

NNHF Programmes: selected updates on activities in Quarter 4 2015 (1 October – 31 December 2015)

Overview

Novo Nordisk Haemophilia Foundation Q4 2015 update	By end Q4 2015
Number of projects approved by NNHF Council since 2005 (new projects since last quarter)	122 (5)
Number of fundraised projects (new projects since last quarter)	11 (0)
Number of fellowships (new fellowships since last quarter)	68 (6)
Number of awards (new awards since last quarter)	12 (0)
HCPs trained since 2005	25,300
Patients and family members educated & patient leaders trained since 2005	28,300
People with haemophilia retested and newly diagnosed	18,800
NNHF engaged in number of countries	67

Regional updates

Region	Project	NNHF programme type	Phase	Activities this quarter	Upcoming activities	NNHF contact
Africa & Middle East	Egypt 2	Project	Execution Started: Q1 2016 Duration: 18 months	- Project partnership agreement was signed.	- Preparation of the project kick off	sysd@nnhf.org
	Jordan 3	Project	Execution Started: Q4 2014 Duration: 2 years	- 60 patients and families participated in an awareness meeting organised by the Jordan Hemophilia Society - The hardware required for creating the Arabic Haemophilia patient association website was purchased.	- Launch the Arabic haemophilia patient association website	sysd@nnhf.org
	Kenya 3	Project	Execution Started: Q1 2015 Duration: 2 years	- Opening of comprehensive care centre at Kenyatta National Hospital (KNH) in presence of KNH CEO - Outreach visit to Mombasa including HCP training and meeting with patients - Diagnosis of 10 new patients from Mombasa.	- Outreach visit to Garisa	sysd@nnhf.org
	Kenya 4	Fellowship	Formalisation To start: Q1 2016 Duration: 4 months	- Fellowship for a general doctor from Mombasa, Kenya to take place in Johannesburg, South Africa.	- Start training in May 2016	sysd@nnhf.org
	Kenya 5	Fellowship	Formalisation To start: Q1 2016 Duration: 3 months	- Fellowship for a Nurse from Mombasa, Kenya to take place in Johannesburg, South Africa.	- Start training in May 2016	sysd@nnhf.org
	Libya 1	Fellowship	Formalisation To start: Q1 2015 Duration: 1 month	- Fellowship for a lab technician from Benghazi, Libya, in Ampang Hospital, Malaysia began.	- The fellow is not able to travel. It will be presented in the next NNHF Council Meeting in March for cancelation	sysd@nnhf.org
	Mali	Project	Formalisation To start: Q1 2016 Duration: 2 years	This project was approved by the NNHF Council in the last meeting in December 2015 with the following objectives: - Establish haemophilia care in the regions by building HCPs capacity - Increase awareness about haemophilia among PwH and traditional circumcision - Advocate for better care for haemophilia patients.	- Signature of Project Partnership Agreement and project kick off	sysd@nnhf.org

	Malawi	Fellowship	Formalisation To start: Q1 2016 Duration: 2 months	- Fellowship for a haematologist from Lilongwe, Malawi, in Johannesburg, South Africa.	- Start training in May 2016	sysd@nnhf.org
	Mauritius	Project	Execution Started: Q3 2015 Duration: 2 years	- Partnership agreement was signed.	- Preparation of the project kick off	sysd@nnhf.org
	Nigeria 2	Project	Execution Started: Q1 2015 Duration: 2 years	- In collaboration with, Dr Fatai 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.	- Outreach to the regions	sysd@nnhf.org
	Pakistan 5	Project	Execution Started: Q4 2014 Duration: 2 years	- 18 stories, testimonials and portraits of PwH were collected for the Positive Diaries - Third Patient Camp was attended by 83 patients, family members from different part of Lahore-Punjab. The camp was designed in an interactive way including patients sensitisation, treatment literacy, motivational lecture, panel group discussion, physiotherapy session and networking exercise - Second awareness Seminar for 97 healthcare providers was organised at National Institute of Blood Disease [NIBD] in collaboration with PHPWS-Karachi Chapter. The Seminar focused on sensitising the future doctors and nurses about haemophilia and other bleeding disorders.	- Awareness Seminar for HCPs - Educational sessions for people with haemophilia and their family members	sysd@nnhf.org
	Palestine	Project	Execution Started: Q2 2014 Duration: 18 months	- The registry software was developed and data entry was started - 70 blood samples were collected and tested using the newly purchased coagulometer - Three educational sessions for PwH and their families were conducted in Ramallah, Nablus and Jenin and attended by 147 participants - Deputy minister of health formalised a committee including adult and paediatric haematologists clinical pharmacists, nurses and lab technicians to establish the treatment and diagnosis guidelines - The Lab in Ramallah was included in IEQAS program.	- Training of Haematologist at Tel Hashomer hospital	sysd@nnhf.org
	South Africa	Project	Execution	- All project activities have been completed.	- Final project report	sysd@nnhf.org

