

NOVO NORDISK
HAEMOPHILIA
FOUNDATION
ANNUAL REPORT 2006

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“OUR OBJECTIVE IS TO IMPROVE THE CARE AND TREATMENT OF HAEMOPHILIA PATIENTS, WHEREVER THEY LIVE”

Kåre Schultz

President of the Novo Nordisk Haemophilia Foundation

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ONE PLANET, DIFFERENT WORLDS

In contrast to some 200,000 people with haemophilia in the developed world who have normal life expectancy, around 400,000 in the developing world often do not survive to adulthood.

The Novo Nordisk Haemophilia Foundation (NNHF) was created in 2005 to address the significant need for improving haemophilia care in the developing world where haemophilia is currently not a healthcare priority and still today many people with haemophilia go undiagnosed or are inadequately treated.

Haemophilia

Haemophilia is a congenital bleeding disorder that affects males. Approximately one in 5,000 males is born with haemophilia. It is estimated that about 600,000 males have haemophilia A or B in the whole world.

Patients with haemophilia A have either absent, decreased or defective production of the blood clotting protein, factor VIII (FVIII).

Those with haemophilia B have similar defects with factor IX (FIX).

Severe haemophilia is often associated with spontaneous bleeding, i.e. bleeding not caused by injury.

Approximately 50% of haemophilia patients have severe disease and may require treatment for bleeding several times a month.

Severe haemophilia usually becomes apparent in the first year of life – when the child starts to move about independently. Haemorrhages often occur in the joints, particularly knees and ankles. These joint bleeds can cause severe pain and permanent damage with disability if not treated properly.



Other mild, moderate or even life threatening bleeds can occur in the muscles, soft tissue, gastrointestinal tract or even the brain. In addition, trauma, major surgery, tooth extractions or other minor surgical interventions require medical attention to manage the associated bleeding.

Care and treatment standards worldwide

While some 200,000 people with haemophilia can be accounted for in North America, Europe, Japan and Australasia and have a normal life expectancy, another estimated 400,000 exist in the developing world. These 75% of people with haemophilia go without proper diagnosis or receive inadequate care and treatment. They have a life expectancy of about thirteen to fifteen years.

The difference in haemophilia standards has many causes, such as insufficient knowledge about the disease – not only amongst health care professionals, but also patients and their families – as well as low prioritisation of haemophilia within health systems.

“WITH PROPER CARE, HAEMOPHILIA IS TREATABLE AND PATIENTS CAN LEAD NORMAL LIVES”

Professor Christine Lee
NNHF Council Member and haemophilia expert



TOWARDS AN AMBITIOUS TARGET

To address the ambitious challenge of moving haemophilia higher on the global agenda and ensure that people with haemophilia in the developing world have better access to care and treatment, the Novo Nordisk Haemophilia Foundation (NNHF) was created in January, 2005.

The NNHF funds programmes to improve haemophilia care and treatment and raise disease awareness by focussing on capacity building, patient education, diagnosis and registries in the developing world. Based in Zurich, Switzerland, the NNHF is established as a non-profit entity. Swiss federal and fiscal supervision ensure that the proceeds of NNHF are spent in accordance with its objectives. The NNHF receives approximately DKK 10 million (CHF 2.1 million, EUR 1.3 million, USD 1.6 million) per year from its main benefactor, Novo Nordisk A/S, in Denmark.

Where and with whom NNHF works

The geographical scope of NNHF covers countries defined in the OECD Development Assistance Committee (OECD DAC) list as developing with

lower, middle and upper incomes. Furthermore, the NNHF is also active in the so-called transition countries, i.e. in those countries which have recently joined the European Union or are intending to do so. The NNHF is particularly interested to expand its project portfolio to the world regions of Central and South America, Central and South East Asia, as well as India.

The NNHF cooperates with partners in these countries, such as health ministries and authorities, healthcare professionals, patient organisations, as well as other foundations and trusts with like interests. To maximise the likelihood of success and sustainability, the NNHF ensures strong local commitment by working closely with these organisations and individuals in partnerships.



First NNHF project completed

The project in Uzbekistan, the first to be completed, is a good example of a successful partnership. Not only were a large number of patients in Uzbekistan diagnosed and registered, but also a new centre was constructed in Tashkent at the Institute of Haematology for the treatment of bleeding disorders.

“It is remarkable that, due to the strong engagement of our project partner, enough public awareness was raised to create sufficient interest for a third party to fund the new centre. An anonymous donor gave this enterprise about ten times the amount of the NNHF seed funding”, explains Susanne Brandl, Senior Project Manager of the NNHF.

