN and their families  
  - Consultations by trained haemophilia doctors in all 5 regions with the support of the Fennex haemophilia team  
  - Psychological support was given to individuals and more sessions were scheduled to consultations by the trained physiotherapists. | - Regional outreach visits organized in Tashkent, Tashkent, Nukus, Khiva, Buxoro, Tashkent, Andijan, Aravan and Lyab-i Hauz provinces. The outreach visits included the following activities:  
  - Educational seminars for local doctors in providing first aid to PHN  
  - Educational seminars for PHN and their families  
  - Consultations by trained haemophilia doctors in all 5 regions with the support of the Fennex haemophilia team  
  - Psychological support was given to individuals and more sessions were scheduled to consultations by the trained physiotherapists. | 2 years Q1 2015 |
| Azerbaijan - AZ  | Establish haemophilia care in Nakhchivan region and improve physiotherapy care across Azerbaijan | Project                 | Formalisation             | Azerbaijan Republic Association of Haemophilia, Baku - Gulvara Huseynova | sysd@nnhf.org                    | Establish Haemophilia care in Nakhchivan for better care for people with haemophilia  
  - Improve physiotherapy care  
  - Raise awareness of patients and families. | - Project partnership agreement to be signed. | 2 years Q1 2017 |
| Bangladesh - BD  | Improving quality of care for haemophilia in three centres in Bangladesh       | Project                 | Execution                | Dhaka Medical College - Prof Sultana Afrose               | snh@nnhf.org                     | Increase capacity of the multicentric teams in Dhaka, Rajshahi and Bangour  
  - Develop diagnostic facilities for coagulation studies  
  - Educate patients and families and encourage them to attend the newly trained centre  
  - Engage authorities and the public for more support to bleeding disorders. | - Training session of healthcare professionals at Rajshahi Medical College, a large Medical Centre outside the capital Dhaka  
  - Education of patients and families and encouraging them to attend the newly trained centre in Rajshahi Medical College. | 1 year Q1 2015 |
| 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                    | Spread knowledge about haemophilia and improving quality of diagnosis and treatment in Georgia.  
  - Update current guidelines for treatment of haemophilia and allied bleeding disorders  
  - Produce educational material for healthcare professionals and patients  
  - Do comprehensive national training programme for healthcare staff  
  - 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 |

### Region: Azerbaijan - Azerbaijan

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<tr>
<th>Country</th>
<th>Programme type</th>
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<th>Programme type</th>
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<th>NNHF contact</th>
<th>Objectives</th>
<th>Status</th>
<th>Programme duration / Start date</th>
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| India 3 - IN3    | Capacity Building and Empowerment program for care givers and parents involved in the Haemophilia Care in North East and India | Project                 | Closing                  | Manipal Acar Medical College, New Delhi - Prof Nareen Gupta | sysd@nnhf.org                    | Capacity Building and Empowerment program for care givers and parents involved in the Haemophilia Care in North East and India  
  - Improve the laboratory facilities  
  - Update current guidelines for treatment of haemophilia and allied bleeding disorders  
  - Produce educational material for healthcare professionals and patients  
  - Do comprehensive national training programme for healthcare staff  
  - 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. | 4 years Q2 2013 |
| India 6 - IN6    | Capacity Building and Empowerment program for care givers and parents involved in the Haemophilia Care in North East and India | Project                 | Closing                  | Haemophilia Federation India - Prof Mukesh Garodia & Dr Richa Mohan | sysd@nnhf.org                    | Capacity Building and Empowerment program for care givers and parents involved in the Haemophilia Care in North East and India  
  - Improve the laboratory facilities  
  - Update current guidelines for treatment of haemophilia and allied bleeding disorders  
  - Produce educational material for healthcare professionals and patients  
  - Do comprehensive national training programme for healthcare staff  
  - 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. | 4 years Q4 2014 |
| India 7 - IN7    | Preventing and Decreasing Musculoskeletal morbidity and Mortality among People with Haemophilia in Southern India | Project                 | Execution                | Haemophilia Federation India - Prof Pamela Naryan | pamelanaryan@yahoo.co.in          | Preventing and Decreasing Musculoskeletal morbidity and Mortality among People with Haemophilia in Southern India  
  - Reduce the incidence of musculoskeletal morbidity  
  - Reduce the number of hospital admissions  
  - Reduce the need for surgical intervention  
  - Increase patient mobility and independence  
  - Improve quality of life  
  - Decrease pain and disability  
  - Reduce the cost of care  
  - Increase patient satisfaction. | - The collected data from the sent survey to physiotherapy facilities was analysed and presented at the HSC congress in Seoul.  
  - A national HSC meeting was organized to agree on national HSC guidelines for India. The meeting was the first of its kind and the guidelines were signed off. | 1 year Q1 2015 |
| India 8 - IN8    | Empowering Parents in South and West India                                      | Project                 | Execution                | Haemophilia Federation India and Empowering Minds Society for Research & Development - Dr Richa Mohan | sysd@nnhf.org                    | Empowering Parents in South and West India  
  - Improve the laboratory facilities  
  - Update current guidelines for treatment of haemophilia and allied bleeding disorders  
  - Produce educational material for healthcare professionals and patients  
  - Do comprehensive national training programme for healthcare staff  
  - 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. | - The train the trainer PEP workshop was held in Bangalore, Karnataka on 17 February for 3 days. 22 participants including a nurse, a social worker, parents, caregivers and professionals representing different chapters of the south region attended the training workshop.  
  - The newly revised and updated PEP manual was published. | 2 years Q1 2016 |
| Myanmar - MM2    | Fellowship in Haemostatological Laboratory                                     | Fellowship              | Fellowship               | Yang Nai, pathologist  
  General Hospital, Mandalay, Myanmar | snh@nnhf.org                     | Fellowship in Haemostatological Laboratory  
  - Improve expertise in diagnostic techniques of inherited and acquired bleeding and clotting disorders  
  - Learn to implement good laboratory practices and the importance of pre-analytical variables in haemostatistics investigations  
  - Acquire in depth knowledge about quality control and the use of appropriate instrumentation and reagents. | - Fellowship completed and final report received. | 6 months Q1 2016 |
| Pakistan 5 - PK5 | Bringing change by improving access to care and awareness: Ca-parity building and leadership initiative | Project                 | Closing                  | Pakistan Haemophilia Patients Welfare Society (PHPWS) - Massoud Famed Malik | sysd@nnhf.org                    | Bringing change by improving access to care and awareness: Ca-parity building and leadership initiative  
  - Improve access to care and awareness: Ca-parity building and leadership initiative  
  - Develop centralized web-based national patients registry. | - At the project activities were completed and the final report was submitted. | 2 years Q2 2014 |
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</table>
| South and Central Asia | Pakistan 6- PK6 | Building partnerships to create awareness and improve care | Project        |       | NA                               | sysd@nnhf.org      | Improve the community through capacity building  
Identify new patients with bleeding disorders through awareness raising activities  
Improve access to care in the regions through advocacy activities in partnership with the provincial and national authorities  
Improve diagnosis rate and update national patient registry. | - Project partnership agreement was signed.  
- All project activities have been completed. Waiting for the final Audit report. | 2 years Q2 2017 |
| South and Central Asia | Sri Lanka - LK | Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community | Project        |       | NA                               | 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. | 3 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        |       | NA                               | sysd@nnhf.org      | Strengthen the rehabilitation care in the haematology Centre in Tashkent  
Start the rehabilitation care in 12 regions by training of HCPs. | - All project activities have been completed. | 1.5 years Q1 2016 |