

IMPROVING CARE WITH COMMUNITY ENGAGEMENT

Activity Report 2009/2010



**NOVO NORDISK
HAEMOPHILIA
FOUNDATION**





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Dear reader,

The Novo Nordisk Haemophilia Foundation (NNHF) has now been active for five years – following its vision of improving care for people with haemophilia and allied bleeding disorders.

In these five years we have reached people across the world, including families, healthcare professionals, organisations and health authorities. Working through dedicated initiatives and with highly engaged community members joining forces to make a difference on the ground.

We are proud that the NNHF development programmes have proven to be valuable in improving standards for care. The programmes accelerate infrastructure development with and for the community focusing on capacity building, awareness creation as well as diagnosis and registries. This eventually leads to long-term impact benefiting people with haemophilia and allied bleeding disorders.

It is our firm belief that we can only achieve our vision through the local community approach NNHF is championing. The leadership of the projects we support belongs to local partners from the community. Our organisation's task is to provide funds and active support through coaching, project management expertise and tools, as well as involving a global network of experts.

Dual approach to leveraging change

In the coming years, two main streams will guide the NNHF on the long road to improving access to care for people with haemophilia and allied bleeding disorders.

One is a continuation and progressive enhancement of the successful approach we have developed for selecting and supporting programmes. In addition to this, we want to further leverage the learnings and experiences from our first five years.

The other will be our work to systematically catalyse better practice sharing and replication of successful and innovative execution of sustainable solutions. One platform for this will be the 2010 NNHF Better Practice Sharing Forum, being held on the occasion of the World Federation of Hemophilia Congress in July 2010, where we also celebrate the launch of two new awards.

By sharing local, regional and international successes and challenges, as well as supporting local drive for change to ensure better access to care, we can contribute to people with haemophilia and allied bleeding disorders being able to follow their desires and live nearly normal lives.

Acknowledging our community

We would like to thank our founder, Council members, benefactors, partners and their teams for their enthusiasm and dedication in joining us to drive sustainable change on a grassroots level. NNHF also thanks ministers of health, their staff and other authorities for their support and cooperation which are keys to success.

We look forward to many more exciting and challenging moments together with you, our friends and partners, on course for fulfilling our vision.

Sincerely,



Kåre Schultz
President of NNHF Council



Susanne Brandl
General Manager of NNHF

OUR VISION

“ALL PEOPLE
WITH HAEMOPHILIA
OR ALLIED BLEEDING
DISORDERS
SHOULD RECEIVE
ADEQUATE CARE
AND TREATMENT
FOR ACUTE BLEEDING,
WHEREVER THEY LIVE.”

THE NNHF COUNCIL: REFLECTIONS AND FUTURE OUTLOOK

Celebrating five years of engagement is a great opportunity to pause for a moment to review our accomplishments so far and look ahead to how we can expand on our impact.

From being a start-up in 2005, busy with setting up the organisation, key processes and approving the first development projects, the foundation has grown into a fast-moving organisation successfully mastering its mandate.

“It is a pleasure to look back to when we registered the NNHF and started our activities with a strong belief and lots of enthusiasm. It was a sign of our commitment to the haemophilia community. Five years later, I am proud to see an established organisation, which is recognised internationally for its many great results leading to real change, on the ground, for people with haemophilia and allied bleeding disorders in the developing world,” says Kåre Schultz, president of the NNHF Council.

An important role to play

That real change truly is necessary is beyond question. Vast differences in the perception of haemophilia and its care and treatment standards exist, depending on where you live. NNHF aims to build bridges between the developed and the developing parts of the world.

“I was initially sceptical about what kind of impact a philanthropic foundation could have on the lives of people with haemophilia and other bleeding disorders. After serving five years on the NNHF Council, it has become clear to me the great role this institution plays in the sustainable improvement of the haemophilia situation in the developing

world,” says Prof Harold Roberts, NNHF Council member and internationally known haemophilia expert.

This last point of view is backed up by Prof Ulla Hedner, NNHF Council member and internationally known haemophilia expert. She says:

“Each of us councillors has our own story to tell about how we personally contribute to making a difference on the ground in haemophilia. I am convinced that increasing awareness of haemophilia will help to change the healthcare situation in many so-called developing countries. It is enriching to see how our support can have substantial influence on the local political situation, care and quality of life. And it is very gratifying to observe how our activities have been initiated in spite of many obstacles on the way.”

Navigating risk

Over the last years, NNHF has learned a lot and further developed its approach to development programmes, which is also reflected in the Council's approvals. In that process, it has become much more obvious that calculated risk-taking is part of our work, as we support initiatives in politically unstable regions or evaluate novel, pioneering or atypical ideas.

“We are very ambitious with our approval of projects in politically unstable countries. It is a great pleasure to see that our project in Iraq has



Our origins and purpose

The Novo Nordisk Haemophilia Foundation (NNHF) was established in 2005 as a non-profit organisation to address the significant need for improving care in the developing world for people with haemophilia and allied bleeding disorders.

An estimated 75% of the global haemophilia population resides in the developing world, where still many people with haemophilia go undiagnosed and are inadequately treated.

NNHF expresses Novo Nordisk's commitment to corporate social responsibility. Improving the haemophilia situation on a global level, by moving haemophilia higher on the global agenda and providing access to care, are key elements fitting into Novo Nordisk's approach to impacting change in disease areas in which the company can make a difference.

Based in Zurich, Switzerland, NNHF receives approximately CHF 3.2 million (EUR 2.3 million) per year from its main benefactor, Novo Nordisk, which remains the main source of funding. Other benefactors are permitted by the foundation's Council.



“ VAST DIFFERENCES IN HAEMOPHILIA CARE AND TREATMENT STANDARDS EXIST, DEPENDING ON WHERE YOU LIVE. NNHF AIMS TO LIFT STANDARDS IN THE DEVELOPING WORLD.”

taken off very successfully. This is not the case in all projects as we have realised for example in connection with our Palestine project. Due to a challenging political situation, the project was not able to begin work despite two years of efforts, so unfortunately we had to cancel it. The doors are left open for a re-submission as soon as the situation allows. We still very much want to change the situation for the benefit of people with bleeding disorders,” says Prof Christine Lee, NNHF Council member and haemophilia expert.

The road ahead: knowledge sharing

Experiences made and exchanged with our partners, communities and experts around the world drive our approach to practical and sustainable development work. We have come to understand that there is a

real need to expand the opportunities for better practice sharing and bringing together people with same goals and dedication.

“ Today, the foundation is making a real difference for people with haemophilia and allied bleeding disorders in 25 emerging countries. It is working with global experts and strives to expand its network of partners and community members around the world. Together, we will make grassroots development work become a reality and ensure sharing of better practices in order to deliver access to care to people with haemophilia and allied bleeding disorders wherever they live,” says Leif Fenger Jensen, NNHF Council member with both commercial and philanthropic experience in emerging markets.





OUR ACHIEVEMENTS: THE LONG ROAD TO IMPROVING CARE

Each year, the foundation and its partners cover one more stretch on the long road to improving access to care in the developing world. The impact of our joint efforts is unquestionable.

As of April 2010, 33 projects and six fellowships in 25 countries as well as donation initiatives have been set up by local partners together with NNHF. In total CHF 7 million (EUR 5 million) have been made available to the programmes.

All of the initiatives share the same goal: to achieve better care and better quality of life for people with haemophilia and allied bleeding disorders in the developing world.

Through our development programmes, over 4,000 healthcare professionals have been trained. Educational efforts have reached more than 9,500 patients, families, community leaders and other stakeholders. About 13,500 patients have been diagnosed or had their diagnosis confirmed, and in most cases these patients are now registered – either in already existing or newly set-up customised haemophilia or bleeding disorders registries.

How access to care is improved

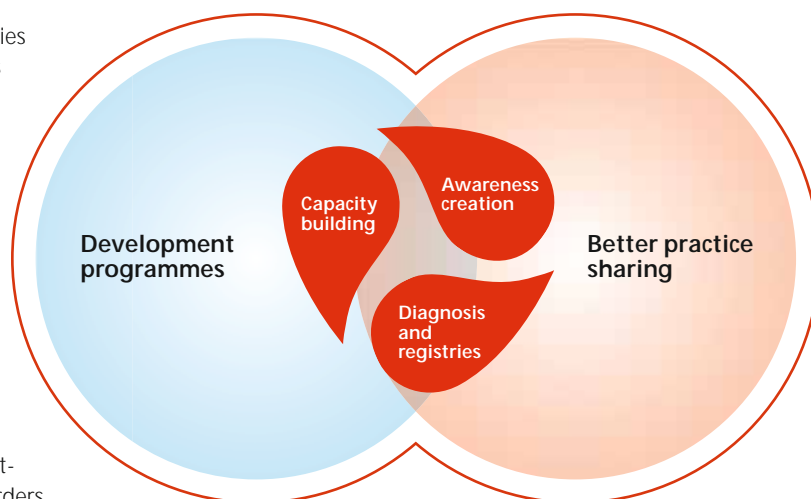
When NNHF was founded in January 2005, we set out to determine our approach to improving care. The result is three focus areas, within which we work with our community partners, to advance access to care. These are:

Capacity building

A key element in improving care is development or upgrade of expertise, personal skills and competences. NNHF supports comprehensive training through lectures, workshops, manuals or creation and implementation of guidelines. Target groups are mainly healthcare professionals. These training programmes are often supported by regional or international experts and take place within the project scope or are granted as educational fellowships abroad.

Awareness creation

Among the most commonly conducted activities in our projects are educational initiatives, such as workshops, patient camps and media



NNHF pursues its vision working in two streams: development programmes and better practice sharing. All activities focus on three areas: capacity building, awareness creation as well as diagnosis and registries. Improvements in each of these focus areas lead to better access to care.

campaigns. They aim to raise the level of haemophilia knowledge held by patients and their families to help them cope with the condition, as well as among community leaders, policy-makers and general society. A greater awareness in society leads to improved public support for the patients and aids them in their social interaction, their psychological stability and the support they receive. It also and increases advocacy to their benefit.

Diagnosis and registries

Correct diagnosis is a prerequisite for adequate care and medical outcomes. In most countries within our scope, this is often absent or inadequate, due to poorly equipped laboratories and lacking expertise of staff. NNHF supports laboratories with the purchase of equipment and consumables for related programmes as well as training of laboratory

3 focus areas

within which NNHF works: capacity building, awareness creation, and diagnosis and registries.

33 projects

have been initiated by local partners together with NNHF.

2 awards

will be granted as of 2010 on an annual basis.

6 fellowships

have been awarded to healthcare professionals from the developing world.

4,000 HCPs

More than 4,000 healthcare professionals (HCPs) have been trained.

staff to ensure performance of quality diagnosis. Subsequently, a comprehensive programme is often run and the data gathered is entered into a patient registry. The registry plays an essential role in providing an overview of the local situation and the impact of the disease, as well as in making precise follow-up on diagnosis possible. It also enables concrete evidence of the need for care and treatment to support the advocacy of patient rights.

A two-pronged approach to change

Supporting activities within the above-mentioned focus areas, our work flows in two streams.

One stream covers our **development programmes**, which can be applied for and for which guidelines exist:

- *Development projects* – which support locally driven, sustainable initiatives.
- *Educational fellowships* – where further education for healthcare professionals in internationally recognised training centres is supported.
- *Awards* – acknowledging outstanding engagement and/or project implementation we hand out two annual awards: ‘Project of the Year Award’ recognising a particularly successful NNHF project; and ‘NNHF Community Award’, which is awarded to an individual or group of the haemophilia community who has initiated and implemented an exceptional initiative with long-term impact.

Our other work stream aims at **better practice sharing**, leveraging learnings and experiences from projects supported by NNHF in its first five years. We want to catalyse the spread of successful and innovative project execution. Sharing knowledge can solve many potential challenges, sometimes already in the planning phase.

