



Better Practice Sharing Forum 2010

Each of NNHF's projects is unique and yet share many challenges with other projects and countries. Using our network we create opportunities for better practice sharing, such as the Forum which took place in July 2010 in Buenos Aires.



Experiences in building multidisciplinary care

On a global level, relatively few physicians are haemophilia specialists and sharing experience within the field can be rare. NNHF sees it as one of its major tasks to help facilitate such knowledge sharing.

“As a member of the NNHF Council, it has been interesting to see how some challenges faced by the countries in which we work are very similar to the ones faced decades ago in the developed countries, when haemophilia care began to be structured and treatment became available. Thus it has become key for us to foster the exchange of experiences between NNHF Council members, NNHF project partners and fellows as well as international specialists that volunteer in our projects. This is the NNHF’s proactive approach to promote better practice sharing, as an underpinning of everything the Foundation does.”

These are the words of Prof Dr Harold Roberts, Sarah Graham Kenan Professor of Medicine and Pathology and Laboratory Medicine at the University of North Carolina, and former member of the NNHF Council. They were spoken at the Better Practice Sharing Forum in Buenos Aires in July 2010, with participants from NNHF projects from across the world. The Forum had the necessity of multidisciplinary care as its key topic, and based on presentations made at this event, this article presents a number of viewpoints and experiences on this subject.

The importance of multidisciplinary care in haemophilia

Treating haemophilia patients has special characteristics and is demanding. Prof Ulla Hedner, MD and PhD and member of the NNHF Council, gave a short review of these specifics and how they call for comprehensive care centres for haemophilia.

Haemophilia is the most serious bleeding disorder and characteristic for haemophilia patients is that they are fragile and need multidisciplinary care. They need special care in association with for example dental care, in case of necessary invasive procedures such as venous or arterial puncture, vaccination etc. When needing surgery they require very special treatment and care.

Furthermore, the whole family of a haemophilia patient needs substantial support especially in the early years, when they all have to

adjust to the situation of having a haemophilia boy in the family. This requires a close relationship between the patient, his family and the responsible doctor. Ideally, they should also have access to a nurse with experience in haemophilia care. There are millions of questions they need help with especially during the first years. Adequate treatment has to be initiated early in life, ideally in the form of home-treatment and prophylaxis, meaning administration of factor concentrates every week. In addition, every trauma – even mild ones – requires extra treatment.

Consequently, it is obvious that a haemophilia centre should have access to experienced physicians, nurses and also specialists in for example dental care, ear-nose-throat, surgery, paediatrics, and not the least orthopaedics. Due to repeated joint bleeds haemophilia patients develop chronic arthropathy and require orthopaedic procedures as well as access to physiotherapy.

The basis of comprehensive care

With this background, centralised haemophilia care centres were established in the 1960s in the UK by Dr Rosemary Biggs active in Oxford. She called these centres “comprehensive care centres”, stressing the necessity of specialists in a number of areas being available.

A “comprehensive haemophilia care centre” should of course, have a laboratory providing special testing for diagnoses as well as for monitoring treatment. A yearly follow-up should be undertaken in all haemophilia patients to check and adjust treatment, check for potential inhibitors, complicating infectious diseases such as various types of hepatitis, HIV and other diseases caused by blood-borne pathogens and potentially transferred by the treatment given.

Good haemophilia care can be achieved without having all the different specialities in the same building. The important thing is to have interested, qualified and skilful specialists available within a reasonable distance. Also, a strong and trustful collaboration between these specialists and the haemophilia doctor has to be established.

In conclusion, an experienced, dedicated haemophilia specialist, who could act as the core of the haemophilia care network, is necessary and most important for the establishment of good haemophilia care.



Prof Dr Harold Roberts at the BPS Forum 2010; Dr Gana from Chile in the background.

Team members of award winning projects. From the left to the right, Prof Glamocanin, Dr Castillo and Dr Traykova.

