### NNHF Programmes: selected updates on activities in the 2nd half year 2017 (1 July – 31 December 2017)

#### Overview

<table>
<thead>
<tr>
<th>Novo Nordisk Haemophilia Foundation H2 2017 update</th>
<th>By end H2 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of projects approved by NNHF Council since 2005 (new projects since last half year)</td>
<td>156 (8)</td>
</tr>
<tr>
<td>- Thereof number of fundraised projects (new projects since last half year)</td>
<td>14 (0)</td>
</tr>
<tr>
<td>Number of fellowships (new fellowships since last half year)</td>
<td>74 (0)</td>
</tr>
<tr>
<td>Number of awards (new awards since last half year)</td>
<td>16 (0)</td>
</tr>
<tr>
<td>HCPs trained since 2005</td>
<td>36'000</td>
</tr>
<tr>
<td>Patients and family members educated &amp; patient leaders trained since 2005</td>
<td>38'150</td>
</tr>
<tr>
<td>People with haemophilia retested and newly diagnosed since 2005</td>
<td>22'750</td>
</tr>
<tr>
<td>NNHF engaged in number of countries (new countries since last half year)</td>
<td>69 (1)</td>
</tr>
</tbody>
</table>
1.5 years

Q1 2016

ESH received the 2nd shock wave machine and Dr Adly Sabour started to treat the complicated haemophilia cases with deformative joints.- For better joint evaluation, ESH purchased ultrasound machine and physiotherapists were trained on using it.-... results achieved by using the shock wave to treat hemophilia patients, helping to correct the deformities of the large loss.

Project

Improve haemophilia care in Egypt by dissemination of care and improvement of haemophilia community

Objectives

- Improve haemostasis care by upgrading and determining the treatment guidelines
- Increase PwH quality of life by improving their self-care skills
- Raise awareness in the community about haemophilia.

Project mate

- Samson Hailemariam

Enhancement of capacity for Africa Asia

Project

Kenyan Hemophilia Association, Nairobi

Project

Hosey Management Res., Market Street

Train healthcare professionals in haemophilia

Create awareness campaign to identify new patients

Empower patients through awareness campaign and national patient education camp.

Project

- Kibet Shikuku

Project

Association Malienne de Lutte contre HD, Dakar

Create an electronic medical registry and complete the identified patient profiling

Empower patients through four awareness campaigns

Empower patients by creating awareness and developing the household

Project

- Megan Buckie Adediran

Project

South African Haemophilia Foundation

Empowering the haemophilia community through youth development and empowerment of health care providers

Project

- Emmanuel Seromba

Project

East Africa 1 - EA1

Enhance the health care for people with haemophilia in various health centres

Project

- Richard Nka

Project

Service d’Haemophilie de Kinshasa

Innovate and strengthen the medical care in Africa

Project

- Richard Nka

Project Closing

Strengthen the patient association and organizational awareness campaign and advocacy

Objectives

- Improve the diagnostic facilities and blood bank capacity
- Create awareness by organising two WHD celebrations
- Improve physiotherapy care in both KNH and MoI.

Project

- Organised a leadership programme for 15 youth in Cape Town. Participants were selected from various regions around South Africa.
- Drafted requirements, specification and functions for the national online registry. So far, phase 1 developed which includes 70% of the needed functionality.
- 10 key opinion leader doctors from the CCCs across South Africa had a meeting in Johannesburg.
- An international consensus meeting was held in Durban.
- The SHF collaborative approach was highly appreciated.