Specific activities within this stream focus on:

- *Facilitation of sharing* experiences and knowledge between project partners and their teams or with other local and international community representatives. We apply specific tools and purpose-built forums, publications and other networking opportunities.

Our geographic scope

We want to focus our activities on making an impact where we trust this impact is sustainable after our funding ends. The initiatives we sup-

port take place in developing countries, preferably in the low, lower-middle and upper-middle income categories, as defined by the OECD Development Assistance Committee (OECD DAC) list.

NNHF is also active in the so-called transition countries, ie countries which have recently joined the European Union or are intending to do so in the near future.

Collaborations and donations

NNHF collaborates and donates funds to the World Federation of Hemophilia (WFH) as well as other partners for specific focus initiatives.

Our collaboration with the WFH extends beyond grants. We are in regular dialogue about activities and plans, in order to ensure that we do not overlap but rather complement each other to optimise scarce funds and resources.

Donations for specific focus initiatives are typically for activities which fall outside the scope of our own programmes, but foster innovative approaches along with an out-of-the-box vision. The initiatives are subject to the same evaluation criteria as our own projects and fellowships and have to support NNHF’s focus and vision to gain approval by our Council.

One such example is seed money donated to Save One Life, a US-based non-profit organisation, for an initiative in Tanzania aiding the nascent haemophilia society in setting up a national network and conducting an outreach programme. The NNHF Council decided to make this donation, because the initiative had the right recipe for success: a good idea, good leadership and a sensible plan.

“Motivated by the seeds set in Tanzania, the dedicated medical team approached the Ministry of Health and received further support! On top, chances of becoming an internationally recognised patient association are promising. Your donation is going to go a long way,” says Laureen A. Kelley, Founder of Save One Life, the organisation managing this initiative.

13,500 patients

have been diagnosed through NNHF projects.

9,500 people

– patients, families, community leaders – have been reached by educational activities.

600,000 people

are estimated to be living with haemophilia worldwide;

25%

of those have confirmed diagnosis and access to adequate care.

75%

of the global haemophilia population lives in the developing world.



SUSTAINABLE CHANGE: LOCAL LEADERSHIP WITH HANDS-ON SUPPORT

Our development programmes are at the heart of everything we do in NNHF. We support efforts on the ground with one goal in mind: to improve access to care.

NNHF must at all times be able to account for how its resources are spent and how its activities ensure impact according to the foundation's purpose. Our approach is to empower local communities to create a sustainable impact. Therefore, we leave local project management in the hands of the community partners, while we provide funds and hands-on support to guide and inspire our partners, and to stimulate results and change.

Through our work in the first five years, we have discovered four key components in successful project implementation.

Key component 1: dedicated partners engaging the community

One essential component in achieving success is finding the best possible partners to lead a project. They need to be strongly motivated, to have local expertise and authority, and an ability to get people behind their leadership and the project. But other qualities are also important:

“Project partners need strong collaborative skills on both a local, regional and ideally also an international level. Information and involvement of the community at an early stage is a key success factor to enable continued progress and to establish a network facilitating multi-stakeholder dialogue and an integrated care approach,” says Susanne Brandl, general manager of NNHF.

Partners come from all parts of the haemophilia community and include healthcare professionals, members of patient and non-governmental organisations, of ministries of health and other healthcare authorities or institutions. Their endorsement and continued support are often keys to the long-term sustainability of the improvements in care.

Key component 2: the right activities tailored to local needs

Before going into a project, we analyse the local situation. Together with the partner and key community stakeholders we define relevant activities tailored to the situation and its needs, making use of our

“WE GO TO GREAT LENGTHS TO MAKE SURE THAT WHAT WE ACHIEVE IS SUSTAINABLE AND LEADS TO BETTER PATIENT CARE.”

experience from other projects and thus securing replication and better practice sharing. The main activities will always be within one or more of our three focus areas: capacity building, awareness creation, and diagnosis and registries.

As the exact order of events and needs is different in each country, we apply a step-by-step approach, which allows for various starting points and degrees of complexity, as well as improvement over time. Getting the starting point right allows for more activities to be undertaken in subsequent projects.

Key component 3: strong project management

We are highly committed to making the programmes we fund a success. We believe focussed project management, including liaising with international key partners, is essential.

“In our experience, results-based project management is the only way to make things happen,” says Susanne Brandl. “As most of the projects are quite complex, there is a large number of organisational and logistical challenges. We use our experience to coach and help our partners in planning and execution.”

In this way, NNHF provides hands-on support, through coaching of local partners and community members from the earliest stages of the project. The earlier we are involved the better. When we start early, we can support future partners in conceptualising and tailoring their project to be ready for the project application and the thorough plan required for that.

Throughout a project’s duration, there is close communication, coaching on a case-by-case basis along with project site visits by the NNHF. This serves the purpose of strengthening the partnership and facilitating communication.

“It is about getting a real understanding of the circumstances project partners are facing. This makes it possible for both parties to give the right feedback on challenges and ideas for ways forward. It also facilitates involving key community stakeholders and establishing an integrated networking process,” says Susanne Brunner, NNHF project manager.

Finally, the project management focus also helps secure transparency and accountability. As a foundation we are expected to secure that our resources are spent according to our foundation’s purpose and in a traceable manner. Only through hands-on support, funding and continuous reporting against targets can we achieve this. It does, however, also imply regular progress monitoring and close controlling.

“We request from our partners a quarterly progress report according to our NNHF reporting template. We get information on qualitative and quantitative progress on milestones and other achievements, as well as insights into risks and challenges,” says Alexandre Alencar, NNHF senior project manager.

Susanne Brunner adds: “This is not the most pleasant part of the project work. Not for our project partners and not for us. However, during

the course of a project we all see the benefit of the reporting process. It is crucial for transparency and control to live up to international standards in development aid. It also enables communication of achievements because you have monitored these all along. And when you are able to tell others what has been achieved, it often helps stimulate interest and accelerate the improvement processes.”

Key component 4: sustainability beyond our support

From the early start of NNHF, sustainability has been the key concern for every programme we supported.

Starting as early as the idea and conceptualisation stage of a project proposal up to the point of detailed planning and execution stages, we keep in mind the eventual goal of ensuring continuity of infrastructure, expertise, processes and tools established with our support.

Most important, but least visible, are the efforts to ensure that all stakeholders, including local authorities, work and perceive themselves as a community pursuing the same goal. More specifically, ensuring sustainability means early consideration of succession planning, financing of continuous availability of consumables, maintenance of systems and established infrastructures, etc.

“Sustainability is an important aspect of the NNHF support. We go to great lengths to make sure that what is achieved is sustainable and leads to better care for the patient. To this end, the NNHF team is very efficient to define lasting outcomes of the investment by empowering local leaders through coaching, training, on-site visits, regular follow-up and controlling and anchorage of responsibilities on local level.

Furthermore, assuring early and continuous involvement of key community members, including relevant authorities, ensures that our programmes match local structures and needs as well as engage members of the community in emerging networks,” says Harold Roberts, NNHF Council member.

Pakistan: step-by-step improvements

One example of a step-by-step approach is our work in Pakistan.

The first NNHF-funded project was a pilot project aimed at improving care limited to one specific location. The second project addressed the need for locally adapted patient education, a need which was discovered as part of the first project.

Upon completion of these two projects, two new projects with the same content but aiming at expansion to a national level have been approved by the NNHF Council. (Read more about Pakistan on pages 13, 24–25 and 40–41).



IMPROVED ACCESS TO CARE: PROGRAMMES STORIES

Celebrating the NNHF's fifth anniversary, we are able to look back at 14 finished projects and two completed fellowships out of a broad programmes portfolio. In 2010, more projects will finish as our work impacts still more people in the worldwide haemophilia community.

Thousands of people with haemophilia have been reached by the programmes we support. Compared to an estimated patient population of 600,000 worldwide, of which only 25% have confirmed diagnosis and access to adequate care, and 75% live in the developing world, the need to continue our work towards our vision is obvious.

In the following pages we tell the stories of seven projects and a fellowship completed between 2009 and 2010.

Project / **PRO-HOPE – Improvement of haemophilia organisation and patient education**
 Partner / **Federação Brasileira de Hemofilia, Cuiaba**
 Represented by / **Dr Sylvia Thomas, MD**
 Duration / **2006–2009**

JOINT FORCES FOR IMPACT

“My dream to strengthen the Federação Brasileira de Hemofilia (FBH) leadership as well as its regional chapters, to build a strong and united haemophilia society became true, with the support of NNHF.”

These are the final lines of text in the final report about the NNHF-supported project in Brazil, a project titled PRO-HOPE. The report was written by Dr Sylvia Thomas, representative of the project partner. She came to the NNHF in 2005 with an idea for a project to strengthen the Brazilian Haemophilia Federation (Federação Brasileira de Hemofilia – FBH). The goal was to build a stronger voice in the fight for better care, a proper supportive patient network and more specialised medical knowledge on haemophilia.

At the outset of the project there was little cooperation between the 26 different chapters of the FBH. This made it difficult to influence the situation where many of the 26 Brazilian states lacked healthcare professionals with the ability to perform haemophilia diagnosis. There was no appropriate structure, organisation, cooperation or training for those involved in haemophilia care, and the families felt isolated without strong representation and no communication network.

Capacity building first

As part of the reinforcement of FBH and creation of a national network through the project, a new office was set up in the town of Cuiaba where the president resided at that time. This helped to improve the contact between FBH, its chapters and the hemocentros. Capacity-building activities were realised aimed at advancing the chapter leaders' knowledge and management skills. NNHF helped to realise this objective by linking FBH with Cesar Garrido, executive director of the Asociación Venezolana para la Hemofilia (AVH), an experienced patient leader and trainer, who conducted the training.

“At the educational session for local leaders from FBH I could feel how much they were interested in benefiting from this opportunity in order to learn leadership and project management skills,” says Cesar Garrido.

These activities empowered FBH to better advocate for patient rights and provide stronger patient representation. Among other important activities, the creation of national groups (technical committees of doctors, nurses and musculoskeletal specialists), regional symposiums for multidisciplinary teams and a nurses' symposium have been supported by the project to further accelerate improvement of care through advancing the skills of healthcare providers. The first Brazilian MSK Workshop was organised by FBH with the help of NNHF and in cooperation with the World Federation of Hemophilia. This activity is now being realised with the sponsorship of the Brazilian Ministry of Health.



Another major accomplishment was the development and execution of an early developed succession plan which played a key role towards guaranteeing the sustainability of the achieved goals and a smooth transition to the well-prepared newly appointed FBH president. In July 2009, the office in Cuiaba was closed and all the materials acquired during the project were transferred to the new president's office in Caxias do Sul.

Tools to build a strong network

Patients and families living all over the country gained an efficient communication and counselling network through the association's website with latest news, educational material and patient forums as well as the distribution of regular newsletters. They were also empowered by training sessions, more prepared leaders and being embedded in a caring network between FBH and its chapters as well as the hemocentros.

Impact on many fronts

In total, 288 healthcare providers and 61 leaders from FBH were trained. Twelve thousand copies of educational material on haemophilia were distributed to healthcare professionals, and 41,300 to patients.

Through the strengthening of both organisation and leadership a much better contact with authorities and the community has been achieved.

Project / **Capacity building in haemophilia care**
Partner / **University Children's Hospital, Skopje**
Represented by / **Prof Sofijanka Glamocanin**
Duration / **2007–2009**

BUILDING THEIR OWN DESTINY

Macedonia is a young country, trying in a multitude of ways to move forward and build smart solutions for the problems they face. These same ambitions marked the project supported by NNHF in Macedonia.

Even though diagnosis and treatment of haemophilia began in Macedonia in 1965, at the start of the project, patient monitoring and management were best described as limited, insufficient and inadequate leading to life-long pain, disabling deformities and other complications. This was due to limited resources and lack of awareness of a condition which requires specialised care. Furthermore, people with haemophilia suffered not only from the physical pain caused by the bleedings, but were often isolated as most people in society do not know how to react to or deal with their condition.

