

Activity update

April 2011

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*Together delivering
life-changing action*

In the spotlight:

World Haemophilia Day 2011 - launch of STRETCH OUT



Show your engagement by STRETCHING OUT...

On World Haemophilia Day 2011, NNHF launched the call to action "STRETCH OUT for haemophilia". Thera-bands serve as a tool to engage as many people as possible from the global haemophilia community and create awareness about haemophilia and allied bleeding disorders as well as the importance of exercise for people with haemophilia.

Join us and take a picture of yourself, your team, family and/or patient association members stretching a thera-band. Send your pictures to info@nnhf.org to show your engagement towards haemophilia and be part of a huge STRETCH OUT mosaic. You can order the thera-bands for your STRETCH OUT activity from NNHF now! Find out more [here](#).

[Click here to read the full article...](#)

NNHF Lab Module – Online application open

NNHF is happy to announce the set up of its first basic coagulation course. This is part of a modular concept for laboratory training composed of one basic and one advanced course to take place every year. Dr Angus McCraw and NNHF have developed these training modules tailored to the working conditions in the developing world.

The first course will take place on 26-28 September 2011 at the Katharine Dormandy Haemophilia Centre and Thrombosis Unit - Royal Free Hospital, in London, United Kingdom. Dr Angus McCraw has designed the 3-days course consisting of theoretical and practical sessions. Further details can be found [here](#).

[Click here to read the full article.](#)



Highlights from around the world

Jordan - As part of the second NNHF project in Jordan a workshop took place on 15 January at the haemophilia education centre located at the Jordan University Hospital. Around 35 patients with their families were present. [Read more here.](#)



China - To further strengthen the basis of quality diagnosis in China, a follow-up laboratory training was delivered through the China 2 project from 25 to 27 February at the Peking Union Hospital. 11 technicians from the seven new centres that report to Beijing (Xinjiang, Shanxi, Haerbin, Tianjin, Shandong, Beijing children's hospital and Wuhan) participated in this training. [Read more here.](#)

Venezuela - The 'Marco Polo' project in Venezuela started in January. By training 13 laboratory technicians and seven haematologists in coagulation testing, a solid basis is set to establish quality diagnosis on a national level. [Read more here.](#)



Mexico - A physiatrist and an orthopaedic surgeon from Hospital Siglo XXI will receive training at Institute Dr Alfredo Pavlovsky & Hospital Juan A. Fernandez in Buenos Aires, scheduled for May 2011. The highly motivated project team of Dr Bernáldez has started creating educational material for a workshop for health care professionals in July.

Ghana - How do people with haemophilia live in a country where the health care system does not cover haemophilia at all? What do health care professionals know and how are the hospitals prepared to provide care to patients with bleeding disorders? NNHF went on a visit to Ghana after having been contacted by Martin Boakye, president of the Ghana Haemophilia Society. [Read more here.](#)



Morocco - As a very important step in the process of setting up the project in Morocco, meetings were held in Rabat at the beginning of February together with representatives from the University Hospitals in Rabat and Casablanca as well as the National Patient Association. [Read more here.](#)



Tanzania - The project carried out by Save One Life through a donation of NNHF shows great benefits for the haemophilia community in Tanzania: the Tanzanian Patient Association was set up effectively and was accredited by the World Federation of Hemophilia as a "National Member Organisation" last year in Buenos Aires. The association continues with activities to reach out from Dar Es Salaam to other regions. Furthermore, a dialogue has been started to set up a Twinning Programme with South Africa to learn from their experiences. More activities will come as the team is very motivated and engaged.

Pakistan - To celebrate World Haemophilia Day, the Haemophilia Patients Welfare Society (HPWS) Rawalpindi and Islamabad chapters organised a picnic for its members. Prof Tahira Zafar, Chairperson of the Medical Advisory Board of the HPWS discussed the challenges faced by people with haemophilia in Pakistan. [Read more here.](#)

Brazil Fellowship - Marcia A. Piccoloto Matta from the IHTC UNICAMP completed a four week fellowship training at Christian Medical College in Vellore, India. Marcia, who is also coordinator of the MSK Brazil Group, will bring the experiences learned to the recently started BR2 project. "I am assured that this experience will be shared with my colleagues in Brazil with the purpose of opening a wide discussion regarding what we have, what we expect and what are the ways to achieve our goals" says Marcia.

Latest approved programmes

Lithuania - The newly approved project will start very soon and will focus on improvement of physiotherapy and rehabilitation care on a national level. The project partner is the Lithuanian Haemophilia Society, who will collaborate closely with the specialists and patients in the country.



Serbia - The objective of this project is to spread the knowledge on haemophilia to healthcare professionals, patients and general public. This will be achieved through several education activities and the development of national treatment guidelines.

India fellowship - A new fellowship was also approved for Dr Nita Radhakrishnan, a paediatric haemato-oncologist from India, to receive specialised training in Angelo Bianchi Bonomi Hemophilia and Thrombosis Centre, Milan, Italy, with Dr. Pier Mannuccio Mannucci.

[For more information about our programmes, please click here.](#)

Did you know...



... that we had changes in our NNHF Council?

... [Dr Amy Shapiro](#), Medical director of the Indiana Hemophilia and Thrombosis Center has been elected as new member of the NNHF Council succeeding Professor Harold R. Roberts. The NNHF Council and management team welcome her warmly and are proud of having her on board.

... about the next application deadlines?

... The deadline to apply for the NNHF Basic Coagulation Course is 31 May 2011.
... The upcoming deadline for project and fellowship applications is 15 June 2011.

We are looking forward to receiving yours!

... that NNHF was at the MSK Congress?

... The MSK Congress in Dubai was very interesting and productive. NNHF had meetings with project partners and fellows. This event proved to be a great opportunity for creating contacts and have first talks about collaboration possibilities.

Questions or comments? E-mail us at info@nnhf.org or call +41 43 222 4376. To remove your name from our mailing list, please [click here](#).

All data is based on publicly available or locally provided information. Although this information is correct to the best of our knowledge at the time of writing, NNHF assumes no responsibility for it.

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