	3 – Eastern Cape		Started: Q2 2014 Duration: 2 years		to come	
	Sudan	Fellowship	Formalisation To start: Q1 2016 Duration: 2 months	- Fellowship for a physiotherapist from Khartoum, Sudan, in Cairo, Egypt planned for the duration of two months.	- Results to be presented in the upcoming NNHF Council Meeting in September 2016	sysd@nnhf.org
	Tanzania 1	Fellowship	Execution Started: Q3 2015 Duration: 3 months	- Fellowship for nurse from Moshi, Tanzania started in November 2015 in Vellore, India.	- Final fellowship report to come	sysd@nnhf.org
	Tanzania 2	Fellowship	Execution Started: Q3 2015 Duration: 3 months	- Fellowship for nurse from Moshi, Tanzania started in November 2015 in Vellore, India.	- Final fellowship report to come	sysd@nnhf.org
	Uganda	Fundraised project	Execution Started: Q3 2015 Duration: 6 months	- Established the first coagulation laboratory facilities in Uganda at Mulago hospital - Provided diagnosis and consultation to 49 newly diagnosed patients - Established a patient registry system and developed ID cards - Organised a patient education camp for patients from all regions attended by 140 participants - Launched a country-wide awareness campaign covered by 27 journalists.	- Organise advocacy activities with MOH and MPs - Media breakfast to create awareness	sysd@nnhf.org
	Uganda	Fellowship	Formalisation To start in Q1 2016 Duration: 3 months	- Fellowship for a haematologist from Kampala, Uganda to take place in Vellore, India.	- Start training in May 2016	sysd@nnhf.org

Region	Project	NNHF programme type	Phase	Activities this quarter	Upcoming activities	NNHF contact
Americas	Argentina 2, South Buenos Aires	Project	Formalisation To start: Q2 2016 Duration: 1.5 years	- This project was approved by the NNHF Council in the meeting in March 2015 with the following objectives: - 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.	- Signature of Project Partnership Agreement and project kick off	deni@nnhf.org
	Bolivia	Fundraised Project	Execution Started: Q2 2014	- The project has helped to sensitise the authorities to the needs in haemophilia care. The Ministry of Health collaborated with the project team to develop a television	- Final project report	deni@nnhf.org

			Duration: 1 year	<p>advert to raise awareness of haemophilia in order to identify more patients.</p> <ul style="list-style-type: none"> - Having the facilities in place to now offer quality diagnosis for these patients, the project team was able to collect accurate epidemiological data and present this to the Ministry of Health alongside their action plan for improving haemophilia care. - On 27 October 2015, the Ministry of Health invited project partner Victor and members of the haemophilia community to a press conference, where Bolivian President Evo Morales presented a bill stating that all people with haemophilia in Bolivia could access on-demand treatment. - To improve the diagnosis rate further, the Ministry of Health will equip a third lab and train healthcare professionals in Cochabamba. 		
	Brazil 2	Project	Execution Started: Q3 2011 Duration: 3 years	<ul style="list-style-type: none"> - Currently working in collaboration with IPSG, the group responsible for the HJHS score, to improve the software functionality and decide on the steps needed for validation. 	- Project will end in Q2 2016	axal@nnhf.org
	Brazil 3, Espirito Santo	Project	Execution Started: Q3 2013 Duration: 2 years	<ul style="list-style-type: none"> - Final project report received. 	- Project in closing phase	axal@nnhf.org
	Brazil 4, Para	Project	Execution Started: Q3 2015 Duration: 2.5 years	<ul style="list-style-type: none"> - A better practice exchange workshop was realised together with the project team from Espirito Santo. This allowed the team from Hemopa to learn about the methodology used for developing educational materials, preparing and delivering the trainings. 		axal@nnhf.org
	Central America, the Caribbean and Venezuela	Project	Execution Started: Q2 2014 Duration: 1.5 years, prolonged until Q2 2016	<ul style="list-style-type: none"> - Each of the participating countries (Venezuela, Panama, Costa Rica, El Salvador, Honduras, Nicaragua, Guatemala, Cuba and Dominican Republic) sent in a report describing the replication of the Leadership Workshop in their communities. - All activities planned in the project were finalised. 	<ul style="list-style-type: none"> - Final project report - Creation of project manual with hands-on tools to be used by the young leaders 	deni@nnhf.org
	Chile 4	Fellowship	Formalisation To start: Q3 2016 Duration: 1 month	<ul style="list-style-type: none"> - The NNHF Council approved the postponement of this fellowship for a nurse from Santiago, Chile to be trained in Campinas, Brazil. 	- Start training in August 2016	deni@nnhf.org
	Chile 2	Project	Execution Started: Q2 2014 Duration: 2 years	<ul style="list-style-type: none"> - Training of 7 teachers and sports teachers from schools attended by the paediatric population from the centre in Santiago. The topics of the training and the material distributed were: what is haemophilia, considerations at school, integration of the patient and physical education. - Training for healthcare professionals working in two 	<ul style="list-style-type: none"> - Training of more primary care centres - Training the team from a hospital in the South of Chile 	deni@nnhf.org