Keeping an eye on progress

At the time of writing, barely two years after its creation, the NNHF supports 18 projects in the developing world. During 2006, 11 new projects were approved. The total project portfolio amounts to CHF 4.1 million (EUR 2.5 million, USD 3.1 million). These projects represent the beginning of the long road to improve haemophilia care and treatment in the developing world.

“We are proud of what has been achieved so far, yet modest compared to the size of the task. The work of the Foundation has been extremely challenging, but also immensely rewarding, seeing the benefits for the patients”, concludes Stephen Robinson, General Manager of the NNHF.

PROJECT PORTFOLIO
18 PROJECTS IN THE DEVELOPING WORLD

ALGERIA

Status Approved 2005, ongoing



CENTRAL AMERICA

Status Approved 2006

CUBA

Status Approved 2007

VENEZUELA

Status Approved 2005, ongoing

CHILE

Status Approved 2007

URUGUAY

Status Approved 2007

BRAZIL

Status Approved 2006, ongoing



POLAND

Status Approved 2005, ongoing

MACEDONIA

Status Approved 2006, ongoing

BULGARIA

Status Approved 2006, ongoing

ROMANIA

Status Approved 2006, ongoing

CHINA

Status Approved 2006, ongoing



PAKISTAN

Status Approved 2006, ongoing

UZBEKISTAN

Status Approved 2005, completed

IRAQ

Status Approved 2006

JORDAN

Status Approved 2006, ongoing

PALESTINE

Status Approved 2006

LEBANON

Status Approved 2006



Partner	Algerian Haematology Society, Algiers
Represented by	Prof. Meriem Belhani
Planned duration	Three years
Population	33.3 mio.
Expected patients	3,330
Known patients	1,017
GDP per capita	USD 6,600

Objectives

Comprehensive national haemophilia education programme:

- Update competencies of health care providers
- Provide patient information

Improve haemophilia diagnosis:

- Perform screening programme
- Establish national haemophilia registry
- Establish specialist care by reinforcing the national reference centre and opening two regional treatment centres

Impact

- Increased disease awareness in the health care system
- Better information of known and newly diagnosed haemophilia patients
- Improved specialist knowledge amongst 160 health care providers
- Increased disease awareness on authority level

Partner	Brazilia Federation of Hemophilia, Cuiabá
Represented by	Dr. Sylvia Thomas
Planned duration	Three years
Population	186 mio.
Expected patients	18,600
Known patients	7,626
GDP per capita	USD 8,100

Objectives

- Improve haemophilia infrastructure and treatment delivery with emphasis on eight regions
- Support re-organisation of Brazilian Federation of Hemophilia (BFH)
- Ensure better cooperation between regional BFH associations and their treatment centres (Hemocentros)
- Educate patients, patient leaders, doctors and nurses
- Establish 2 national laboratories and train laboratory technicians
- Update patient registries

Impact

- BFH reorganised and strengthened
- 28 patient leaders, 70 health care professionals, 200 patients and family members educated

Partner	National Center of Haematology and Transfusiology, Sofia
Represented by	Prof. Toshko JeleV Lissitchkov
Planned duration	Two years
Population	7.4 mio.
Expected patients	740
Known patients	580
GDP per capita	USD 8,200

Objectives

- Form Comprehensive Haemophilia Treatment Centre in Sofia
- Train and educate for a multidisciplinary approach
- Update current haemophilia guidelines for prevention and treatment of bleeding
- Create awareness programme in West Bulgaria
- Support and update national haemophilia registry

Impact

- Raised standards of haemophilia care in West Bulgaria
- About 12 haematologists and 7 nurses trained
- Around 100-150 specialists and 600 patients targeted to receive education materials
- 150-200 patients examined, screened and received regular rehabilitation
- 150-200 patients in regular rehabilitation
- More than 100 patients and families received genetic consultation

CENTRAL AMERICA

Latin American haemophilia network

Partner **Partner and representative to be determined according to pilot country chosen**

Planned duration **One year**

Population **Not applicable**

Expected patients **Not applicable**

Known patients **Not applicable**

GDP per capita **Not applicable**

Objectives

- Develop generic needs assessment tool for haemophilia in developing countries
- Implement assessment tool in pilot country to determine development project scope
- Develop a national haemophilia registry

Impact

- 10-15 healthcare professionals as well as 75-80 patients and families trained
- Haemophilia platform created and treatment improved
- Increased awareness and data on authority level