Project

- Emmanuel Seromba
<table>
<thead>
<tr>
<th>Region</th>
<th>Programme title</th>
<th>Project Execution</th>
<th>Project objective</th>
<th>Status</th>
<th>Date</th>
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</thead>
<tbody>
<tr>
<td>Africa</td>
<td>NNHF half yearly programmes update - H2, 2017</td>
<td>Increase public awareness about haemophilia and PTH through workshops in Kenya, Nairobi and Uganda regions to identify new haemophilia patients and encourage patients knowing about haemophilia to seek better care for haemophilia patients.</td>
<td>Active</td>
<td>2017-06-29</td>
<td></td>
</tr>
<tr>
<td>Africa</td>
<td>Uganda 2</td>
<td>Agnes Kibuale, executive secretary</td>
<td>Multisite leadership workshops were organised in Kabale, Mbarara, and Hoima regions to train health workers and health service providers in the Eastern, Northern and Central regions. Village health teams were equipped with the basic knowledge about haemophilia.</td>
<td>Active</td>
<td>2017-06-30</td>
</tr>
<tr>
<td>Africa</td>
<td>Malawi 2</td>
<td></td>
<td>Multisite leadership workshops were organised in Mzuzu, Lilongwe and Blantyre in this district. This district showed challenges and circumstances. Much progress was made in ensuring comprehensive and appropriate services in case of bleeding problems.</td>
<td>Active</td>
<td>2017-07-01</td>
</tr>
<tr>
<td>Asia</td>
<td>Thailand 2</td>
<td></td>
<td>The management team was successfully organised on the 15th December 2017 with the theme “Youth and Women through Awareness Seminar”. The camp empowered the youth and the patient support groups, intended to create a united advocacy voice. The following sessions were included in the camp:</td>
<td>Active</td>
<td>2017-05-15</td>
</tr>
<tr>
<td>Asia</td>
<td>Cambodia 5</td>
<td></td>
<td>Training workshops for rural health care workers were conducted to identify haemophilia patients. Participants trained to provide appropriate care for haemophilia patients.</td>
<td>Active</td>
<td>2017-08-31</td>
</tr>
</tbody>
</table>

**Organisational impacts**

- One press release was published with Daily Monitor newspaper. It covered the patient's camp and captured patients' stories.

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**Upcoming activities**

- Organise outreach programme by training community health workers, traditional and non-medical circumcisers.
- Improve self-care of people living with haemophilia through education.
- Establish first haemophilia treatment centre.

**Project Execution**

- smqy@nnhf.org

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**Project Evaluation**

- smqy@nnhf.org

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**Project Achievements**

- smqy@nnhf.org

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**Follow-up activities**

- smqy@nnhf.org

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**Project Progress**

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**Region** | **Programme title** | **Programme type** | **Phase** | **Partner** | **NNHF contact** | **Objectives** | **Status** | **Programme duration** | **Notes** |
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in Argentina 1</td>
<td>National Health Security Office (NHSO), IHTC Bangkok, Faculty of Medicine/Chiang Mai University and the Thai Haemophilia Patient Club, Bangkok</td>
<td>Hathaiwut Lamthean- Prof Ampaiwan Chuansumrit- Dr Rungrote Natesirinilkul- Mr Ekawat Suwantaroj</td>
<td>Improve care and access to comprehensive care for patients with haemophilia, strengthen the haemophilia network in Argentina and care offered by HCPs at the Haemophilia Clinic, General Hospital Set up basic care points in various villages of the State of Yucatan Empower patients and their families for better self-care.</td>
<td>Project approved even full grant</td>
<td>01/2018</td>
<td></td>
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in Nicaragua 2</td>
<td>Nicaraguan Association of Hemophilia</td>
<td>Dr Rene Berrios</td>
<td>Improve coagulation laboratory and train the staff to do diagnosis Outreach visits to patients outside of the city.</td>
<td>Project approved even full grant</td>
<td>Q2 2017</td>
<td></td>
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in Palestine 3</td>
<td>Princess Sumaya University for Technology</td>
<td>Dr Maria Sol Cruz</td>
<td>Establish comprehensive care of patients with Haemophilia in Palestine will provide information on haemophilia and allied bleeding disorders for various target groups.</td>
<td>Project approved even full grant</td>
<td>01/2018</td>
<td></td>
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in South America 4</td>
<td>Haemophilia Foundation of Salta</td>
<td>Dr Susana Garbiero</td>
<td>Establish comprehensive care of patients with Haemophilia in Salta Improve coagulation laboratory and train the staff to do diagnosis Outreach visits to patients outside of the city.</td>
<td>Project approved even full grant</td>
<td>01/2018</td>
<td></td>
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in Vietnam 5</td>
<td>Vietnamese Health Media Office (VHMO)</td>
<td>Baiba Ziemele</td>
<td>Improve care and access to comprehensive care for patients with haemophilia, strengthen the haemophilia network in Vietnam and care offered by HCPs at the Haemophilia Clinic, General Hospital Set up basic care points in various villages of the State of Yucatan Empower patients and their families for better self-care.</td>
<td>Project approved even full grant</td>
<td>01/2018</td>
<td></td>
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<tr>
<td>NNHF</td>
<td>Project Execution</td>
<td>2 years</td>
<td>Improving haemophilia care in Zimbabwe 6</td>
<td>Zimbabwe Haemophilia Society (ZHS)</td>
<td>Dr Eric Gutierrez</td>
<td>Improve care and access to comprehensive care for patients with haemophilia, strengthen the haemophilia network in Zimbabwe and care offered by HCPs at the Haemophilia Clinic, General Hospital Set up basic care points in various villages of the State of Yucatan Empower patients and their families for better self-care.</td>
<td>Project approved even full grant</td>
<td>01/2018</td>
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### Region: South America