Improving the situation

To improve the situation, the project aimed at assessing the health and clinical status of all persons with haemophilia in Macedonia, as well as re-diagnosis in order to have a complete picture of the situation in the country. This was realised during visits by a team of three representatives from the project team to the regions. On the same occasions, educational sessions were performed for patients and families, who also received written material to take home.

In parallel with the assessment and screening activities, a new web-based national registry was set up, where all regional centres can update the data of their patients directly. Seminars on usage of the registry were organised as part of the visits, ensuring the regional centres' ability to keep the registry up-to-date.

To further improve the quality of care and diagnosis, educational workshops accompanied by material for doctors and other healthcare professionals were also performed. More than 500 doctors, 100 nurses and 20 laboratory technicians took part in these workshops.

Another major activity was the translation of the 'Guidelines for the Management of Haemophilia', which were subsequently also accepted by the Macedonian Haematology Association as national guidelines and are now used on a regular basis in all haemophilia centres.

This was all made possible through close and good collaboration by all involved parties. This way, they also managed to overcome challenges caused by organisational changes at the hospitals.

Knowledge is power

As a result of the screening and assessment, the project stakeholders were able to present new and accurate data as well as unified recom-

mendations for treatment and management of the condition. This information was crucial in the dialogue with the authorities.

The need for better treatment and its inclusion in the country's new health strategy was put on the agenda at workshops and meetings with healthcare professionals and authorities.

This dialogue has not only provided haemophilia with a more prominent position in the health strategy. Also, a centralised distribution of products for the treatment of haemophilia and payment by the national budget were accepted in the Law of Health Care.

"We are proud of the significant benefits for people with haemophilia realised through this project's activities. Key to these achievements is the good collaboration between all involved parties – hospitals, patients and families. These results have set an important basis ensuring better care and treatment for people with haemophilia and serve as a platform for driving the next steps on a national level," says Prof Sofijanka Glamocanin.

On this background, the NNHF Council has approved a follow-up project aiming at the establishment of a National Comprehensive Haemophilia Treatment Centre.



Project / **Capacity building for haemophilia care programme – a pilot study**
 Partner / **National Institute of Blood Disease and Bone Marrow Transplantation (NIBD), Karachi**
 Represented by / **Dr Tahir S. Shamsi**
 Duration / **2007–2010**

START SMALL – FINISH BIG

“We’ve reached a new milestone in haemophilia care in this country. Now is the time to capitalise on it and make haemophilia a national responsibility.”

These are the words of Dr Tahir Shamsi, after the completion of a NNHF-funded regional pilot project in and around Karachi. The talk of ‘national responsibility’ eludes to the fact that NNHF has decided to fund a follow-up project, aiming at extending the results to the rest of the country.

The country challenge

Haemophilia in Pakistan is marked by no formal national registry, not enough factor preparations to treat, limited knowledge and resources, inadequate diagnosis, monitoring and treatment. High support for haemophilia comes from the patients’ society and other NGOs.

Dr Shamsi came to NNHF with the idea of upgrading the Karachi treatment centre to be able to engage with regional leaders and training of colleagues upon completion of the project.

Specific results

An observational study to collect data and confirm diagnosis and severity was designed. More than 600 haemophilia patients and their families were screened and educated and four medical staff were trained as master trainers.

Today, a very comprehensive and practical laboratory manual and guidelines for the diagnosis of congenital bleeding disorders have been developed and are being distributed, which increases knowledge of haemophilia in the healthcare community and at government level.

Other sponsors of the project were also engaged, of which one is promising to sponsor 500 people with haemophilia for life. This translates directly into better access to care.

Dedication saves project

In the course of the project, two major challenges were faced and overcome. All due to the partner’s dedication and leadership skills.

“The environment is very complex and with very strong groups. Dr Shamsi is contagiously positive, has a very well-organised team and is not afraid to share the credit for the successes they experience,” says Alexandre Bento Costa Alencar from NNHF.

Firstly, at the outset of the project it was somewhat difficult to recruit patients and their families for screening and diagnosis. Through con-



centrated advocacy, the Ministry of Health was convinced of the benefit of them writing letters directly addressed to the patients, and Dr Shamsi was invited to participate in a widely heard radio show. With these efforts, patients started turning up at the clinic.

“Sharing experiences with other project countries at the annual project partner meeting of NNHF, in respect to how to increase the number of patients turning up, helped us improve the execution of our screening programme,” says Dr Shamsi.

Secondly, the hospital where the project was initially anchored closed down one year into the project period. Equipment bought particularly for this project, plus funds already released were lost. The partner found a non-profit hospital, the NIBD, in which to locate his activities, but was still short of funds to replace his equipment. Through a dedicated effort Dr Shamsi managed, with the help of other non-profit organisations, to make the required equipment available and to realise the test and diagnose patients and their families with the help of other doctors.

A brighter future

At the project’s closing meeting in March 2010, the community stakeholders including Ministry of Health representatives were all present. This implies increased sustainability of future work in improving haemophilia care.

Project / **Improvement of haemophilia care through outreach**
 Partner / **Emergency Clinical Hospital 'Louis Turcanu' Haemophilia Centre, Timisoara**
 Represented by / **Prof Dr Margit Serban**
 Duration / **2007–2010**

AMBITIOUS IN SPITE OF CHALLENGES

In Romania, people with haemophilia face many challenges. Diagnosis is lacking, and access to adequate care and rehabilitation is rare.

Due to limited resources and means, Romanian healthcare professionals have often been at a loss to provide proper care. This leaves many people with haemophilia with little confidence in medical and social services.

More than 80% of people with severe haemophilia in Romania live with some form of disability, interfering with their quality of life as they are limited professionally and socially.

Prior to this project, only two centres were able to provide complete haemophilia diagnosis and expertise. Many people with haemophilia had to travel over long distances in order to access diagnosis, therapy and monitoring. Travelling is difficult due to precarious public transport and roads, which for people with haemophilia signifies increased risk of bleedings. Added to that, travel is often a substantial financial burden, which meant that patients had stopped looking for medical care.

An ambitious project

On this background, a project was suggested to NNHF by Prof Dr Serban aiming at creating first more haemophilia centres to broaden the geographical coverage with infrastructure and educational programmes, and secondly, a country-wide database giving evidence of the health status, economic burden and needs of the patients in order to increase awareness at the authority level.

Taking into account the complex, ambitious aims of the project focusing on the whole country, a study group consisting of important specialists was set up and doctors from all the centres with functioning haematology clinics were involved.

The project faced a number of challenges, for example financial pressure on hospitals, lacking networking and collaboration between stakeholders as well as difficulties to locate patients.

Promising outlook for haemophilia care

Nevertheless, the project provided five centres with clinical abilities and functional laboratory facilities to become functional haemophilia centres. In order to improve capabilities, numerous workshops for healthcare professionals from the whole country, patients and their families were conducted. Through screening, the registry was updated. 544 new patients have been added to the registry, and all 1,665 patients registered received a proper diagnosis. Three different questionnaires



on quality of life, health status and economic data were developed and distributed to the patients. The results were put into a database and analysed to be published in several abstracts.

An important accomplishment as a consequence of this project is the creation of a National Alliance for Rare Diseases embracing caregivers, patients, family members, media, pharmaceutical companies and representatives of the Ministry of Health. In a concerted effort, this group managed in 2010 to influence health authorities to increase the budget of the National Health Programme for Haemophilia by 69%.

“Even though we don't have a signed agreement with decision-makers yet, in a letter addressed to the national Haemophilia Association by the Minister of Health we have been assured about the firm decision to go on in the forthcoming period with this positive attitude towards haemophilia care in Romania,” says Prof Dr Serban.

On both fronts, this project achieved important results with strong engagement of the partner and her team; and forces were unified to take next steps.

Project / **Improvement of haemophilia care by awareness creation**
 Partner / **Centro Hospitalario Pereira Rossell, Montevideo**
 Represented by / **Dr Ismael Rodríguez Greco**
 Duration / **2008–2010**

PROGRESS THROUGH UNITY

Haemophilia care in Uruguay is reasonable, but awareness and knowledge among many healthcare professionals is low.

Prof Ismael Rodríguez has best described the project objectives: “The objective of this project is to create, develop, implement and promote different preventive and health promotion activities in the hospital environment, aimed at the community of children, adolescents and their families that are served by this institution.”

The level of haemophilia care in Uruguay is reasonable. The challenges faced are different in this small country with good roads. However, at the time of this project's initiation, the general state of awareness

amongst many healthcare professionals as well as the interest in activities for patients and their families can best be described as low.

This meant that healthcare professionals, for example general practitioners or dentists outside the capital area, were often unsure how they should provide care for haemophilia patients, due to a lack of knowledge. This meant that patients were going to specialised clinics in the country's capital for nearly all their care needs.

Situation improves

Through the project's activities, the situation has improved considerably. Up to 10 workshops for patients and their families as well as healthcare professionals were organised. On these occasions, educational booklets were distributed, covering basic information about haemophilia.

Patients united

The haemophilia community has again grown closer and the patients are growing in force and self-consciousness.

Prior to the project, patients were loosely connected and had little shared purpose. The project's activities have increased and improved the organisation of the patients and parents, enabling them to unite.

Through real empowerment of the patients and their families the efforts to increase the awareness of the healthcare community in Uruguay have grown. There are now self-driven projects supported through, for example, a Facebook page for the haemophilia community. In this way, a positive spiral benefiting people with haemophilia has been set in motion by this project and will surely continue to the benefit of the haemophilia community.



Project / **School for children at the national haemophilia centre**
 Partner / **Scientific Research Institute of Hematology and Blood Transfusion, Tashkent**
 Represented by / **Dr Aziza Dj. Makhmudova**
 Duration / **2008–2009**

LEARNING FOR LIFE

Hospitalised children with haemophilia get new resources and new learning opportunities bringing back 'normal' life.

“Imagine a small child away from his normal life for up to eight months; something that will feel like a lifetime for a child of this age. With no school, no sports and no other activities. But this haemophilia school will change all of this. It will bring ‘normal’ life back to these children and tremendously improve their chances and quality of life,” says Aziza Makhmudova, MD, head of Haematology Institute, Tashkent.

In Uzbekistan, as in many other countries where proper care is not available in all regions, and treatment is scarce, children with bleeding disorders are cared for at a specialised hospital. Sometimes for several months, many times a year, away from their home, family and friends.

Today, the team of Dr Makhmudova has successfully set up a school at the first newly built specialised haematology institute in Tashkent. The institute was made possible by local funds raised through awareness created by the first NNHF project in Uzbekistan, which aimed at country-wide diagnosis, education and set-up of a national registry.

The follow-up project, supported by NNHF, ensures dedicated care for the children’s educational and social needs, while they are admitted to the hospital.

Learning how to cope

In addition to the standard school curriculum, children are offered activities specifically designed to help them develop social skills and adapt more easily to life with haemophilia.

Art classes, where they can relate to their situation in a creative way, is one example. Teaching the children how to swim offers them the opportunity to exercise their bodies in a way that does not jeopardise their health.

Finally, the children have sessions – in groups and individually – with a psychologist. This has been found to impact their self-esteem beyond what was expected.

“First of all, these children need to be helped to forget about their condition and not feel like they are sick,” says Javdat Pulatov, the school psychologist. “Some children with haemophilia slowly withdraw from social life. We help them see that they too have a place and are needed in society, to attain personal growth, and that they can reach their goals just as anyone else.”



The school also works with parents, showing them how to deal with the routines of daily life. And most importantly helping them understand the need to avoid differential treatment of the child with haemophilia by themselves and others in society.

“We noticed that most of the children have started to look at life with more interest. They enjoy the classes so much that they don’t want to go home and we allow them to stay as long as they want to,” says Dr Makhmudova.

Future funding secured

Through the strong contacts and relationships formed in both NNHF projects in Uzbekistan, the local partner has raised additional funds from a local foundation and managed to secure the future of the school, as the country’s Ministry of Health in collaboration with the clinic has taken over responsibility for the operation and further development of the school and its activities.

