

## NNHF Programmes: selected updates on activities in Quarter 2 2015 (1 April – 31 June 2015)

### Overview

Novo Nordisk Haemophilia Foundation Q2 2015 update	By end Q2 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
<b>Africa &amp; Middle East</b>	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 - Training 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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<b>Americas</b>	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	- Meetings with the Ministry of Health representative to work on the awareness campaign - 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	- The regional leadership workshop was executed in June bringing together 8 countries from Central America, Caribbean and Venezuela	- Replication of training by new leaders in each country	deni@nnhf.org

	Chile 2	Fellowship	Formalisation To start: Q2 2015 Duration: 2 weeks	- Fellow went to Valencia for a two weeks training to get specialised in the use of ultrasonography diagnosis	- Results to be presented to the Council	deni@nnhf.org
	Chile 3	Fellowship	Formalisation To start: Q2 2015 Duration: 2 weeks	- Fellow went to Valencia for a two weeks training to get specialised in the use of ultrasonography diagnosis	- Results to be presented to the Council	deni@nnhf.org
	Chile 4	Fellowship	Formalisation To start: Q3 2015 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in March 2015 for a nurse from Santiago, Chile to be trained in Campinas, Brazil.	- Start training in September 2015	deni@nnhf.org
	Chile 2	Project	Execution Started: Q2 2014 Duration: 2 years	- A workshop on emotional aspects in the education of children was held for haemophilia patients and their parents. The workshop was attended by 10 parents and 7 children. - On World Haemophilia Day there was a little celebration	- School visits to be prepared	deni@nnhf.org
	Colombia 4	Fellowship	Formalisation To start: Q3 2015 Duration: 2 month	- This fellowship was approved by the NNHF Council in the meeting in December 2014 for a physician from Bogota, Colombia to be trained in Oxford, UK.	- Start training in August 2015	deni@nnhf.org
	Costa Rica	Fellowship	Formalisation To start: Q2 2015 Duration: 1 month	- Fellow went to Campinas to get specialised training in multidisciplinary haemophilia care for a month	- Results to be presented to the Council	deni@nnhf.org
	Cuba 2	Project	Formalisation To start: Q4 2015 Duration: 2 years	The project with the Institute of Hematology 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	Formalisation To start: Q3 2015 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in March 2015 for a haematologist and paediatrician from Quito, Ecuador to be trained in Campinas, Brazil.	- Start training in September 2015	deni@nnhf.org
	Ecuador 2	Fellowship	Formalisation To start: Q3 2015 Duration: 1 month	- This fellowship was approved by the NNHF Council in the meeting in March 2015 for a dentist from Quito, Ecuador to be trained in Campinas, Brazil.	- Start training in September 2015	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	- Signature of Project Partnership Agreement and project kick off	deni@nnhf.org