				primary care centres in Santiago. The training had a theoretical and a practical part, focussing on infusion.	in all aspects included in this project	
	Chile 5	Fellowship	Formalisation To start: Q4 2016 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in December 2015 for a haematologist from Santiago, Chile to be trained in Valencia, Spain.	- Prepare training	deni@nnhf.org
	Chile 6	Fellowship	Formalisation To start: Q3 2016 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in December 2015 for a social worker from Santiago, Chile to be trained in Campinas, Brazil.	- Prepare training	deni@nnhf.org
	Colombia 5	Fellowship	Formalisation To start: Q2 2016 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in September 2015 for a physiotherapist from Bogota, Colombia to be trained in Valencia, Spain.	- Start training in April 2016	deni@nnhf.org
	Cuba 2	Project	Formalisation To start: Q1 2016 Duration: 2 years	- The project with the Institute of Haematology and Immunology (IHI) from Havana was approved by the NNHF Council at the end of March 2013. The project will focus on decentralisation of care to the Eastern and Southern part of the country. It has been endorsed by the Cuban Ministry of Health and will start soon.	- Start of project activities in Q1 2016	deni@nnhf.org
	Guatemala	Project	Formalisation To start: Q1 2016 Duration: 2 years	- This project was approved by the NNHF Council in the meeting in September 2014 with the following objectives: - 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.	Signature of Project Partnership Agreement and project kick off	deni@nnhf.org
	Jamaica	Project	Execution Started: Q3 2014 Duration: 2 years	- Additional lab training by Angie Tuttle focussing on vWF testing for 3 technologists - Laboratory studies, joint evaluations and quality of life questionnaires have been applied on 18 patients.	- Create educational concept and organise training for patients and family members	deni@nnhf.org
	Mexico 2, Monterrey	Project	Execution Started: Q1 2014 Duration: 2 years	- Educational session on laboratory testing in haemophilia for patients and family members to better understand the various tests they undergo - Educational session on bleeding control for patients and their families focussing on the most frequent bleeding sites, how to treat them, first aid management, life-threatening bleedings, muscular bleedings, RICE and how to prevent accidents - Year-end meeting with patients, family members and the	- Finalisation of the registry - Project completion	deni@nnhf.org

				multidisciplinary care team to share thoughts and experiences to strengthen the relationship between the medical team and the patient community.		
	Mexico 3	Project	Execution Started: Q2 2015 Duration: 1.5 years	<ul style="list-style-type: none"> - There were internal meetings held in each participating hospital. - Planning of the HCP training is ongoing. 	- HCP training focussing on MSK	deni@nnhf.org
	Nicaragua	Project	Execution Started: Q1 2016 Duration: 2 years	<ul style="list-style-type: none"> - Project Partnership Agreement signed - Planning of first activities focussing on lab equipment and training of personnel. 	- Lab training and strengthening lab	deni@nnhf.org
	Panama 2	Fellowship	Formalisation To start: Q4 2016 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in March 2015 for a haematologist from Panama City, Panama to be trained in Santiago de Chile, Chile.	- Start training in April 2016	deni@nnhf.org
	Paraguay	Project	Execution Started: Q1 2016 Duration: 1.5 years	<ul style="list-style-type: none"> - Project Partnership Agreement signed - Planning of first activities focussing on lab equipment and training of personnel. 	- Lab training and strengthening lab	deni@nnhf.org
	Peru 2	Project	Formalisation To start: Q2 2016 Duration: 1 year	- In the process of signing the Project Partnership Agreement.	- Kick off project	deni@nnhf.org