“The joy of the children and grateful parents inspired us to capture this great example in a film in order to share better practices and show the great impact of the newly built school. The film is available on our website, www.nnhf.org,” says Nuriye Ulucan, communications manager of the NNHF.

Fellowship /	Learning advanced diagnosis and quality assurance
Partner /	Royal Free Hospital in London and the WHO Standards Laboratory for Coagulation with the NIBSC, North London
Represented by /	Dr Jing Dai, Ruijin Hospital, Department of Clinical Transfusion, Shanghai
Duration /	Five months starting in May 2009

A FELLOW READY FOR NEW RESPONSIBILITIES

Two of the issues in haemophilia care in China are lack of proper testing to provide accurate diagnosis, and quality assurance in laboratories.

To alleviate this situation, a fellowship focusing on laboratory training was awarded to Dr Jing Dai.

Her goal was to improve knowledge in diagnosis including new detection techniques, and to learn how to assure the quality of lab testing and set up standards of performance. This was seen as a route to implementing international standards at Ruijin Hospital by establishing a quality control system, and subsequently setting up a national reference laboratory.

The long-term outcome of the fellowship and the new project 'Improve and extend comprehensive care in China', should be consistency throughout the country by the dispersion of knowledge about diagnosis and quality assurance. In this project, Dr Jing Dai will travel to haemophilia centres in other regions in China to provide a skills upgrade of their staff.

According to Dr Jing Dai, the "expertise gained in London is very useful. I plan to set up new tests in my laboratory and set up quality control systems, and to train the laboratory technicians from other centres in China through workshops. I am proud to be responsible for moni-



toring and supervising the quality of laboratory work in Southern China, within the ongoing China 2 project, and collaborating closely in this respect with Dr Baolai Hua from Beijing, who is responsible for Northern China."

NNHF Fellowships

NNHF also supports fellowships for healthcare professionals from the countries within our scope. The fellowships consist of specialised training for physicians, nurses and laboratory technicians or other healthcare professionals.

To receive a fellowship, the recipient must have some prior experience in haemophilia and, upon completion of the fellowship, is expected to have gained further specialty knowledge which through training activities will be spread to other healthcare professionals in their home region.

For application forms and guidelines, please visit the NNHF website: www.nnhf.org



Project / **Desafío Orinoco 2010**
 Partner / **Asociación Venezolana para la Hemofilia (AVH), Caracas**
 Represented by / **Cesar A. Garrido, executive director. Co-sponsored by Bayer Health Care in Venezuela**
 Duration / **2009–2010**

SWIMMING FOR BETTER HEALTH

Twelve young Venezuelans with haemophilia or allied bleeding disorders and carriers prepared for nine months to participate in the internationally recognised swimming event 'Paso a Nado Orinoco' (Orinoco swimming competition).

The goal of the initiative was to demonstrate the importance of physical exercise for people with haemophilia and allied bleeding disorders for improving their joint status and quality of life. Increased awareness of haemophilia could also be achieved, it was hoped.

In total, more than 900 participants swam the distance of 3,100 metres on 25 April 2010, but it was the first time a team of people with haemophilia and carriers was part of the race.

"In our work in the developing countries, we experience the lack of knowledge in the haemophilia community when it comes to the importance of preventive activities, to keep joints healthy, through physical improvement as a supplement to conventional treatment. We want to change this by offering education on this subject for patients, families, medical specialists and other community members," says Susanne Brandl, general manager of NNHF.

Strong outcomes

The project was initiated by the National Haemophilia Association of Venezuela (Asociación Venezolana para la Hemofilia – AVH). Swimming is one of the most recommended sports for people with haemophilia as it is associated with minimum risk of bleedings while building muscles. Strong muscles help stabilise and protect joints like knees, elbows, ankles and shoulders, which otherwise risk becoming target joints.

The project confirmed that people with haemophilia and other allied bleeding disorders can compete with other people who do not have the same condition – given that they get access to adequate care and lead disciplined lives.

A multidisciplinary team of haematologists and physiotherapists evaluated the swimmers regularly during the project period. At the trainings they were always accompanied by nurses, a psychologist and personal trainers. The training increased the muscle mass making the joints more stable. Improvement of the movement angle of some joints in some of the participants was also recorded. Ultrasound was used to document their muscle development.

A life-changing experience

For the participants, the project changed a lot more than their muscle mass and the angle of joint movement.



For more information, pictures and movies about the project go to www.nnhf.org and www.desafioorinoco.com

One team member explains how the competition changed the way he sees himself.

"During the competition I completely forgot that I have haemophilia. I was a swimmer – a sports person as any other with the same goal: crossing the rivers. Now, I feel I can do everything," he says with a laugh. "It showed me that I am able to do a lot more and that gives me confidence in facing new challenges."

Spreading the word

Aside from the direct benefits for the participants, such as the improved articulations and the positive effect on their self-esteem, the project is also hoped to motivate others to follow their example. Crossing the Orinoco is not for everyone, but regular exercise and a disciplined life can be.

"We were all so nervous – the families, friends, physicians – while waiting at the finish line: nine months of intense training, a lot of efforts from a lot of people, a lot of conversations, evaluations, etc. All this was done to prepare them for this day where they could show what they were able to do. When the swimmers arrived one by one it was an amazing feeling. Seeing them so happy and proud we knew that it was great that we supported this initiative," say Susanne Brunner and Nuriye Uluçan from NNHF.



JINGER'S PERSONAL CHALLENGE

"I'm a teenager with dreams. Haemophilia is my constant companion while I reach for them."

Jinger is 16 years old and lives in Caracas, the capital of Venezuela. In many important ways, Jinger is a teenager just like any other. But one thing distinguishes Jinger from other teenagers. He was diagnosed with severe haemophilia A at the age of one.

For five years he has been on primary prophylaxis. The number of bleedings has been considerably reduced, resulting in a lot less pain, lower school absenteeism and allowing him to do activities every teenager loves to do such as for example singing and swimming.

One activity he is very proud of is his participation in the Orinoco-Caroni River Crossing on 25 April 2010.

His mother explains that when Jinger heard about the 'Desafío Orinoco 2010' project he was consumed by the idea of participating. He trained intensively and qualified for the project in the national competition in August 2009 when the team was assembled.

The training schedule was heavy and the regular evaluations had to be passed. A small bleeding in the elbow caused by falling down the stairs a couple of months ago forced him to reduce the training for a while,

and it was a little bit difficult to get back into the training schedule. But Jinger was motivated by the other swimmers in the team, the trainer and also the haematologist, he wanted to be part of the competition. Over time through the training his muscle strength improved, making his joints more stable and less prone to bleed.

Jinger says, "I feel a lot healthier through the regular trainings. It makes me feel stronger and I have more confidence that the bleeding will hurt now but will be over and then I can do what I like to do. Since I have been training more, my knee also hurts less."

Swimming in open waters was new to Jinger, crossing long distances as well. The psychological support provided helped him overcome the unease in this respect and he says, "this will help me forever as I learnt to have more confidence in what I can do."

The competition was not about winning but about crossing the river together with his team: all together! It was the realisation of a dream! Jinger, as many of the others in the team, is determined to continue swimming after the competition, as it is clear to him that regular swimming makes him feel better, healthier and stronger.







THE IMPORTANCE OF QUALITY DIAGNOSIS AND CARE

Ulla Hedner, MD, PhD

Professor emeritus, Lund University
Lund, Sweden

Haemophilia is a rare bleeding disorder and often not on the health agenda due to a lack of awareness of the local situation and the impact of the disease. Accurate diagnosis provides consistent data, a key component in improving care and treatment.

The main reason for improper care is an extensive lack of knowledge about the disease, which leads to a low priority in healthcare systems. This is especially true in so-called developing countries where four-fifths of the world's population live.

To improve haemophilia care, a first step to undertake is to gain a better overview of the local situation and the impact of the disease. Quality diagnosis is especially important, given the fact that accurate diagnosis and follow-up on treatment are essential to successful care.

Focus has to be on *the establishment of diagnosing and care centres providing high quality of laboratory as well as clinical competence.*

Important learnings from two projects

An important part of increasing knowledge about this condition is the development of laboratory facilities for quality diagnosing of haemophilia.

The findings of a first project supported by the NNHF (Pakistan 1, see page 13 and 24–25), support this importance: when re-tested about 20% of patients in Pakistan were found to have a wrong diagnosis. The need for high-quality diagnosing centres outside the capital in order to secure a good patient care also on a regional level was recognised in Venezuela (see pages 26–27). This is now the focus of an upcoming second NNHF project in this country.

Necessary for improved haemophilia care, thus, are:

1. The establishment of *high-quality diagnosing centres*. Such centres should have reliable technical equipment and should be working according to Good Laboratory Practice (GLP). This means that they should be subjected to accreditation including Quality Assurance (QA). Furthermore, these quality diagnosing centres should continuously participate in External Quality Assessment (EQA). (Read more about quality assurance in the NNHF Annual Report 08/09, which is available on www.nnhf.org).
2. However, high-quality diagnosing centres should also include a *well-educated staff of healthcare providers* able to interpret the results from the laboratory diagnosing, integrating the laboratory results with the clinical picture and helping the patient and his family to cope with the situation. This means close contact with the patients,

advice regarding rehabilitation, general help in association with bleeding episodes as well as social support (school, work etc). By working and networking with the patients and their families as well as with the medical society they will provide the basis for lobbying for improved healthcare for haemophilia patients through the health authorities in their countries.

3. There also needs to be a focus on *awareness creation and establishment of a functioning network*. Based on the quality diagnosing centres, knowledge about haemophilia and its care will be spread in the country through local, regional and national health agencies. In the long run this will help provide support to a nationwide haemophilia network, care and treatment supported by health authorities.

Dedicated staff with strong support

As pointed out by Dr Shamsi in Pakistan in his article on the following pages, special emphasis has to be on finding the right human resources and expose them to tailored comprehensive training and support. The chosen centres should have adequate resources in terms of laboratory equipment in order to avoid apathy and feelings of hopelessness among the staff.

Increased knowledge about and recognition of haemophilia by authorities is necessary for support of haemophilia care. An example of such a development is seen in Pakistan, where the Ministry of Social Welfare, Pakistan Bait-ul-Maal, has initiated a haemophilia patients' support programme, initially in three major cities, planning to expand it to the rest of the country in the years to come.

The NNHF projects in Pakistan and Venezuela, described on the following pages, have contributed and will further add to the development of a haemophilia network including high-quality diagnosing centres and thus prepared the basis for an increased awareness of haemophilia in these countries. In the long run this will result in improved haemophilia care.

CORRECT TREATMENT REQUIRES QUALITY DIAGNOSIS

Dr Tahir Shamsi, MD, MSc

Director, National Institute of Bleeding Disease and Bone Marrow Transplantation (NIBD)
Karachi, Pakistan

It is known that for correct treatment, the right diagnosis is needed. This is especially true for chronic/genetic disorders.

In countries with limited resources, limited diagnostic facilities, marginally trained manpower, maintained equipment and adequate consumables to perform the diagnostic tests and then to interpret them, lead to incorrect diagnosis. On top of this, no or inappropriate treatment jeopardises the lives of people with haemophilia and other bleeding disorders. One of the important reasons for this is that such disorders fall in the lowest priority in the healthcare system of these countries.

Improving diagnosis on a national level is a stepwise approach – from a regional pilot project to national expansion, with a focus on setting laboratory quality standards and ensuring expertise, performing a national diagnosis programme and establishing a consistent database.

Ensuring correct and quality results requires simple basic rules. The selection of the right equipment and reagents has to suit the given local environment, the laboratory facility, the staffing and available expertise. The development of local standard operating procedures as well as the implementation of internal quality control and external quality assessment schemes plus networking with an advanced reference centre, are some of the steps which will ensure quality diagnostic results.