				<ul style="list-style-type: none"> <li>PwH</li> <li>Educate patients and their families by the multidisciplinary care team</li> <li>Create a national technical committee for haemophilia and institutionalise it</li> <li>Create national haemophilia treatment guidelines</li> <li>Project Partnership Agreement will be signed soon.</li> </ul>		
	Jamaica	Project	<p>Execution Started: Q3 2014 Duration: 2 years</p>	<ul style="list-style-type: none"> <li>Collecting of blood samples has been stopped for the moment as they are still not able to do all the test</li> <li>Database for the registry is being developed with definitions</li> <li>Two hospitals have been contacted to gather all patient information in one file.</li> </ul>	<ul style="list-style-type: none"> <li>Continue to contact other hospitals to get a complete patient list</li> <li>Create educational concept</li> </ul>	deni@nnhf.org
	Mexico 2, Monterrey	Project	<p>Execution Started: Q1 2014 Duration: 2 years</p>	<ul style="list-style-type: none"> <li>WHD activities: <ul style="list-style-type: none"> <li>A symposium was held for HCPs and attended by 180 participants</li> <li>In a workshop kids were using LEGO bricks to express their feelings about their life</li> <li>A ceremony and a blood donation campaign was done at the medicine school</li> </ul> </li> <li>A psychologist was trained in Mexico City and a haematologist went for a training to Houston.</li> </ul>	<ul style="list-style-type: none"> <li>Educational sessions at patient's school</li> <li>Create a registry and implement it in hospitals</li> </ul>	deni@nnhf.org
	Mexico 3	Project	<p>Formalisation To start: Q2 2015 Duration: 1.5 years</p>	<ul style="list-style-type: none"> <li>A kick-off meeting with all three centres was held to start the project</li> <li>On the first Friday of each month there will be a general talk about haemophilia for patients and their family</li> </ul>	<ul style="list-style-type: none"> <li>Preparation for the HCP training</li> </ul>	deni@nnhf.org
	Nicaragua	Project	<p>Formalisation To start: Q4 2015 Duration: 2 years</p>	<ul style="list-style-type: none"> <li>This project was approved by the NNHF Council in the last meeting in December with the following objectives: <ul style="list-style-type: none"> <li>Improve coagulation laboratory to define the epidemiological picture of haemophilia</li> <li>Promote and improve comprehensive care through creation of national treatment guidelines and training</li> <li>Educate patients and families on haemophilia</li> <li>Strengthen the haemophilia care centre and the patient association.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Signature of Project Partnership Agreement and project kick off</li> </ul>	deni@nnhf.org
	Panama 1	Fellowship	<p>Formalisation To start: Q3 2015 Duration: 1 month</p>	<ul style="list-style-type: none"> <li>This fellowship was approved by the NNHF Council in the meeting in March 2015 for a social worker from Panama City, Panama to be trained in Campinas, Brazil.</li> </ul>	<ul style="list-style-type: none"> <li>Start training in September 2015</li> </ul>	deni@nnhf.org
	Panama 2	Fellowship	<p>Formalisation To start: Q4 2015 Duration: 1 month</p>	<ul style="list-style-type: none"> <li>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.</li> </ul>	<ul style="list-style-type: none"> <li>Start training in November 2015</li> </ul>	deni@nnhf.org
	Paraguay	Project	<p>Formalisation To start: Q4 2015 Duration: 1.5</p>	<ul style="list-style-type: none"> <li>This project was approved by the NNHF Council in the last meeting in December with the following objectives: <ul style="list-style-type: none"> <li>Strengthen care offered to patients with haemophilia through training</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Signature of Project Partnership Agreement and project kick off</li> </ul>	deni@nnhf.org

			years	<ul style="list-style-type: none"> <li>- Set up a coagulation laboratory at the Hospital de Clínicas de San Lorenzo and train the staff to achieve quality diagnosis</li> <li>- Execute a nationwide census to diagnose and register patients</li> <li>- Empower patients and families through education.</li> </ul>		
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Asia	China 3	Project	Execution Started: Q2 2012, extended to Q4 2015	<ul style="list-style-type: none"> <li>- NEQAS team from Sheffield is providing guidance to update the national diagnosis guidelines</li> <li>- Last NEQAs sample produced by the team will be shipped in November.</li> </ul>	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"> <li>- 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.</li> </ul>		axal@nnhf.org
	Cambodia	Project	Execution Started: Q1 2012 Duration: 3 years	<ul style="list-style-type: none"> <li>- 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</li> <li>- The patient association has conducted two workshops, one in Siem Reap and one in Phnom Penh.</li> </ul>	<ul style="list-style-type: none"> <li>- Regional trainings to start</li> </ul>	axal@nnhf.org
	India 2	Project	Execution Started: Q1 2012 extended to Q4 2015 Duration: 3 years	<ul style="list-style-type: none"> <li>- The training of ASHA workers progressed in the districts of Dakshina Kannada.</li> <li>- Number of ASHA trained in this quarter in Sullia &amp; Belthangadi taluk were 77 &amp; 180 respectively. All ASHA's of Sullia &amp; Belthangadi districts are trained.</li> <li>- 257 pamphlets with survey records were distributed.</li> </ul>	<ul style="list-style-type: none"> <li>- Collection of data of ASHA's from the districts and processing</li> <li>- Preparation of educative material, poster &amp; pamphlet to create awareness among general public, primary health centers and district hospitals</li> </ul>	axal@nnhf.org
	India 3	Project	Execution Started: Q3 2012 Duration: 2 years	<ul style="list-style-type: none"> <li>- Release of "Self-infusion brochure" and start of "Self-infusion programme for young achievers"</li> <li>- 588 people participated at the WHD event. Dr. Naresh Gupta highlighted the achievements of the Haemophilia Centre at MAMC &amp; 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"</li> <li>- Dr Gupta stressed on the different activities and programmes being run in the Haemophilia Centre, be it the</li> </ul>		axal@nnhf.org