THE PEOPLE'S REPUBLIC OF CHINA Haemophilia education, screening and registration

Partner **Ruijin Hospital, Shanghai**

Represented by **Prof. Hongli Wang**

Planned duration **Two years**

Population **1.3 bn**

Expected patients **130,000**

Known patients **4,500**

GDP per capita **USD 5,600**

Objectives

- Establish cooperation between major haemophilia centres (Shanghai, Tianjin, Beijing, Hefei, Guangzhou, Jinan)
- Educate doctors, nurses, lab technicians and patients – train-the-trainer concepts
- Optimize 3 designated reference laboratories for haemophilia diagnosis
- Run screening programme
- Improve national patient registry

Impact

- 500 patients educated, 2000 patients received newsletter, patient website established
- 1,500 out of 4,500 registered patients (re-)screened
- 3 equipped haemophilia testing laboratories
- Doctors, nurses and lab technicians in 6 major centres trained
- National haemophilia registry updated to a networked system

CHILE

National improvement of haemophilia treatment

Partner **Roberto del Río Hospital, Santiago**

Represented by **Dr. María Mercedes Morales Gana**

Planned duration **Three years**

Population **16.1 mio.**

Expected patients **1,610**

Known patients **1,200**

GDP per capita **USD 10,700**

Objectives

- Perform broad multidisciplinary educational programme to upgrade existing level of treatment standards
- Assess clinical, psychological and social patient status
- Confirm laboratory status in screening and re-screening
- Update national haemophilia registry

Impact

- Multidisciplinary training team created
- 30 health care providers educated
- 1,200 patients diagnosed and/or re-screened
- Upgraded treatment guidelines

Partner	Instituto de Hematología e Immunología (IHI), La Habana
Represented by	Prof. José M. Ballester Santovenia
Planned duration	Two years
Population	11.4 mio.
Expected patients	1,140
Known patients	359
GDP per capita	USD 3,000

Objectives

- Improve IHI to be established as national reference centre
- Set up two regional comprehensive care centres in Pinar del Rio and Villa Clara

Impact

- Comprehensive haemophilia care introduced
- About 70 patients educated, their diagnoses confirmed and educational material provided
- 12 haemophilia specialists trained
- Laboratory equipped and 4 laboratory technicians trained
- Workshops held for about 60 health care specialists

Partner	Al-Mustanseriyah University, Baghdad
Represented by	TBD
Planned duration	One and a half year
Population	26.1 mio.
Expected patients	2,610
Known patients	800
GDP per capita	USD 2,100

Objectives

- Improve diagnosis and introduce a comprehensive screening programme
- Establish a national haemophilia registry
- Create national haemophilia treatment guidelines
- Increase disease awareness also on authority level

Impact

- 15 haematologists, 7 lab technicians, 6 nurses trained
- IT specialists trained for implementation of registry
- Patients educated
- Guidelines published
- Authorities involved in improvement process

Partner	Jordan University Hospital, Amman
Represented by	Dr. Abdalla S.S. Awidi
Planned duration	Two years
Population	5.8 mio.
Expected patients	580
Known patients	290
GDP per capita	USD 4,500

Objectives

- Establish regional molecular reference laboratory
- Perform carrier detection and pre-natal diagnosis
- Ensure genetic counselling
- Provide national database

Impact

- Competent regional molecular reference lab established (for Jordan, Syria and Iraq)
- National database established
- 290 Patients educated and counselled
- 40 doctors and 60 nurses as well as lab technicians from Jordan and region trained
- Results of genetic diagnosis published

Partner	Hotel Dieu de France Hospital, Beirut
Represented by	Dr. Claudia Djambas Khayat
Planned duration	Two years
Population	3.8 mio.
Expected patients	380
Known patients	139
GDP per capita	USD 5,000

Objectives

- Strengthen the haemophilia treatment centre in Beirut by implementing multidisciplinary approach
- Design and implement a broad educational haemophilia programme for health care professionals, patients with their families
- Extend basic programme to 4 regions

Impact

- 200 new patient diagnoses expected
- Overall 400 patients educated
- Haemophilia capacity of first line doctors and nurses improved, haematologists trained
- Regular medical consultation services established
- Disease awareness at authority level improved

Partner	University Children's Hospital, Medical Faculty, Univ. "Ss Cyril and Methodius", Skopje
Represented by	Prof. Sofijanka Glamocanin
Planned duration	One year
Population	2.1 mio.
Expected patients	210
Known patients	286
GDP per capita	USD 7,100

Objectives

- Assess haemophilia patients' health and clinical status
- Perform regional workshops for health care professionals
- Perform advanced haemophilia diagnosis
- Upgrade national haemophilia registry
- Create disease awareness at authority level