Diagnosis challenges

Haemophilia patients most often visit the hospital or known haemophilia centre in proximity to their homes for acute bleeding episodes. In resource-poor countries, lack of appropriate expertise and care results in inadequate, ie sub-optimal treatment. Apathy of 'healthcare providers' in local hospitals or haemophilia centres due to non-availability of resources harms people with haemophilia and other inherited bleeding disorders.

Therefore, mildly affected patients are not diagnosed until they have a catastrophic bleeding after injury or surgery. People with moderate or severe symptoms are the ones most often diagnosed. Most laboratories performing screening tests for bleeding disorders are not equipped properly, they do not have standard operating procedures (SOPs) in place for internal quality control, no external quality assurance scheme exists, which makes assurance of consistent results and quality diagnosis very difficult, if not impossible.

Taking steps

To analyse the situation in Pakistan we used the NNHF lab assessment tool in our first pilot project in Karachi and its region, to evaluate haematology departments of five teaching hospitals on their ability to



perform coagulation tests. The survey has shown limitations when regarding results of bleeding time, prothrombin time and activated partial thromboplastin time. Over 20% of patients proved to have a wrong diagnosis when re-tested during the further execution of the project.

To improve the situation, we established a quality control programme within our above mentioned project including the development of standard operating procedures (SOPs) and a comprehensive lab manual for all procedures starting from patient history recording, sample collection procedure, sample processing and storage, analysis of specimen, instrument calibration and proficiency testing, result documentation, troubleshooting of errors plus reagents storage and quality control. Furthermore, our labs started to participate in the WFH/WHO external quality assurance programme through NEQAS, UK. All the related initiatives greatly improved our performance and diagnostic abilities.

Having set the basis for quality testing, we started a diagnosis programme embracing known patients for re-testing to confirm or rectify their diagnosis as well as diagnosing new people with haemophilia or allied bleeding disorders. Resulting consistent patient data were registered in a newly created database.

National coverage in new project

Aiming at expanding the above described approach focusing on quality diagnosis, registration and education to a national level, a new follow-up project has recently been approved and will be starting soon. In a

first phase, 'haemophilia treatment facilities' in five major cities along with a teaching hospital where a haematology department exists, will be asked if they want to participate in this lab assessment and screening programme.

Once the laboratories have been assessed, equipped and their staff well trained, the participating centres will need and receive reagents, consumables, a computer for the national haemophilia registry database and any missing equipment to start the screening programme. They will be asked to report all the results of daily quality control procedures to the national project office at NIBD and enter patients' information in the database.

Logistically, it will be a challenge to carry out this project. Training, follow-up, networking and provision of technical assistance will need to be readily available at every step.

The project coordinator at NIBD will evaluate their performance and rectify any issue on a regular basis. Regular communications and surveillance visits to participating centres will be planned to review activities, consult, share experiences and troubleshoot any problem which a centre might be facing.

Emphasis needs to be placed also on the information of the general public as well as the people with haemophilia and other inherited bleeding disorders and their families, to reach all to be re-tested or newly diagnosed people.

To make this national initiative become a success, the haemophilia community needs to work together and dedicate all its efforts to the benefit of people with haemophilia and other bleeding disorders.

Signs of positive change

With this approach we are sure to jointly reach our aim to establish quality diagnosis and care in Pakistan benefiting the community. We will gain consistent prevalence data and information about the status of our patient population and hope to be able to offer adequate treatment over time. A continuous flow of information to health authorities, such as the Ministry of Health directly through NIBD, involved



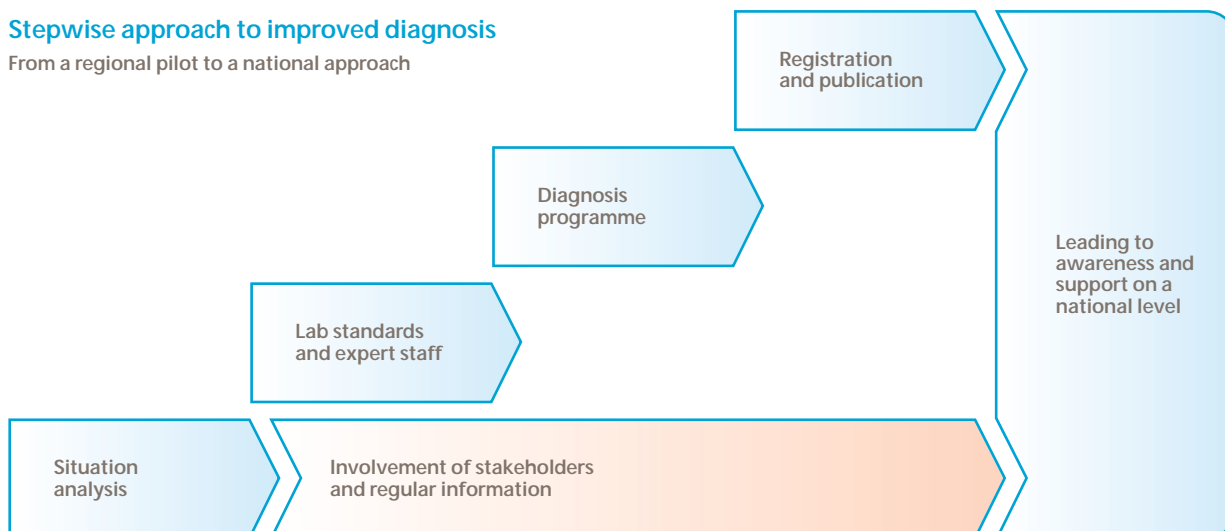
haemophilia treatment facilities, haemophilia patients' societies and media will support disease awareness and haemophilia becoming part of national health initiatives and programmes.

The first strong positive signs are already taking place. A subsidiary of the Ministry of Social Welfare, Pakistan Bait-ul-Maal, initiated a haemophilia patients' support programme initially in three major cities and plans to expand it to the rest of the country in the next few years.

We believe that a well-organised and knowledgeable haemophilia community including patients, their families and healthcare professionals can reach out through disease awareness activities and lobbying initiatives to talk to health authorities, such as the Ministry of Health for recognition of haemophilia as a problem and finally join forces to accelerate care and treatment.

Stepwise approach to improved diagnosis

From a regional pilot to a national approach



DECENTRALISATION OF QUALITY STANDARDS

Dr Arlette Ruiz-Sáez, MD, MSc

Head of the National Haemophilia Centre at the Banco Metropolitano de Sangre Caracas, Venezuela

Decentralising quality diagnosis facilities and expertise will help further improve the diagnosis and treatment standards throughout Venezuela.

The clinical and laboratory diagnosis of haemophilia and other haemostasis disorders is essential to initiate appropriate and timely treatment to the patient and allow its inclusion in the National Register. Both will support the design of health programmes aimed at improving haemophilia care and quality of life for patients. For the results of laboratory tests being reliable it is required to have properly trained personnel and compliance with quality management programmes.

Need for expanding diagnosis and treatment

The National Haemophilia Centre (CNH-BMS) in Caracas, functions as reference centre, where all patients with bleeding disorders are diagnosed and treated. The centre also keeps the National Register of these pathologies updated. Since 1997, the NHC and the AVH-BMS (NMO), working together and with the support of foundations like NNHF and WFH, have been able to establish a network of haemophilia treatment centres (22) and subsidiaries of the NMO (11) throughout the country. To achieve this goal several strategies were used which were based on educational activities, patient outreach programmes and a multidisciplinary approach.

During this period, in most of the visits to the different regions, one of the activities included was laboratory screening by taking samples of the patients locally which were forwarded to the CNH-BMS for processing in its centralised reference laboratory in Caracas. This strategy allowed identification of people with haemophilia, haemophilia carriers and patients with other coagulopathies.

Through these visits, the need for laboratories in the regional centres that serve a significant number of patients, or in centres far from the capital (CNH-BMS), became clear. Secondly, the necessity to improve the diagnosis of von Willebrand disease and other inherited bleeding disorders became evident.

Currently in the regional centres, doctors use the general hospital laboratory where only the basic tests of PT and PTT can be performed. Only one centre in Western Venezuela occasionally measure FVIII and FIX.

This reality makes the management of clinical emergencies, invasive procedures or complications difficult. In addition, new patients must travel to the capital to confirm the diagnosis of their coagulopathy including virology and complications such as inhibitors. This situation exposes the patient to inadequate treatment due to lack of proper diagnosis, in addition to the economic cost the travelling represents to the family.

The strategy applied

To address these needs, the new regional coagulation laboratories should have trained staff to diagnose new cases, study possible carriers, measure factor levels for therapy control and investigate the presence of inhibitors regularly, particularly in cases of severe bleeding, or prior to an invasive procedure. All these activities would allow the medical haematologist in the region to make more convenient decisions for the patient and thus make rational use of therapeutic products.

To achieve this objective we developed a programme to be implemented in stages over three years:

Phase 1: situation analysis & identification of needs

- Contact and motivate local treatment centre haematologists and involve them in the programme.
- Assess the conditions of the centre, especially human resources available, laboratory installations and existing equipment and consumables.
- This first stage allowed selection of seven public hospital laboratories located in areas with higher population density.

Phase 2: instalment of equipment & preparation of teaching material

- Ensure provision of equipment and materials, supplies and reagents needed for three years.
- Preparation of a guide to be used in the designated centres, including technical recommendations for use by all laboratories to unify criteria and procedures to follow.

Decentralisation of diagnosis Venezuelan four-phase model





Phase 3: comprehensive regional training programme

- Organisation of a theoretical-practical workshop in the CNH-BMS, addressed to the haematologists and laboratory technicians of the regional treatment centres. This workshop focused on the management of semi-automated equipment, conduct and interpretation of screening tests, determination in stage by the method of FVIII and FIX testing, quantification of inhibitors by the Bethesda method, and the fundamentals of internal and external quality assurance programme.
- Training in the CNH-BMS of laboratory personnel from the western parts of the country in FVWAG and VWF:RCo techniques.

Phase 4: establish regular monitoring process resulting in a national quality control programme

- Continuous assessment of regional laboratory performance through indicators previously agreed upon by the team.
- Establish a quality control programme through the preparation and shipment of CNH-prepared samples to the regional laboratories.

Goal: national coverage

With the completion of this programme led by the CNH and the AVH, we achieved:

- The creation of a *national laboratory network* focusing on diagnosis of haemorrhagic diseases at the regional level and thus contribute to improving the quality of life of our patients, in part, by preventing the patients having to go to the capital for diagnosis.
- *Strengthening of the regional centres*: a certified laboratory facilitates the control of patient care, especially their treatment, which is necessary to evaluate prophylaxis regimens, immune tolerance and the performance of elective surgeries.

- *Optimisation of the national registry* of patients with bleeding disorders and their complications.
- *Improved level of knowledge* about the diagnosis and management of haemorrhagic disease among healthcare professionals.
- *Improved diagnosis* of haemophilia and vWD as well as other bleeding disorders.

Securing continued support

We are thankful to the NNHF for their support of the above described development project.

Very important for us as well as our sponsor is the programme's continuity. To ensure sustainability of the achievements, we need the involvement and long-term engagement of all community members within our national haemophilia network.

To address the need for rational and proper use of the equipment and reagents during the project as well as afterwards, a comprehensive training schedule as well as regular communication for experience exchange, inventory controls as well as monitoring visits were planned beyond the project duration. Furthermore, participation of local, regional and national health agencies was planned to maintain constant communication about the importance of this specialised resource.

We are confident that we will accelerate haemophilia care significantly on a national basis by making a difference through focusing on the importance of regional quality diagnosis and registration.



Speaker
electronic
machine
electronic

ADIDAS
FOR
VAON



MAP OF PROGRAMMES

As of April 2010, NNHF has supported 33 locally-managed projects and six educational fellowships in 25 developing countries.



