

NNHF Programmes: selected updates on activities in Quarter 3 2015 (1 July – 30 September 2015)

Overview

Novo Nordisk Haemophilia Foundation Q3 2015 update	By end Q3 2015
Number of projects since 2005 (new projects since last quarter)	116 (2)
Number of fundraised projects (new projects since last quarter)	9 (0)
Number of fellowships (new fellowships since last quarter)	62 (3)
Number of awards (new awards since last quarter)	12 (0)
HCPs trained since 2005	24,000
Patients and family members educated & patient leaders trained since 2005	26,300
People with haemophilia retested and newly diagnosed	18,570
NNHF engaged in number of countries	66

Regional updates

Region	Project	NNHF programme type	Phase	Activities this quarter	Upcoming activities	NNHF contact
Africa & Middle East	Egypt	Project	Execution Started: Q1 2013 Duration: 3 years	- The order for purchasing the equipment for four physiotherapy clinics was made. The expected delivery time is on August.	- Close the project	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 website was purchased.	- Educational material will be prepared	sysd@nnhf.org
	Kenya 3	Project	Formalisation Started: Q1 2015 Duration: 2 years	- The work in establishing the comprehensive care centre at KNH were finished it is planned to open the centre on September.	- Planning for opening ceremony for Comprehensive Care Centre - HCPs training in Mombasa	sysd@nnhf.org
	Kenya 2	Fellowship	Formalisation To start: Q2 2015 Duration: 6 month	- Fellowship for a haematologist from Eldoret, Kenya, started in Johannesburg, South Africa in April	- Results to be presented in the upcoming NNHF Council meeting in September 2015	sysd@nnhf.org
	Kenya 3	Fellowship	Formalisation To start: Q1 2015 Duration: 2 month	- Fellowship for a physiotherapist from Kenyatta, Kenya, in Johannesburg, South Africa for two months finished on April	- Results to be presented in the upcoming NNHF Council meeting in September 2015	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	- Results to be presented in the upcoming NNHF Council meeting in September 2015	sysd@nnhf.org
	Libya 2	Fellowship	Formalisation To start: Q1 2015 Duration: 6 month	- Fellowship for a haematologist from Benghazi, Libya, began in Ampang Hospital, Malaysia for three months finished on April	- Results to be presented in the upcoming NNHF Council meeting in September 2015	sysd@nnhf.org

	Mali	Fellowship	Formalisation To start: Q1 2015 Duration: 2 month	- Fellowship for a nurse from Bamako, Mali, finished on May at Montpellier, France	- Results to be presented in the upcoming NNHF Council meeting in September 2015	sysd@nnhf.org
	Mauritius	Project	Formalisation To start: Q3 2015 Duration: 2 years	- Partnership agreement was signed	- Preparation of the project kick off	sysd@nnhf.org
	Nigeria 2	Project	Formalisation Started: Q1 2015 Duration: 2 years	- Partnership agreement was signed	- Signature of Project Partnership Agreement and project kick off	sysd@nnhf.org
	Pakistan 5	Project	Execution Started: Q4 2014 Duration: 2 years	- The second Patient Camp was successfully organised. It was participated by 44 patients and 32 family members from different part of Karachi-Sindh - The association website was developed and it is in the testing phase.	- Additional leadership training for Youth Group - Awareness Seminar for HCPs - Educational sessions for People with Haemophilia and their family members - Provincial Visits	sysd@nnhf.org
	Palestine	Project	Execution Started: Q2 2014 Duration: 18 months	- The educational materials for the following trainings were designed - Hardware required for the registry was purchased.	- Organise patient education sessions - Start establishing the national registry	sysd@nnhf.org
	South Africa 3 – Eastern Cape	Project	Execution Started: Q2 2014 Duration: 2 years	- Workshop conducted for Pharmacist and Pharmacist Assistants at the Port Elizabeth Provincial Hospital - raining for medical officers conducted at the Dora Nginza Hospital - Youth camp was organised at Cintasa - Outreach visits organised to the community in Cala - Meeting with department of health in Queenstown to NNHF initiative and plan activities in the region - Awareness training for nurses organised in Cradock.	- Planning for additional training other EMS personnel - Training for laboratory staff planned - Additional training for registry software planned for Q3 2015 - Team members will prepare training session material	sysd@nnhf.org