Impact

- 286 patients assessed and educated
- Diagnosis results included in national registry
- 3 regional workshops held – 75 doctors, 50 nurses from 20 regional centres trained
- Haemophilia treatment prioritised in National Health Strategy

Partner	Bismillah Taqee Institute, Karachi
Represented by	Dr. Tahir S. Shamsi
Planned duration	One and a half year
Population	162.4 mio.
Expected patients	16,240
Known patients	1,250
GDP per capita	USD 2,200

Objectives

- Update knowledge and skill level of doctors, nurses and laboratory technicians in a regional pilot project in Karachi and environs
- Establish effective and adaptable model of diagnosis
- Implement a haemophilia database
- Increase awareness and knowledge in the haemophilia community, including authorities and institutions

Impact

- 650 patients educated and screened
 - 4 medical professionals trained as master trainers for later stage national rollout
 - Haemophilia database created
 - Disease awareness within haemophilia community increased
-

Partner	Palestinian Authorities, Ministry of Health
Represented by	TBD
Planned duration	Two years
Population	3.7 mio.
Expected patients	370
Known patients	125
GDP per capita	Not applicable

Objectives

- Provide means for diagnosis
- Ensure capacity building by implementing train-the-trainer concept
- Establish regular treatment follow up and monitoring
- Educate patients
- Implement a national haemophilia registry

Impact

- 240 patients educated and (re-)screened
- About 120 health care professionals trained
- National haemophilia registry implemented
- Disease awareness increased in general public and at authority level

Partner	Haematology Department, Paediatric Clinic, Warszawa
Represented by	Dr. Anna Klukowska
Planned duration	Two years
Population data	38.6 mio.
Expected patients	3,860
Known patients	2,269
GDP per capita	USD 12,000

Objectives

- Establish multi-centre collaboration between haemophilia doctors, nurses and laboratory technicians
- Train health care professionals and update treatment guidelines
- Educate patients and their families
- Screen about 850 severe haemophilia patients
- Update the national haemophilia registry

Impact

- About 850 severe haemophilia patients screened and diagnosis confirmed
- Approximately 170 doctors, 50 nurses and 850 patients trained
- Treatment guidelines updated (70 health professionals involved)
- National haemophilia registry implemented

Partner	Emergency Clinical Hospital «Louis Turcanu» Haemophilia Centre, Timisoara
Represented by	Prof. Margit Serban
Planned duration	Two years
Population	22.4 mio.
Expected patients	2,240
Known patients	1,210
GDP per capita	USD 7,700

Objectives

- Create 4 haemophilia centres in the main regions based on existing infrastructure
- Improve laboratory status and train laboratory technicians
- Standardize diagnosis and train doctors and nurses
- Educate patients
- Improve existing national haemophilia registry
- Create a specialised group of haemophilia caregivers

Impact

- Regional access to haemophilia care and treatment created
 - About 15 doctors, 10 lab technicians trained
 - More than 1,000 patients educated and screened
-

Partner	Centro Hospitalario Pereira Rossell, Montevideo
Represented by	Dr. Ismael Rodríguez
Planned duration	One year
Population	3.4 mio.
Expected patients	340
Known patients	202
GDP per capita	USD 14,500

Objectives

- Create awareness in haemophilia community
- Design and implement comprehensive training programme for doctors, nurses, laboratory technicians, patients and their families
- Develop diagnostic, treatment and rehabilitation protocols
- Improve personal care and preventive measures

Impact

- 2 annual plenary haemophilia community workshops held
- About 10 haematologists, 25 laboratory technicians and specialised representatives of 18 departmental health centres trained
- Diagnostic, treatment and rehabilitation protocols developed
- Educational material for patients and health care professionals developed and distributed
- Interactive workshops for 60 patients, their families and health care professionals held in cooperation with patient organisation

Partner	Hematology and Transfusion Scientific institute, Tashkent
Represented by	Dr. Aziza Makhmudova
Planned duration	One year (completed)
Population	26.9 mio.
Expected patients	2,690
Known patients	1,138
GDP per capita	USD 1,800

Objectives

- Educate regional doctors and nurses
- Establish national reference laboratory and train laboratory staff
- Perform a national screening programme
- Create national haemophilia registry

Impact

- National reference laboratory set up and staff trained
- 13 screening programmes performed nationwide – More than 1,000 patients screened
- National haemophilia registry installed and in operation
- Haemophilia patient educational booklet published
- Film about haemophilia care in Uzbekistan produced
- New haemophilia centre built with leveraged private funds