				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.		
	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	<ul style="list-style-type: none"> <li>- 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.</li> </ul>	<ul style="list-style-type: none"> <li>- Last project activity to take place in November</li> </ul>	axal@nnhf.org
	Vietnam 2	Project	Execution Started: Q2 2013 Duration: 3 years	<ul style="list-style-type: none"> <li>- On April 11st, Vietnam Hemophilia Association has celebrated the world hemophilia day and held a patients conference at National Institute of Haematology and Blood Transfusion. The celebration received the attention and participation of the Ministry of Health, artists, sponsors, journalists and over 400 patients and patient's families</li> <li>- On April 16<sup>th</sup> 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 17<sup>th</sup></li> <li>- 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.</li> </ul>	<ul style="list-style-type: none"> <li>-</li> </ul>	axal@nnhf.org
	Thailand	Project	Execution Started: Q4 2013 Duration: 1 year	<ul style="list-style-type: none"> <li>- Project results are being compiled</li> </ul>	<ul style="list-style-type: none"> <li>- IHTC Training in Suphanburi</li> <li>- Training for district hospital HCPs in Nakorn Si Thammarat or Krabi</li> </ul>	axal@nnhf.org

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Europe & Caucasus	Armenia	Project	Execution Started: Q4 2014 Duration: 2 years	<ul style="list-style-type: none"> <li>- Purchased the computers and the server for the web based registry</li> <li>- Works related to development of software for a web based registry and a haemophilia website were started</li> <li>- Purchasing lab equipment including Coagulometer and Agregometer. It is expected to receive the equipment at the centre on July.</li> </ul>	<ul style="list-style-type: none"> <li>- Training of HCPs abroad</li> <li>- Further develop the national haemophilia registry</li> </ul>	sysd@nnhf.org
	Georgia	Project	Execution Started: Q1 2013 Duration: 2 years	<ul style="list-style-type: none"> <li>- A workshop for families and their families were executed in Tbilisi</li> <li>- One home visit for a patients from Racha in west region of Georgia</li> <li>- Home visits for 4 patients were organized in Kvemo Kartli, east region of Georgia.</li> </ul>	<ul style="list-style-type: none"> <li>- Continue patients home visits</li> </ul>	sysd@nnhf.org
	Lithuania 2	Project	Execution Started: Q2 2013 Duration: 2 years	<ul style="list-style-type: none"> <li>- Follow up visit for training and joint evaluation was done to Ukraine (8 patients)</li> <li>- The final north Eastern Europe network meeting was held in Lithuania (7 countries attended).</li> </ul>	<ul style="list-style-type: none"> <li>- Results to be presented at the next Council meeting</li> </ul>	deni@nnhf.org
	Serbia 2	Project	Execution Started: Q1 2015 Duration: 2 years	<ul style="list-style-type: none"> <li>- 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</li> <li>- 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.</li> </ul>		axal@nnhf.org