	Sudan	Fellowship	Formalisation To start: Q1 2015 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 2015	sysd@nnhf.org
	Tanzania 1	Fellowship	Formalisation To start in Q3 2015 Duration: 3 months	- Fellowship for nurse from Moshi, Tanzania to take place in Vellore, India	- Start training in May 2015	sysd@nnhf.org
	Tanzania 2	Fellowship	Formalisation To start in Q3 2015 Duration: 3 months	- Fellowship for nurse from Moshi, Tanzania to take place in Vellore, India	- Start training in May 2015	sysd@nnhf.org

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Americas	Argentina 2, South Buenos Aires	Project	Formalisation To start: Q4 2015 Duration: 1.5 years	- This project was approved by the NNHF Council in the last meeting in March 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 Duration: 1 year	- The awareness spot has been created in collaboration with representatives from the Ministry of Health - About 100 patients have been diagnosed and will be provided with an ID-card soon	- To show the awareness campaign on the national TV - ID-cards for patients	deni@nnhf.org
	Brazil 2	Project	Execution Started: Q3 2011 Duration: 3 years	- Two trainings focusing on how to perform the FISH, HJHS, HAL AND Ped HAL are taking place in Campinas for Physiotherapists from others states	- Project will end in Q4 2015	axal@nnhf.org
	Brazil 3	Project	Execution Started: Q3 2013 Duration: 2 years	- All project activities have been completed	- Waiting for project final report	axal@nnhf.org
	Central America, the Caribbean and Venezuela	Project	Execution Started: Q2 2014 Duration: 1.5 years	- Back from the regional leadership workshop in the Dominican Republic all seven participated countries were doing a replication training in their own country	- Write final project report - Results to be presented at the next Council	deni@nnhf.org

					meeting	
	Chile 4	Fellowship	Formalisation To start: Q3 2016 Duration: 1 month	- The NNHF Council approved the postponement of this fellowship at the last meeting in September 2015 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	- Due to previous strikes of teachers and priority being shifted it has been agreed that instead of visiting each school separately there will be a bigger education session at the hospital according to the train-the-trainer concept. - An estimated date for the training of the other centres has been defined	- Educational session for schools - Leadership training	deni@nnhf.org
	Colombia 4	Fellowship	Execution Started: Q3 2015 Duration: 2 month	- A physician from Bogota, Colombia went for specialised training in care of paediatric haemostasis disorders to Oxford, UK.	- Results to be presented at the next Council meeting	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: Q4 2015 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 is still in the endorsement process by the Ministry of Health.	- Start of project activities in Q4/2015	deni@nnhf.org
	Ecuador 1	Fellowship	Closing Started: Q3 2015 Duration: 1 month	- Fellow went for training in optimisation of medical knowledge in haemophilia care to Campinas, Brazil for one month.	- Results to be presented at the next Council meeting	deni@nnhf.org
	Ecuador 2	Fellowship	Closing Started: Q3 2015 Duration: 1 month	- To get training in dental care in haemophilia the fellow went to Campinas, Brazil in September 2015.	- Results to be presented at the next Council meeting	deni@nnhf.org
	Guatemala	Project	Formalisation To start: Q4 2015 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 Project Partnership Agreement will be signed soon.	Signature of Project Partnership Agreement and project kick off	deni@nnhf.org