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Asia	China 3	Project	Execution Started: Q2 2012, extended to Q4 2015	<ul style="list-style-type: none"> - Coagulation factors testing standardization training course: took place in November 2015, it was jointly organized by Shanghai Ruijin Hospital and the Clinical Laboratory Centre of the Ministry of Health. A total of 189 laboratory staff and doctors from departments of clinical laboratory and haematology attended the course. The training including theoretical and practical sessions, offered an opportunity to all the participants to learn about the clinical diagnosis and laboratory examination of both bleeding and thrombosis disorders. The participants also raised the problems they encountered during routine work, and discussed them establishing an exchange network. - Project sum-up meeting: the meeting was held in Taiyuan, Shanxi Province. A total of 20 project team members from sixteen hemophilia centres that form the HTCCN attended. After a brief welcoming ceremony, all the representatives began to introduce their work and activities undertaken for hemophilia since 2011. This included: hemophilia care, patient registration, how to conduct patient education, 	Project in closing phase	axal@nnhf.org

				standardized treatment and care, the difficulties that existed in the present work and the problems needed to be addressed. One representative from Guangzhou Nanfang Hospital introduced the establishment of a mobile phone chat with patients, which answers their questions and provides them with assistance effectively and efficiently. Director Xiaojing Li from Chengdu Women and Children's Hospital described how to better provide reasonable health insurance policy. Each representative shared their own work experience, and also proposed problems needed to be solved in follow-up projects with NNHF.		
	China 4, Shandong	Project	Execution Started: Q3 2014 Duration: 2,5 years	<ul style="list-style-type: none"> - 69 new patients were diagnosed and registered. - Training session on how to use Colour Doppler Ultrasound to detects joint damage and bleeding in haemophilic arthropathy using the scoring method for Haemophilia Early Arthropathy Detection with Ultrasound (HEAD-US) - First round of follow up visits has started with the visit to Heze City haemophilia centre. 		axal@nnhf.org
	China 5, Jiangsu	Project	Formalisation To start: Q1 2016 Duration: 3 years	<ul style="list-style-type: none"> - Project partnership agreement sent for signature. 	-	axal@nnhf.org
	China 6, Sichuan	Project	Formalisation To start: Q1 2016 Duration: 3 years	<ul style="list-style-type: none"> - Project partnership agreement sent for signature. 	-	axal@nnhf.org
	Cambodia	Project	Execution Started: Q1 2012 Duration: 3 years	<ul style="list-style-type: none"> - Medical education and coagulation workshop have been conducted in Siem Reap. 	<ul style="list-style-type: none"> - Regional trainings to be completed - Awaiting approval of national diagnosis and treatment guidelines 	axal@nnhf.org
	India 2, Manipal	Project	Execution Started: Q1 2012 extended to Q4 2015 Duration: 3 years	<ul style="list-style-type: none"> - 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. More information will be published at the NNHF website. 	<ul style="list-style-type: none"> - Waiting for final project and audit reports 	axal@nnhf.org
	India 3, Delhi	Project	Execution Started: Q3 2012 Duration: 2 years	<ul style="list-style-type: none"> - Patient and family self-help group meeting addressed individual doubts and questions patients have besides infusion: physiotherapy sessions should be boosted, as they believed that the number of recurrent bleeds were less as compared when the patients followed a less active or sedentary lifestyle. It was found that, in each session a reason of major anxiety among the patients and their 	<ul style="list-style-type: none"> - Project to be extended until Q4 2016 	axal@nnhf.org