NEW PROJECTS

- 1 **CHINA 2**
Improve and extend comprehensive haemophilia care
- 2 **MACEDONIA 2**
Establish national comprehensive haemophilia treatment centre
- 3 **MEXICO**
Creation of a regional high-level paediatrician training centre
- 4 **MOROCCO**
Road to comprehensive haemophilia care in Morocco
- 5 **PAKISTAN 3**
Extension of education programme to a national level
- 6 **PAKISTAN 4**
Capacity building for improvement of haemophilia care on a national level
- 7 **VENEZUELA 2**
Improvement of quality of diagnosis of hereditary bleeding disorders on a national level

ONGOING PROJECTS

- 1 **ALGERIA**
Programme towards national comprehensive care
- 2 **BULGARIA 2**
Extension of comprehensive care to a national level
- 3 **CHILE**
National improvement of haemophilia treatment
- 4 **CUBA**
Establishment of comprehensive haemophilia care
- 5 **INDIA**
Establish a national network for paediatric patients
- 6 **IRAQ**
Improvement of diagnosis and establishment of national registry
- 7 **JORDAN 2**
Establish national registry for hereditary bleeding disorders
- 8 **LEBANON**
Multidisciplinary haemophilia care
- 9 **MALAYSIA**
Educational programme for haemophilia and vWD patients and parents
- 10 **PANAMA**
Latin American haemophilia network – pilot project
- 11 **SOUTH AFRICA**
Comprehensive haemophilia care in KwaZulu Natal
- 12 **VIETNAM**
Improvement of haemophilia diagnostic and treatment level



COMPLETED PROJECTS

- 1 **BRAZIL**
Improvement of haemophilia organisation and patient education (2009)
- 2 **BULGARIA**
Creation of comprehensive haemophilia treatment centre (2008)
- 3 **CHINA**
Haemophilia education, screening and registration (2008)
- 4 **JORDAN**
Molecular genetic analysis in haemophilia population (2009)
- 5 **MACEDONIA**
Capacity building in haemophilia care (2009)
- 6 **PAKISTAN 1**
Capacity building for haemophilia care programme – a pilot study (2010)
- 7 **PAKISTAN 2**
Education of people with haemophilia and their families at a national level (2009)
- 8 **POLAND**
Standardisation of haemophilia diagnosis and treatment (2007)
- 9 **ROMANIA**
Improvement of haemophilia care through outreach (2010)
- 10 **URUGUAY**
Improvement of haemophilia care by awareness creation (2010)
- 11 **UZBEKISTAN**
Improvement of haemophilia diagnostic and treatment level (2007)
- 12 **UZBEKISTAN 2**
School for children at the national haemophilia centre (2010)
- 13 **VENEZUELA**
Optimisation of haemophilia organisation (2007)
- 14 **VENEZUELA**
Desafio Orinoco (2010)

CANCELLED

- PALESTINE**
Train-the-trainer – education, screening and registry (2010)

FELLOWSHIPS

- NEW**
- BRAZIL**
Studies in Italy of effective physiotherapy care
- IRAQ**
Multidisciplinary studies in the UK of bleeding disorders in women
- SRI LANKA**
Studies in the US to acquire knowledge in diagnosis and management of patients with bleeding disorders
- THAILAND**
Studies in the US to improve research skills in molecular pathogenesis of coagulation disorders with emphasis on haemophilia

COMPLETED

- CHINA**
Studies in 2008 in the UK of methods to improve the diagnosis and treatment levels of bleeding disorders.
- CHINA**
Studies in 2009 in the UK of diagnosis and quality assurance in laboratories.



OVERVIEW: OUR DEVELOPMENT PROGRAMMES

NEW PROJECTS

1 CHINA 2 Improve and extend comprehensive haemophilia care to further regions

Partner / **Ruijin Hospital, Shanghai**
 Represented by / **Dr Hongli Wang**
 Planned duration / **Two years, approved 2009**

OBJECTIVES

- Set up national laboratory quality assurance scheme and train laboratory staff
- Extend haemophilia care – establish 10 new haemophilia centres in existing infrastructure
- Improve diagnosis of known patients and diagnose new patients
- Educate patients and medical staff to enhance expertise
- Update web-based registry and expand it to national level under the auspices of MoH

Country information

Population / **1.3 billion**
 Expected patients / **130,000**
 Known patients / **6,300**
 GDP per capita (USD) / **6,600**
 Health expenditure per capita (USD) / **342**

2 MACEDONIA 2 Establish national comprehensive haemophilia treatment centre

Partner / **National Institute of Transfusion Medicine, Skopje**
 Represented by / **Dr Violeta Dejanova-Ilijevska**
 Planned duration / **One year, approved 2010**

OBJECTIVES

- Establish a national comprehensive haemophilia treatment centre
- Train healthcare professionals and create a multidisciplinary team
- Education programme for healthcare professionals on comprehensive care
- Awareness creation about importance of comprehensive approach

Country information

Population / **2.1 million**
 Expected patients / **210**
 Known patients / **185**
 GDP per capita (USD) / **9,000**
 Health expenditure per capita (USD) / **623**

3 MEXICO Creation of a regional high-level paediatrician training centre – pilot project

Partner / **Unidad Medica de Alta Especialidad, Hospital de Pediatria, Centro Medico Nacional Siglo XXI, Mexico City**
 Represented by / **Dr Roberto Bernáldez Ríos**
 Planned duration / **One year, approved 2010**

OBJECTIVES

- Pilot project to improve regional haemophilia care
- Establish comprehensive education centre at Siglo XXI to become a regional reference training centre
- Develop treatment guidelines
- Create an interactive website to assist healthcare professionals
- Generate an updated patient registry

Country information

Population / **111.2 million**
 Expected patients / **11,120**
 Known patients / **4,300**
 GDP per capita (USD) / **13,500**
 Health expenditure per capita (USD) / **756**



4 MOROCCO
Road to comprehensive haemophilia care in Morocco

Partner / **National Haemophilia Committee**
 Represented by / **Contacts at four University Hospital Centres and the national patient association**
 Planned duration / **Two years, approved 2009**

OBJECTIVES

- Perform comprehensive national training programme for HCPs and patients
- Create comprehensive treatment centre in Rabat with focus on multidisciplinary team
- Support comprehensive treatment centre in Casablanca as well as regional haemophilia centres
- Strengthen national patient association and its chapters

Country information

Population / **33.8 million**
 Expected patients / **3,800**
 Known patients / **667**
 GDP per capita (USD) / **4,600**
 Health expenditure per capita (USD) / **273**

5 PAKISTAN 3
Extension of education programme to a national level

Partner / **Pakistan Haemophilia Patients Welfare Society (PHPWS), Islamabad**
 Represented by / **Dr Tahira Zafar**
 Planned duration / **One year, approved 2009**

OBJECTIVES

- Develop educational training modules, material and publications in Sindhi, Balochi, Pashto
- Establish inter-provincial collaboration of haemophilia stakeholders
- Perform comprehensive education for patients and their families
- Create awareness among government representatives

Country information

Population / **176.2 million**
 Expected patients / **17,620**
 Known patients / **1,250**
 GDP per capita (USD) / **2,600**
 Health expenditure per capita (USD) / **51**

6 PAKISTAN 4
Capacity building for improvement of haemophilia care on a national level

Partner / **National Institute of Blood Disease & Bone Marrow Transplantation (NIBD), Karachi**
 Represented by / **Dr Tahir S. Shamsi**
 Planned duration / **One and a half years, approved 2010**

OBJECTIVES

- Training of 20 regional healthcare professionals to become master trainers: train-the-trainer concept
- Develop treatment guidelines for haemophilia complications
- Establish 'Practical Haemostasis' handbook (Pakistan 1) as national reference
- Expand Pakistan 1-registry as national registry of congenital bleeding disorders
- Submit results to Pakistan Medical Research Council and Ministry of Health

Country information

Population / **176.2 million**
 Expected patients / **17,620**
 Known patients / **1,250**
 GDP per capita (USD) / **2,600**
 Health expenditure per capita (USD) / **51**



7 VENEZUELA 2
Marco Polo – establish quality diagnosis of hereditary bleeding disorders on a national level

Partner / **Asociación Venezolana para la Hemofilia (AVH) and National Haemophilia Centre (CNH), Caracas**
 Represented by / **Dr Arlette Ruiz de Sáez and Cesar A. Garrido**
 Planned duration / **Three years, approved 2010**

OBJECTIVES

- Optimise diagnostic laboratory units in seven regional centres
- Improve knowledge of regional healthcare professionals in diagnostic techniques
- Establish national laboratory network and strengthen regional treatment centres
- Improve diagnosis rate

Country information

Population / **26.8 million**
 Expected patients / **2,680**
 Known patients / **1,723**
 GDP per capita (USD) / **13,100**
 Health expenditure per capita (USD) / **396**

ONGOING PROJECTS

1 ALGERIA
Programme towards national comprehensive care

Partner / **Société Algérienne d'Hématologie et de Transfusion Sanguine (SAHTS), Algiers**
 Represented by / **Prof Meriem Belhani**
 Planned duration / **Three years, started 2006, prolonged**

OBJECTIVES

- Conduct comprehensive national haemophilia education programme for healthcare professionals and patients
- Improve diagnosis of haemophilia patients
- Establish national haemophilia registry
- Reinforce specialist care to strengthen the national reference centre and support regional treatment centres

Country information

Population / **34.2 million**
 Expected patients / **3,420**
 Known patients / **1,445**
 GDP per capita (USD) / **7,000**
 Health expenditure per capita (USD) / **188**

2 BULGARIA 2
Extension of comprehensive care to national level

Partner / **Specialised Haematological Hospital 'Joan Pavel', Sofia**
 Represented by / **Prof Toshko JeleV Lissitchkov**
 Planned duration / **Two years, started 2009**

OBJECTIVES

- Form and train multidisciplinary teams in medical universities
- Standardise screening and testing methods
- Perform regular examinations and consultations of patients with congenital bleeding disorders
- Educate healthcare professionals and patients
- Create awareness programme in South and North Bulgaria

Country information

Population / **7.2 million**
 Expected patients / **720**
 Known patients / **791**
 GDP per capita (USD) / **12,600**
 Health expenditure per capita (USD) / **741**



3 CHILE
National improvement of haemophilia treatment

Partner / **Roberto del Río Hospital, Santiago**
 Represented by / **Dr María Mercedes Morales Gana**
 Planned duration / **Three years, started 2009**

OBJECTIVES

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

Country information

Population / **16.6 million**
 Expected patients / **1,660**
 Known patients / **1,283**
 GDP per capita (USD) / **14,700**
 Health expenditure per capita (USD) / **697**

4 CUBA
Establishment of comprehensive haemophilia care

Partner / **Instituto de la Hematología e Inmunología (IHI), Havana**
 Represented by / **Prof José M. Ballester Santovenia**
 Planned duration / **Two years, started 2008**

OBJECTIVES

- Improve IHI to be established as national reference centre
- Train healthcare professionals and patients on a national level
- Set up two regional comprehensive care centres in Pinar del Río and Villa Clara

Country information

Population / **11.5 million**
 Expected patients / **1,150**
 Known patients / **398**
 GDP per capita (USD) / **4,500**
(source: economist.com)
 Health expenditure per capita (USD) / **342**

5 INDIA
Create a national network for paediatric care

Partner / **Sir Ganga Ram Hospital, New Delhi**
 Represented by / **Dr Anupam Sachdeva**
 Planned duration / **Three years, started 2009**

OBJECTIVES

- Develop training modules to improve diagnosis, treatment and preventive measures
- Perform regional workshops for paediatricians – train-the-trainer concept
- Conduct patient education camps

Country information

Population / **1.2 billion**
 Expected patients / **120,000**
 Known patients / **10,000**
 GDP per capita (USD) / **2,900**
 Health expenditure per capita (USD) / **109**



6 IRAQ
Improvement of diagnosis and establishment of national registry

Partner / **Medical City Hospital, Baghdad**
 Represented by / **Dr Nazar Al-Anbaki**
 Planned duration / **Two years, started 2007, prolonged**

OBJECTIVES

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

Country information

Population / **28.9 million**
 Expected patients / **2,890**
 Known patients / **1,200**
 GDP per capita (USD) / **4,000**
 Health expenditure per capita (USD) / **124**