	Jamaica	Project	Execution Started: Q3 2014 Duration: 2 years	<ul style="list-style-type: none"> - Contact information from 85 patients have been validated - A site visit to the Bustamante Hospital for Children and the University Hospital was done - A pilot test was done to set up the registry 	<ul style="list-style-type: none"> - Continue to contact other hospitals to get a complete patient list - Create educational concept 	deni@nnhf.org
	Mexico 2, Monterrey	Project	Execution Started: Q1 2014 Duration: 2 years	<ul style="list-style-type: none"> - This year's summer camp was held in June and attended by 70 participants (48 patients and relatives; rest: medical students, nurses, haematologists, fellows etc.) - From 30 July to 1 August Laura and her team were presented with a booth at the national haemophilia meeting 2015. - It has been agreed on which data will be collected and included in the patient registry 	<ul style="list-style-type: none"> - implement registry in hospital - Educational sessions in patients' school 	deni@nnhf.org
	Mexico 3	Project	Execution Started: Q2 2015 Duration: 1.5 years	<ul style="list-style-type: none"> - There were internal meetings held in each hospital separately - Dr Felipe Querol has been contacted to conduct part of the HCP training in Q1 2016 	<ul style="list-style-type: none"> - Preparation for the HCP training 	deni@nnhf.org
	Nicaragua	Project	Formalisation To start: Q4 2015 Duration: 2 years	<ul style="list-style-type: none"> - This project was approved by the NNHF Council in the December 2014 meeting with the following objectives: - Improve coagulation laboratory to define the epidemiological picture of haemophilia - Promote and improve comprehensive care through creation of national treatment guidelines and training - Educate patients and families on haemophilia - Strengthen the haemophilia care centre and the patient association. 	<ul style="list-style-type: none"> - Signature of Project Partnership Agreement and project kick off 	deni@nnhf.org
	Panama 1	Fellowship	Closing Started: Q3 2015 Duration: 1 month	<ul style="list-style-type: none"> - Fellow went for training in strengthening of comprehensive social work with people with haemophilia and their families for a month to Campinas, Brazil. 	<ul style="list-style-type: none"> - Results to be presented at the next Council meeting 	deni@nnhf.org
	Panama 2	Fellowship	Formalisation To start: Q4 2015 Duration: 1 month	<ul style="list-style-type: none"> - 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. 	<ul style="list-style-type: none"> - Start training in November 2015 	deni@nnhf.org
	Paraguay	Project	Formalisation To start: Q4 2015 Duration: 1.5 years	<ul style="list-style-type: none"> - This project was approved by the NNHF Council in the last meeting in December with the following objectives: - Strengthen care offered to patients with haemophilia through training - Set up a coagulation laboratory at the Hospital de Clínicas de San Lorenzo and train the staff to achieve quality diagnosis - Execute a nationwide census to diagnose and register patients - Empower patients and families through education. 	<ul style="list-style-type: none"> - Signature of Project Partnership Agreement and project kick off 	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"> - NEQAS team from Sheffield is providing guidance to update the national diagnosis guidelines - Last NEQAs sample produced by the team will be shipped in November. 	Project closing meeting on December in Beijing	axal@nnhf.org
	China 4	Project	Execution Started: Q3 2014 Duration: 2,5 years	<ul style="list-style-type: none"> - Training sessions of HCP Education in Linyi: 39 doctors, 12 nurses, 18 lab techs from four centres participated. A total of 49 patients and 34 patient family members also attended education sessions. 		axal@nnhf.org
	Cambodia	Project	Execution Started: Q1 2012 Duration: 3 years	<ul style="list-style-type: none"> - Mrs Robyn Devenish has been working with Dr Chean Sophal to develop the training program and organize with the Provincial hospital clinicians and lab staff for the best dates for the regional trainings - The patient association has conducted two workshops, one in Siem Reap and one in Phnom Penh. 	<ul style="list-style-type: none"> - Regional trainings to start 	axal@nnhf.org
	India 2	Project	Execution Started: Q1 2012 extended to Q4 2015 Duration: 3 years	<ul style="list-style-type: none"> - The training of ASHA workers progressed in the districts of Dakshina Kannada. - Number of ASHA trained in this quarter in Sullia & Belthangadi taluk were 77 & 180 respectively. All ASHA's of Sullia & Belthangadi districts are trained. - 257 pamphlets with survey records were distributed. 	<ul style="list-style-type: none"> - Collection of data of ASHA's from the districts and processing - Preparation of educative material, poster & pamphlet to create awareness among general public, primary health centers and district hospitals 	axal@nnhf.org
	India 3	Project	Execution Started: Q3 2012 Duration: 2 years	<ul style="list-style-type: none"> - Release of "Self-infusion brochure" and start of "Self-infusion programme for young achievers" - 588 people participated at the WHD event. Dr. Naresh Gupta highlighted the achievements of the Haemophilia Centre at MAMC & LN Hospital during the past year, and the national level advocacy programmes undertaken for widening the haemophilia care services in the country. He also announced the launch of "ONE COUNTRY, ONE TREATMENT" - Dr Gupta stressed on the different activities and programmes being run in the Haemophilia Centre, be it the comprehensive care, or focused projects on haemophilia awareness and training programmes (HATS), diagnostics, carrier screening, capacity building and most importantly the patient empowerment through regular patient meets, self-help groups for haemophilia, and their active involvement in decision on newer haemophilia care initiatives. 		axal@nnhf.org