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<tr>
<td><strong>H2, 2017</strong></td>
<td><strong>NNHF half yearly programmes update</strong></td>
<td><strong>Objective</strong></td>
<td><strong>Status</strong></td>
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<tr>
<td><strong>BR0</strong></td>
<td><strong>Building the national haemophilia centres in Brazil</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
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<tr>
<td><strong>H2, 2017</strong></td>
<td><strong>Training of health-care professionals and patient associations as strategies for sustainable diagnoses</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
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<tr>
<td><strong>BR1</strong></td>
<td><strong>Regional training for care professionals and patient associations in the Rio de Janeiro region</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
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<tr>
<td><strong>BR5</strong></td>
<td><strong>Training of haemostasis laboratories</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
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<td><strong>BR6</strong></td>
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<td><strong>BR7</strong></td>
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<td><strong>BR8</strong></td>
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<td><strong>Project</strong></td>
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<td><strong>BR9</strong></td>
<td><strong>South America</strong></td>
<td><strong>Project</strong></td>
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### Region: South and Central Asia

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<td><strong>Asia</strong></td>
<td><strong>Regional data</strong></td>
<td><strong>Objective</strong></td>
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<tr>
<td><strong>IN5</strong></td>
<td><strong>Training of health-care professionals and patient associations as strategies for sustainable diagnoses</strong></td>
<td><strong>Project</strong></td>
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<td><strong>IN6</strong></td>
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<td><strong>IN7</strong></td>
<td><strong>South and Central Asia</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
<td></td>
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<tr>
<td><strong>IN8</strong></td>
<td><strong>South and Central Asia</strong></td>
<td><strong>Project</strong></td>
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### Region: Europe

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<tr>
<td><strong>Europe</strong></td>
<td><strong>Building the national haemophilia centres in Europe</strong></td>
<td><strong>Objective</strong></td>
<td><strong>Status</strong></td>
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<tr>
<td><strong>Europe</strong></td>
<td><strong>Regional data</strong></td>
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<td><strong>Middle East</strong></td>
<td><strong>Regional training for care professionals and patient associations in the Rio de Janeiro region</strong></td>
<td><strong>Project</strong></td>
<td><strong>Execution</strong></td>
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<tr>
<td><strong>Middle East</strong></td>
<td><strong>South America</strong></td>
<td><strong>Project</strong></td>
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<tr>
<td>South and Central Asia</td>
<td>Pakistan 6-PK6</td>
<td>Building partnerships to create awareness and improve care</td>
<td>Project</td>
<td>Pakistan Hemophilia Patients Welfare Society, President Hassan Raza, President</td>
</tr>
<tr>
<td>South and Central Asia</td>
<td>Sri Lanka 1-LK1</td>
<td>Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community</td>
<td>Project</td>
<td>Haemophilia Association of Sri Lanka, President P. Sudhakar, President</td>
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