7 JORDAN 2
Establish national registry for hereditary bleeding disorders

Partner / **Jordan University Hospital, Amman**
 Represented by / **Prof Abdalla S. S. Awidi**
 Planned duration / **One and a half years, started 2009**

OBJECTIVES

- Establish national registry of hereditary bleeding disorders
- Expand genetic testing and counselling, carrier detection as well as pre-natal diagnosis
- Perform educational programme for healthcare professionals and patients

Country information

Population / **6.3 million**
 Expected patients / **630**
 Known patients / **290**
 GDP per capita (USD) / **5,000**
 Health expenditure per capita (USD) / **611**

8 LEBANON
Multidisciplinary haemophilia care

Partner / **Association Libanaise de l'Hémophilie, Beirut**
 Represented by / **Dr Claudia Djambas Khayat**
 Planned duration / **Two years, started 2007, prolonged**

OBJECTIVES

- Strengthen haemophilia treatment centre in Beirut by implementing multidisciplinary approach
- Design and implement broad educational haemophilia programme for healthcare professionals and patients with families
- Extend basic programme to four regions

Country information

Population / **4 million**
 Expected patients / **400**
 Known patients / **154**
 GDP per capita (USD) / **13,900**
 Health expenditure per capita (USD) / **608**



9 MALAYSIA
Educational programme for haemophilia and vWD patients & parents

Partner / **The National Blood Centre, Kuala Lumpur**
 Represented by / **Dr Faraizah Abdul Karim**
 Planned duration / **Three years, started 2008**

OBJECTIVES

- Develop training modules for newly diagnosed patients and families, children, teenagers and women with bleeding disorders
- Create national platform for patients to meet and share their experiences
- Perform workshops for patients, parents and healthcare providers

Country information

Population / **25.7 million**
 Expected patients / **2,570**
 Known patients / **1,713**
 GDP per capita (USD) / **15,700**
 Health expenditure per capita (USD) / **500**

10 PANAMA
Latin American haemophilia network – pilot project

Partner / **Centro Nacional de Hemofilia, Panama City**
 Represented by / **Dr Belgica Moreno**
 Planned duration / **One year, started 2008, prolonged**

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
- Training of healthcare professionals and education of patients

Country information

Population / **3.4 million**
 Expected patients / **340**
 Known patients / **250**
 GDP per capita (USD) / **11,900**
(source: economist.com)
 Health expenditure per capita (USD) / **721**

11 SOUTH AFRICA
Comprehensive haemophilia care in KwaZulu Natal

Partner / **Nelson R Mandela School of Medicine, Durban**
 Represented by / **Dr Rajendra Thejpal**
 Planned duration / **Two years, started 2009**

OBJECTIVES

- Consolidate the KwaZulu Natal HCCC by offering multidisciplinary care
- Decentralise haemophilia care – set up two satellite centres and perform outreach activities
- Run regional screening programme
- Educate patients and healthcare professionals
- Establish regional haemophilia registry

Country information

Population / **49.1 million**
 Expected patients / **4,910**
 Known patients / **532***
 GDP per capita (USD) / **10,400**
 Health expenditure per capita (USD) / **869**

*(in KwaZulu Natal)



12 VIETNAM
Improvement of haemophilia diagnostic and treatment level

Partner / **National Pediatrics Hospital, Hanoi**
 Represented by / **Dr Duong Ba Truc**
 Planned duration / **Two years, started 2008**

OBJECTIVES

- Develop guidelines for diagnosis and care of people with hereditary bleeding disorders
- Carry out screening programme
- Set up registry
- Enhance patient support network

Country information

Population / **87 million**
 Expected patients / **8,700**
 Known patients / **754**
 GDP per capita (USD) / **2,900**
 Health expenditure per capita (USD) / **264**

COMPLETED PROJECTS (presented in this report on pages 11–19)

1 BRAZIL
Improvement of haemophilia organisation and patient education

Partner / **Federação Brasileira de Hemofilia – FBH, Cuiaba**
 Represented by / **Dr Sylvia Thomas**
 Planned duration / **Three years, completed 2009**

ACHIEVEMENTS

Infrastructure

- National haemophilia patient organisation strengthened, processes, organisation and president's office set up
- National network founded together with regional chapters and hemocentros
- New FBH website established
- Regular distribution of FBH newsletters to members and other stakeholders

Training & education

- 288 healthcare specialists trained in eight regions
- 61 haemophilia leaders educated
- Nurses workshops held in regions, leading to the formation of Brazilian Nurses Working Group
- Haemophilia manual 'Convivendo com a Hemofilia' created and illustrated by patient
- Six WFH manuals translated into Portuguese, printed and distributed during leader training
- 2,000 copies of NNHF comic 'The amazing adventure of Alejandro' printed and distributed
- 41,300 copies of printed educational material distributed

Country information

Population / **201.1 million**
 Expected patients / **20,110**
 Known patients at end of project / **8,168**
 GDP per capita (USD) / **10,200**
 Health expenditure per capita (USD) / **765**



5 MACEDONIA Capacity building in haemophilia care

Partner / **University Children's Hospital, Medical Faculty, Univ. 'Ss Cyril and Methodius', Skopje**
 Represented by / **Prof Sofijanka Glamocanin**
 Planned duration / **One year, completed 2009**

ACHIEVEMENTS

Training & education

- 500 haematologists, paediatricians and orthopaedists trained
- 114 nurses, 21 lab technicians educated
- 115 patients, 92 family members and other community stakeholders educated
- 2,000 copies of educational material for healthcare professionals developed and produced
- 1,650 copies of educational material for patients and families developed and produced
- 'Guidelines for the Management of Haemophilia' translated and accepted as national guidelines

Diagnosis

- Screening programme executed with three teams visiting centres in east, central and western Macedonia
- 185 patients (re-)tested
- Survey conducted to assess haemophilia patients' health and clinical status

Country information

Population / **2.1 million**
 Expected patients / **210**
 Known patients at end of project / **185**
 GDP per capita (USD) / **9,000**
 Health expenditure per capita (USD) / **623**

6 PAKISTAN 1 Capacity building for haemophilia care programme – a pilot study

Partner / **National Institute of Blood Disease and Bone Marrow Transplantation (NIBD), Karachi**
 Represented by / **Dr Tahir S. Shamsi**
 Planned duration / **Two years, completed 2010**

ACHIEVEMENTS

Training & education

- Four master trainers trained in Karachi to perform testing of specific clotting factor levels and learn how to train other healthcare providers
- Training materials for healthcare professionals developed and distributed: 'Practical Haemostasis: basic facts and practical application' – book
- Five full-day haemostasis workshops conducted by master trainers
- Six posters and one oral presentation delivered at haematology conference in 2009 in Karachi
- Project completion report and relevant documents submitted to Director General Health, Ministry of Health, Government of Pakistan and the Executive Director, Pakistan Medical Research Council
- Self-sustained model for haemophilia care established at NIBD

Diagnosis & registries

- Patient database developed and available for use.
- Almost 600 haemophilia and other allied bleeding disorder patients diagnosed – 140 new patients
- Guidelines for diagnosis of congenital bleeding disorders developed and submitted to Ministry of Health

Country information

Population / **176.2 million**
 Expected patients / **17,620**
 Known patients at end of project / **1,250**
 GDP per capita (USD) / **2,600**
 Health expenditure per capita (USD) / **51**



9 ROMANIA
Improvement of haemophilia care through outreach

Partner / **Emergency Clinical Hospital 'Louis Turcanu' Haemophilia Centre, Timisoara**
 Represented by / **Prof Dr Margit Serban**
 Planned duration / **Two years, completed 2010**

ACHIEVEMENTS

Infrastructure

- Five new functional haemophilia centres in main regions

Training & education

- Workshops for healthcare professionals, patients and families
- Written educational materials for doctors, nurses and patients developed and distributed
- Numerous meetings with the patient organisation and authorities
- Creation of a National Alliance for Rare Diseases

Diagnosis & registries

- Updating of national haemophilia registry and creation of a database on health and socioeconomic data
- Improved diagnosis through testing of 1,081 samples collected

Country information

Population / **22.2 million**
 Expected patients / **2,220**
 Known patients at end of project / **1,316**
 GDP per capita (USD) / **11,500**
 Health expenditure per capita (USD) / **610**

10 URUGUAY
Improvement of haemophilia care by awareness creation

Partner / **Centro Hospitalario Pereira Rossell, Montevideo**
 Represented by / **Dr Ismael Rodríguez Greco**
 Planned duration / **One year, completed 2010**

ACHIEVEMENTS

Training & education

- Plenary workshops carried out for healthcare professionals from whole country and patients with their families on a wide scope of topics such as sport, 'to grow in health', etc
- Educational materials developed and distributed
- Two summer camps held for children and adolescents, respectively

Country information

Population / **3.5 million**
 Expected patients / **350**
 Known patients at end of project / **230**
 GDP per capita (USD) / **12,700**
 Health expenditure per capita (USD) / **989**



12 UZBEKISTAN 2
School for children at the national haemophilia centre

Partner / **Scientific Research Institute of Hematology and Blood Transfusion, Tashkent**
 Represented by / **Dr Aziza Dj. Makhmudova**
 Planned duration / **One year, completed 2010**

ACHIEVEMENTS

Infrastructure

- School created with a classroom as well as a computer room and playroom for children with haemophilia (age 2–10)
- Library established with books, DVDs on eg history, geography, art, world culture
- 24-hour telephone hotline set up to provide qualified consultation

Training & education

- Classes organised in compulsory basic knowledge as well as computer and art
 - Psychological sessions provided for haemophilia patients and families
 - Swimming classes provided
 - Excursions organised with project minibus to museums, exhibitions and parks
- Sustainability of school assured through Ministry of Health in close collaboration with hospital
 - Since its opening over 300 children have attended programmes at the school

Country information

Population / **27.9 million**
 Expected patients / **2,790**
 Known patients at end of project / **1,138**
 GDP per capita (USD) / **2,000**
 Health expenditure per capita (USD) / **177**

14 VENEZUELA
Desafio Orinoco 2010

Partner / **Venezuelan Haemophilia Association (AVH) and National Haemophilia Centre (CNH), Caracas**
 Represented by / **Dr Arlette Ruiz de Sáez and Cesar A. Garrido**
 Co-sponsored by / **Bayer Health Care in Venezuela**
 Planned duration / **One year, completed 2010**

ACHIEVEMENTS

- Clinical evaluations showed the reduction of joint bleedings through increased muscle and improved movement angles of joints
- Patients and supporters witnessed the increased self-esteem of the patients
- The entire team completed the swim across the two rivers and extensive media coverage raised awareness of haemophilia and what people with haemophilia can accomplish

Country information

Population / **26.8 million**
 Expected patients / **2,680**
 Known patients / **1,723**
 GDP per capita (USD) / **13,100**
 Health expenditure per capita (USD) / **396**



COMPLETED PROJECTS (previously presented)

2 BULGARIA 1 Creation of comprehensive haemophilia treatment centre

Partner / **National Centre of Haematology and Transfusiology (NCHT); Haematology Hospital 'Joan Pavel', Sofia**
Represented by / **Prof Toshko Jeleu Lissitchkov**
Planned duration / **Two years, completed 2008**

Project presented in the NNHF Annual Report 2008/2009, page 12

3 CHINA Haemophilia education, screening and registration

Partner / **Ruijin Hospital, Shanghai**
Represented by / **Prof Hongli Wang**
Planned duration / **Two years, completed 2008**

Project presented in the NNHF Annual Report 2008/2009, page 10–11

4 JORDAN 1 Molecular genetic analysis in haemophilia population

Partner / **Jordan University Hospital, Amman**
Represented by / **Prof Abdalla S.S. Awidi**
Planned duration / **Two years, completed 2008**

Project presented in the NNHF Annual Report 2008/2009, page 14

7 PAKISTAN 2 Education of people with haemophilia and their families at a national level

Partner / **Pakistan Haemophilia Patients Welfare Society (PHPWS), Islamabad**
Represented by / **Dr Tahira Zafar**
Planned duration / **One year, completed 2009**