				family members were related to the genetic transferability of the condition in their next generation, on which Dr. Sandeep presented a detailed explanation on the inheritance pattern and the role of carriers in transmission.		
	India 6, Northeast	Project	Execution Started: Q4 2014 Duration: 2 years	<ul style="list-style-type: none"> - Team from CMCH, Vellore will deliver one refresher lab technician training in Manipur. - PEP (parents empowering parents) train the trainer workshop for the North Region has conducted in Jaipur from 4 to 6 Dec 2015. This was the last workshop of a series of four workshops planned as part of this project. A complete report will be made available at the NNHF website. 	- Waiting for final project and audit reports	axal@nnhf.org
	India 7	Project	Execution Started: Q4 2015 Duration: 3 years	<ul style="list-style-type: none"> - The Project was submitted to the Fernandez Hospital, IRB as an independent project in September, 2015. It was approved by their Scientific Committee first online and then presented to and approved by the Ethics Committee on December 7, 2015. - An online survey of current practices in physiotherapy will be undertaken simultaneously. Alternately, surveys on current physiotherapy practice will be carried out at the Workshops for training on using the online MSK Registry as well. 	- Examine the Registry and organise 4 regional workshops in Hyderabad, Surat, Lucknow and Kolkatta to train physiotherapists in use of the Registry	axal@nnhf.org
	Indonesia	Project	Execution Started: Q1 2013 Extended to Q1 2016	<ul style="list-style-type: none"> - NNHF Project closing meeting was held in Sahid Hotel Jakarta. - Semarang, Surabaya, Banjarmasin and Samarinda will be included for the next project with NNHF which is being planned by the team. - 400 leaflets (haemophilia and inhibitor), 100 haemophilia in picture books, and 200 posters (haemophilia and inhibitor) were printed. 	- Waiting for final project and audit report	axal@nnhf.org
	Malaysia 3	Project	Formalisation To start: Q1 2015 Duration: 3 years	- Women leadership training planned for 12 to 14 March 2016. The programme will include medical aspects of bleeding disorders, psychosocial support, leadership and media training.	- to create a leadership manual for the Women's group in Malaysia	axal@nnhf.org
	Myanmar	Project	Execution Started: Q4 2013 Duration: 18 months	- Patient association registration is still ongoing.		axal@nnhf.org
	Nepal	Project	Formalisation To start: Q1 2015 Duration: 6 months	- Medical training activity planned in collaboration with the Mary Gooley Care Center (Rochester, NY) has been postponed to later this year.		axal@nnhf.org

	Philippines	Project	Execution Started: Q3 2012 Duration: 3 years	<ul style="list-style-type: none"> - 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. 	- Waiting for Institutional Review Board approval of the registry	axal@nnhf.org
	Vietnam 2	Project	Execution Started: Q2 2013 Duration: 3 years	<ul style="list-style-type: none"> - 33 new patients were diagnosed this quarter, total of 86 new patients through this project. - One summer camp for 60 patients and families in the South of Vietnam on 5th December, 2015. Activities included an update in the knowledge about the disease, how to care for hemophilia, training about functional rehabilitation and self-infusion. - Organised the third meeting of the national haemophilia committee, including the Executive Boards of Vietnam Hemophilia Association, Vietnam Hemophilia Association Officers and keys doctors to summarize the activities in 2015 and propose working plan for 2016. - Meeting on 2nd December, 2015 with delegates of the World Federation of Hemophilia, Irish Hemophilia Society, National Institute of Hematology and Blood Transfusion, Executive Boards of Vietnam Hemophilia Association to discuss the Global Alliance for Progress (GAP) program. - Created and published 2 publications about hemophilia: Information for the carrier (2,000 books) and information about von Willebrand (1,000 books). 	-	axal@nnhf.org
	Thailand	Project	Execution Started: Q4 2013 Duration: 1 year	<ul style="list-style-type: none"> - IHTC Training in Suphanburi - Training for district hospital HCPs in Nakorn Si Thammarat. 	- Waiting for final project report	axal@nnhf.org

Region	Project	NNHF programme type	Phase	Activities this quarter	Upcoming activities	NNHF contact
Europe & Caucasus	Armenia	Project	Execution Started: Q4 2014 Duration: 2 years	<ul style="list-style-type: none"> - Dr Heghine Khachatryan was trained at "Sapienza" University, Rome. Upon her return, she organised a HCP training on 18 December. - Lab equipment purchased to improve diagnosis facilities - Tanya Khachatryan, President of Armenian Association of Hemophilia and Tsaghik Vardanyan, Head of Department of Health Care Policy of Ministry of Health had a meeting with 30 haemophilia patients and their family members to discuss the challenges facing PwH. 	<ul style="list-style-type: none"> - 4 week training for a physiotherapist will take place in Lithuania 	sysd@nnhf.org
	Georgia	Project	Execution Started: Q1 2013 Duration: 2 years	<ul style="list-style-type: none"> - All project activities have been completed. 	<ul style="list-style-type: none"> - Final project report to come 	sysd@nnhf.org
	Serbia 2	Project	Execution Started: Q1 2015 Duration: 2 years	<ul style="list-style-type: none"> - The psychosocial rehabilitation camp for adults was postponed to January 22 -24 2016. 	<ul style="list-style-type: none"> - Educators training camp 	axal@nnhf.org
	Uzbekistan	Project	Execution Started: Q1 2016 Duration: 18 months	<ul style="list-style-type: none"> - Project partnership agreement was signed. 	<ul style="list-style-type: none"> - Preparation of the project kick off 	sysd@nnhf.org