	India 4	Project	Execution Started: Q3 2013	- Final report received.	-	axal@nnhf.org
	India 5	Project	Execution Started: Q1 2014 Duration: 18 months	- Waiting for final report.	-	axal@nnhf.org
	India 6	Project	Execution Started: Q4 2014 Duration: 2 years	- Team from CMCH, Vellore will deliver one refresher lab technician training in Manipur.	- PEP train the trainer workshop for the North Region. will be conducted in Jaipur from 4 to 6 Dec 2015	axal@nnhf.org
	Indonesia	Project	Execution Started: Q1 2013 Extended to Q1 2016	- NMO Training was attended by 2 representatives from 16 chapters of the Indonesian Hemophilia Society (IHS). This activity aimed to strengthen the organization, sharing about lobbying government, making a good strategic planning, recruiting volunteers, and establishing cooperation with stakeholders.	- Training of Trainers in Yogyakarta and two satellite cities of Purwokerto and Surakarta	axal@nnhf.org
	Malaysia	Project	Formalisation To start: Q1 2015 Duration: 3 years	- Waiting for project partnership agreement signature.		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	- Train of trainer in advocacy took place from 19 to 22 June. Twenty five participants were the chapter representatives from five local district chapters i.e. Sunsari, Parsa, Chitwan, Bhaktapur and Chitwan.		axal@nnhf.org
	Philippines	Project	Execution Started: Q3 2012 Duration: 3 years	- Provision of 1 computer to the Department of Paediatric Haematology-Oncology Unit of the Univ. of the Philippines-Philippine General Hospital. Computer unit was received by Dr. Anna Patricia A. Alcasabas, Consultant - Paediatric Hematologist-Oncologist.	- Last project activity to take place in November	axal@nnhf.org
	Vietnam 2	Project	Execution Started: Q2 2013	- On April 11st, Vietnam Hemophilia Association has celebrated the world hemophilia day and held a patients conference at National Institute of Haematology and Blood	-	axal@nnhf.org

			Duration: 3 years	<p>Transfusion. The celebration received the attention and participation of the Ministry of Health, artists, sponsors, journalists and over 400 patients and patient's families</p> <ul style="list-style-type: none"> - On April 16th the Centre of Haematology and Blood Transfusion (Hue Centre Hospital) organized the conference of patients and patient's families to celebrate world hemophilia day. At the conference, there was about 100 patients and families. The conference covered: propagation and dissemination of knowledge about hemophilia, activities of the Vietnam Hemophilia Association in the Middle of Vietnam, dissemination of common rights and obligations of members, and encourage patients and their families to take part in the Vietnam Hemophilia Association. In this conference, the Advocacy Committee for the Middle Vietnam branch was established. Information about the conference was broadcasted on VTV Hue newsletter at 6:30 am, April 17th - On May 15th, in Can Tho City, Vietnam Hemophilia Association (V.H.A) in collaboration with the National Institute of Haematology and Blood Transfusion and Can Tho General Hospital organized a workshop on hemophilia and officially announced the establishment of the South-west region Branch of V.H.A. 		
	Thailand	Project	Execution Started: Q4 2013 Duration: 1 year	<ul style="list-style-type: none"> - Project results are being compiled 	<ul style="list-style-type: none"> - IHTC Training in Suphanburi - Training for district hospital HCPs in Nakorn Si Thammarat or Krabi 	axal@nnhf.org

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Europe & Caucasus	Armenia	Project	Execution Started: Q4 2014 Duration: 2 years	<ul style="list-style-type: none"> - Purchased the computers and the server for the web based registry - Works related to development of software for a web based registry and a haemophilia website were started - Purchasing lab equipment including Coagulometer and Agregometer. It is expected to receive the equipment at the centre on July. 	<ul style="list-style-type: none"> - Training of HCPs abroad - Further develop the national haemophilia registry 	sysd@nnhf.org
	Georgia	Project	Execution Started: Q1 2013 Duration: 2 years	<ul style="list-style-type: none"> - A workshop for families and their families were executed in Tbilisi - One home visit for a patients from Racha in west region of Georgia - Home visits for 4 patients were organized in Kvemo Kartli, east region of Georgia. 	<ul style="list-style-type: none"> - Continue patients home visits 	sysd@nnhf.org
	Serbia 2	Project	Execution Started: Q1 2015 Duration: 2 years	<ul style="list-style-type: none"> - From 14 to 16 of May, the first of the psychosocial workshops took place in city of Nis. A group of 19 adolescents and young adults living in different cities in Serbia had a chance to explore psychological meanings and impact of hemophilia on their personal and social life. Also, 7 adults from the Society were present during the workshops - The goals of the workshops were: raising awareness, understanding and normalization of personal feelings and experiences of adolescents in respect to their condition through exchange and sharing of experiences with the others; strengthening of the process of gaining independence in the care about their disorder and treatment; development of skills required for better integration in peer groups and school environment, strengthening of the positive concept of themselves and their bodies. 	<ul style="list-style-type: none"> - 	axal@nnhf.org