Project presented in the NNHF Annual Report 2008/2009, page 15



8 POLAND
Standardisation of haemophilia diagnosis and treatment

Partner / **Haematology Department, Paediatric Clinic, Warsaw**
Represented by / **Dr Anna Klukowska**
Planned duration / **Two years, completed 2007**

Project presented in the NNHF Annual Report 2008/2009, page 13

11 UZBEKISTAN 1
Improvement of haemophilia diagnostic and treatment level

Partner / **Hematology and Transfusion Scientific institute, Tashkent**
Represented by / **Dr Aziza Makhmudova**
Planned duration / **One year, completed 2007**

Project presented in the NNHF Annual Report 2007/2008, page 8–9

13 VENEZUELA
Optimisation of haemophilia organisation

Partner / **Venezuelan Haemophilia Association (AVH) and National Haemophilia Centre (CNH), Caracas**
Represented by / **Dr Arlette Ruiz de Sáez and Cesar A. Garrido**
Planned duration / **Two years, completed 2007**

Project presented in the NNHF Annual Report 2007/2008, pages 10–11



NEW FELLOWSHIPS

BRAZIL

Fellow / **Janaina Bosso, physiotherapist, MSc, State University of Campinas, Campinas**
Host institute / **Hemophilia and Thrombosis Center Angelo Bianchi Bonomi – World Health Organization – Collaborating Center of Inherited Coagulation Disorders, Milan, Italy**
Duration / **Eight weeks**

OBJECTIVES

- Improve knowledge of effective physiotherapy care to improve quality of life in patients with haemophilia
 - To enhance the level of knowledge in Brazil on improvement of quality of life through physiotherapy techniques.
-

IRAQ

Fellow / **Dr Brwa Ali Hussein, Nanakali Hospital for Cancer and Blood Diseases, Erbil**
Host institute / **Royal Free Hospital, London, United Kingdom**
Duration / **12 months**

OBJECTIVES

- Training in foetal medicine and prenatal diagnosis; attendance in genetic clinic and counselling
 - Training in gynaecological manifestations of inherited bleeding disorders and management of pregnancy
 - To multiply the knowledge acquired and increase awareness among HCPs in Iraq
-

SRI LANKA

Fellow / **Dr R. D. H. Ramanayake, National Blood Center/Blood Bank National Hospital, Colombo**
Host institute / **University of North Carolina, Chapel Hill, US**
Duration / **Three months**

OBJECTIVES

- Acquire knowledge in diagnosis and management of patients with bleeding disorders
 - Learn how to prepare and provide special types of blood products, eg cryoprecipitate
 - To help haematologists and clinicians in Sri Lanka provide aid to patients and manage complications
-

THAILAND

Fellow / **Dr Noppacharn Uprasert, Faculty of Medicine, Chulalongkorn University, Bangkok**
Host institute / **University of North Carolina, Chapel Hill, US**
Duration / **12 months (including an additional research grant)**

OBJECTIVES

- Improve research skills in molecular pathogenesis of coagulation disorders with emphasis on haemophilia
- To bring insights and expertise to Thailand to establish a haemostasis research and educational centre of excellence



COMPLETED FELLOWSHIPS

CHINA 1

Fellow / **Dr Baolai Hua, Peking Union Medical College Hospital (PUMCH), Department of Hematology, Beijing**
Host institute / **The Royal Free Hospital, London, United Kingdom**
Duration / **Five months (2008)**

ACHIEVEMENTS

- ▶ Learned global haemostasis assays, including thromboelastography and TGT, assays for the diagnosis of von Willebrand disease (vWD), such as vWF multimer analysis, vWF cofactor assay, CBA and gene diagnosis
- ▶ Learnings will improve diagnosis and treatment levels of bleeding disorders in Beijing and surrounding areas in future – Dr Baolai Hua serves as responsible for laboratory training and supervision for Northern China

Fellowship presented in the NNHF Annual Report 2008/2009, page 24

CHINA 2

Fellow / **Dr Jing Dai, Ruijin Hospital – Department of Clinical Transfusion, Shanghai**
Host institute / **Royal Free Hospital, London, United Kingdom for Coagulation with the NIBSC, North London**
Duration / **Five months (2009)**

ACHIEVEMENTS

- ▶ Trained in routine diagnosis, preparation of normal pooled plasma
- ▶ Expertise gained in setting up a quality assurance scheme and quality control policies and processes
- ▶ Educated in bleeding state workup: factor assays; platelet function assay; vWF function assays – multimers, factor VIII binding, CBA, Rcof, RIPA
- ▶ Learned skills help to establish quality control system according to international standards in centre's lab as well as extend the system to other centres of China – Dr Jing Dai serves as responsible for laboratory training and supervision for Southern China

Fellowship presented in this report on page 17

ACCOUNTANTS' REPORT

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

As statutory auditors, we have examined the financial statements of Novo Nordisk Haemophilia Foundation, which comprise the balance sheet, income statement and notes, for the year ended 31 December 2009.

These financial statements are the responsibility of the Board. Our responsibility is to perform a limited statutory examination on these financial statements. We confirm that we meet the licensing and independence requirements as stipulated by Swiss law.

We conducted our examination in accordance with the Swiss Standard on Limited Statutory Examination. This standard requires that we plan and perform a limited statutory examination to identify material misstatements in the financial statements. A limited statutory examination consists primarily of inquiries of foundation personnel and analytical procedures as well as detailed tests of foundation documents as considered appropriate in the circumstances. However, the testing of the operational processes and the internal control system, as well as inquiries and further testing procedures to detect fraud or other legal violations, are not within the scope of this examination.

Based on our limited statutory examination, nothing has come to our attention that causes us to believe that the financial statements do not comply with Swiss law and the foundation's deed and internal regulations.

PricewaterhouseCoopers AG



Patrick Balkanyi
Audit expert
Auditor in charge



Thomas Illi
Audit expert

Zurich, 27 January 2010

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

ANNUAL ACCOUNTS 2009

Balance sheet as of 31 December
(in Swiss Francs)

Assets	2009	2008
Cash and Equivalents	2,885,399	2,178,057
Other Receivables		
to third parties	25,124	5,180
to related parties	0	24,170
Prepaid expenses	1,211	524
Total Assets	2,911,734	2,207,931
Equity and Liabilities		
Short-term liabilities		
Trade accounts payable		
to third parties	39,257	14,416
to related parties	84,349	10,440
Deferred Income	2,423,078	1,567,706
	2,546,685	1,592,562
Long-term liabilities		
Other provisions	32,421	19,987
Equity		
Locked-up capital	200,000	200,000
Retained earnings	132,628	395,382
	332,628	595,382
Total Equity and Liabilities	2,911,734	2,207,931

Income statement for the business year
(in Swiss Francs)

	2009	2008
Income donation income	3,197,923	2,143,686
exhibition and conferences	(35,992)	(15,473)
personnel costs	(1,170,141)	(845,661)
travel and communication costs	(274,341)	(167,701)
project grants	(1,777,350)	(760,207)
Project-related costs	(3,257,823)	(1,789,042)
rent costs	(88,074)	(85,211)
service fees	(23,000)	(23,000)
administration costs	(84,074)	(62,608)
Administration costs	(195,148)	(170,819)
Operating profit (loss)	(255,048)	183,825
interest income	3,461	1,476
bank fees	(1,518)	(1,368)
currency gains (losses)	(9,649)	(1,518)
Financial income (expense)	(7,706)	(1,410)
Gain (Loss)	(262,754)	182,415

Notes to the annual financial statements

1. Disclosures according to Art 663b OR (in Swiss Francs)	2009	2008
Liabilities towards pension funds	9,000	31,000

2. Risk assessment

The Novo Nordisk Haemophilia Foundation Council makes an adequate risk assessment annually and has initiated appropriate measures in consequence, in order to ensure that the risk of a significant error in the foundation accounts can be regarded as small.

There are no further facts requiring disclosures according to Art 663b OR.

GOVERNANCE: THE RULES WE LIVE BY

The Novo Nordisk Haemophilia Foundation (NNHF) is established as a non-profit organisation.

Adhering to high foundation governance standards is a key objective for our organisation and its operations as grant-making foundation. NNHF is an associated partner of Swiss Foundations and orients its corporate governance to the principles and recommendations of the 'Swiss Foundation Code'.

NNHF is governed by the Foundation Council, chaired by the chief operating officer (COO) of Novo Nordisk A/S. Along with globally renowned external experts in the field of haemophilia, the Council consists of members from Novo Nordisk drawn from the company's global experience in haemophilia, as well as management of corporate social responsibility and operations in emerging countries. The Council members of NNHF exercise their duty without remuneration except for the reimbursement of their expenses.

Roles and responsibilities

The NNHF Council ensures that the foundation's goals, activities and structures are as transparent as possible and appropriate to the foundation's purpose. The Foundation Council convenes up to four times a year and is the supervisory and main decision body of NNHF to ensure proper handling of funds and their distribution. It decides about submitted programmes and on the strategic direction, supervises financial and liquidity planning, approves the annual budget as well as the reporting on risk and financial management as submitted by NNHF Management. The NNHF Council entrusts daily management to NNHF Management, a team of five employees.

NNHF Management is responsible for the operational management of NNHF and submits received programme applications to its Council for decision with appropriate recommendations according to NNHF programme guidelines. NNHF Management also ensures results-oriented programmes management, allocation of funds and budget controlling and is obliged to regularly update the Council on the financial and operative situation.

Clear operating principles and processes aim at achieving efficient and sustainable results fulfilling the purpose of the foundation to improve access to care for people with haemophilia and allied bleeding disorders.

Our project management principles and tools are publicly available on our website as well as upon request to ensure the highest transparency and quality standards when selecting programmes as well as monitoring and controlling them.

The annual financial statements of NNHF are audited by PricewaterhouseCoopers AG.

Swiss authorities ensure that the proceeds of NNHF are spent in accordance with its objectives and inspect proper financial and liquidity planning along with financial reporting.

THE NNHF COUNCIL

Kåre Schultz (President)
Leif Fenger Jensen (Vice President)
Lars Rebien Sørensen
Charlotte Ersbøll
Ulla Hedner
Christine A. Lee
Anne Prener
Harold Roberts

The Council members of NNHF exercise their duty without remuneration except for the reimbursement of their expenses.

THE NNHF MANAGEMENT

General Manager
Susanne Brandl

Project Manager
Susanne Brunner

Senior Project Manager
Alexandre Bento Costa Alencar

Communications Manager
Nuriye Ulucan

Team Assistant
Michelle Lagoa-Hegg (until January 2010)
Chantal Vroom-Bezuijen (since April 2010)

Trainee
Denise Ineichen

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ABOUT HAEMOPHILIA

Haemophilia is a hereditary bleeding disorder that affects males. Approximately 1 in 5,000 males is born with haemophilia.

An estimated 600,000 males have haemophilia A or B. According to the World Federation of Hemophilia, only 25% have confirmed diagnosis and access to adequate care. 75% of people with haemophilia are expected to live in the developing world.

Patients with haemophilia A have either decreased, defective or absent production of the blood clotting protein factor VIII. Those with haemophilia B have similar deficiencies with clotting factor IX.

For people with haemophilia, bleeds often occur in the joints, particularly knees and ankles. Bleeds can also occur in the muscles, soft tissues, gastrointestinal tract or even the brain. Trauma, major surgery, tooth extractions or other minor surgical interventions require medical intervention to manage the associated bleeding.

Without treatment the bleeds are painful and can cause lasting damages most often leading to impaired mobility.

Treatment of haemophilia A and B patients is normally based on substitution of the missing clotting factor by intravenous injection. This may be carried out when bleeding occurs or prophylactically. The replacement clotting factors have typically been obtained from human plasma or, more recently, from recombinant technology.

Read more about haemophilia on our website: www.nnhf.org

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