Partner	Venezuelan Association of Haemophilia, Caracas
Represented by	Dr. Cesar A. Garrido
Planned duration	Two years
Population	25.4 mio.
Expected patients	2,540
Known patients	1,800
GDP per capita	USD 5,800

Objectives

- Establish 5 new regional haemophilia associations and offices
- Identify, diagnose, register and educate haemophilia patients
- Train haemophilia patient leaders
- Promote cooperation between haemophilia associations and treatment centres

Impact

- Community-wide beneficiaries: approximately 1,800 patients, 12,000 parents and relatives, 25 association leaders, 20 haematologists, 10 nurses and about 20 specialists trained
- About 90 new patients diagnosed and registered

ACCOUNTANTS REMARKS

Report of the statutory auditors
to the Board of Foundation of
Novo Nordisk Haemophilia Foundation
Zürich

As statutory auditors, we have audited the financial statements (balance sheet, income statement and notes) of the Novo Nordisk Haemophilia Foundation for the year ended 31 December 2006 regarding the compliance with law.

These financial statements are the responsibility of the Board of Foundations. Our responsibility is to express an opinion on these financial statements based on our audit. We confirm that we meet the legal requirements concerning professional qualification and independence.

Our audit was conducted in accordance with auditing standards promulgated by the Swiss profession, which require that an audit be planned and performed to obtain reasonable assurance about whether the financial statements are free from material misstatement. We have examined on a test basis evidence supporting the amounts and disclosures in the financial statements.

We have also assessed the applicable accounting principles used, significant estimates made and the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements comply with the Swiss law and the charter and regulations of the foundation.

We recommend that the financial statements submitted to you be approved.

PricewaterhouseCoopers AG



Patrick Balkanyi
Auditor in charge



Thomas Illi

Zürich, 26 April 2007

Enclosure:
Financial statements (balance sheet, income statement and notes)

ANNUAL ACCOUNTS 2006

NOVO NORDISK HAEMOPHILIA FOUNDATION, ZÜRICH

Balance sheet as of December 31

Assets	2006	2005
	Swiss Francs	Swiss Francs
Cash and Equivalents	2 662 510	1 747 226
Prepaid expenses	146 028	0
Total Assets	2 808 538	1 747 226
Equity and liabilities		
Short term liabilities		
Trade accounts payable		
to third parties	528	2 431
to related parties	95 109	0
Deferred Income	1 293 946	5 500
	1 389 583	7 931
Long term liabilities		
Other provisions	15 595	0
Equity		
Locked up capital	200 000	200 000
Retained earnings	1 203 360	1,539 295
	1 403 360	1 739 295
Total Liabilities & Equity	2 808 538	1 747 226
Income statement for the business year		
	Swiss Francs	Swiss Francs
Income	3 087 870	1 883 333
donation income		
exhibition and conferences	(335 301)	0
personnel costs	(829 233)	(250 701)
travel and communication costs	(248 087)	(29 185)
project grants	(1 639 245)	0
Project related costs	(3 051 866)	(279 886)
rent costs	(48 011)	(8 239)
service fees	(16 967)	0
administration costs	(294 653)	(54 616)
Administration costs	(359 631)	(62 855)
Operating profit	(323 627)	(1 540 592)
Interest income	960	0
bank fees	(4 156)	(400)
currency gains (losses)	(9 113)	(897)
Financial income (expense)	(12 309)	(1 297)
Profit (Loss)	(335 935)	1 539 295

Notes to the annual financial statement

1. Disclosures according to Art. 663b OR (in Swiss Francs) 68 000 0

There are no further facts requiring disclosure according to ART. 663b OR

2. Consistency in the presentation of the income statement

The classification of the income statement has been changed

**NOVO NORDISK
HAEMOPHILIA
FOUNDATION**

ANNUAL REPORT 2006

Contributors

Photos

Jesper Westley

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AGERGAARD visual communication

Printing and binding

Litotryk København as

All data are based on publicly available or locally provided information.

Although this information is correct to the best of its knowledge at the time of writing, NNHF assumes no responsibility for it.

Joining forces to strive for
improvement of haemophilia care

The NNHF supports improved haemophilia care in the developing world through partnering with health care providers, patient groups, authorities and others engaged in the haemophilia community around the world.

This includes provision of funding, counselling, serving as sparring partner to NNHF project leaders as well as any other activity supporting the haemophilia community and its leaders in their engagement to improve haemophilia care and treatment delivery.

The NNHF would like to take this opportunity to thank the project partners and teams as well as all other supporters of the haemophilia community for their engagement in carrying out the projects and making a difference to the benefit of people with haemophilia in the developing world.

Novo Nordisk Haemophilia Foundation

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