Establishment of a Haemophilia Training Centre in Campinas, Brazil

As an example of a successful establishment of a comprehensive haemophilia care centre in a emerging country, Dr Margareth Castro Ozelo, PhD from IHTC “Cláudio Luiz Pizzigatti Correa” presented the care centre at the University of Campinas in Brazil. Upon return from research and clinical work in Canada, Dr Ozelo began the development of this centre.

The Hemocentro UNICAMP is part of the University of Campinas, a public institution that provides general haematological assistance and transfusion medicine services. The centre is reference for a population of over 5.8 million habitants in Sao Paulo State, Brazil.

Until 2000, patients with haemophilia and other bleeding diseases were assisted at the Hemocentro UNICAMP with good haematological and dental services, and a well-recognized haemostasis laboratory, including molecular biology. However, there was a lack of other specialised assistance, such as rehabilitation and psychological care. Motivated by the increasing demand, the professionals and some volunteers began developing a comprehensive haemophilia care centre.

Advancing care

The resources to achieve this goal were obtained through participation in several clinical trials, the organisation of specialisation courses, and through partnerships with private and public institutions.

In 2005, we started a collaborative programme, the “Wild Card Programme”, sponsored by Novo Nordisk Brazil, which significantly helped the development of our centre. The goals of this initiative included providing resources to support the development of a national reference centre in Brazil. In return, our contribution to the programme was to perform laboratory tests and lab training in locus for other haemophilia centres around the country. Initially six centres received

the support of our lab staff. After three years, five of them were able to provide routine laboratory diagnosis for their patients. This programme was also used as a model for the following laboratory training programme supported by the Brazilian Ministry of Health.

Being recognised

In 2009, the Unit of Haemophilia “Cláudio Luiz Pizzigatti Corrêa” from Hemocentro UNICAMP was recognised by the World Federation of Haemophilia as the third International Haemophilia Training Centre (IHTC) in Latin America. Currently, more than 600 patients with inherited bleeding disorders are cared for by the centre’s multi-professional team of more than 20 people. We also continue to provide support and training for patients and professionals from Brazil and other countries.

How to achieve state support for haemophilia care

In the long run state support is required in order to achieve nation-wide, sustainable haemophilia care. Prof Christine Lee, MA MD DSc (Med) FRCP FRCPath FRCOG and a member of the NNHF Council, shared with the BPS Forum participants her experiences from the UK on how to achieve such support. She particularly stressed the importance of creating registers of patients with bleeding disorders.

The availability of relevant registries provides data to demonstrate to the Government authorities the long-term advantages of establishing a high quality haemophilia care. Even with data it can be hard to get governmental support, but Prof Lee advises participants not to be deterred by initial complacency.

“There are five steps in achieving state support,” Prof Lee said. “First, you need a champion. Then, you need to ensure quality diagnosis to



Workshop team finding solutions to challenges in haemophilia care.

feed a database which is the third step. Analysis and usage of this information to lobby is the next step complemented with a parallel step of increasing knowledge expertise and awareness in the country.”

“Data are power! Keep collecting your data and keep your morale up. One day the doors will open,” said Prof Lee.

After a correct diagnosis has been made, a database is the most vital requirement for good haemophilia care. The main functions for a database are in healthcare planning, epidemiologic research and pharmaco-vigilance.

Healthcare planning

Data from the Center for Disease Control (CDC) in the US has shown that the provision of haemophilia treatment centres results in better outcomes, as measured by mortality and hospitalisation, than haemophilia care provided outside of centres.

In the global context, data collected by the World Federation of Haemophilia (WFH) has been used to show the relationship between economic capacity and the number of adults surviving with haemophilia. Age can therefore be used as a surrogate marker to indicate that care provision has improved in any particular population – but this is dependent on good data collection.

The WFH Global Survey has further analysed the relationship between the prevalence of haemophilia A in a given population, and the usage of FVIII per capita of whole population in the specific country. In this way it can be shown that prevalence increases sharply up to a usage of 1IU FVIII per capita, but then the curve flattens off. This means only a small provision of treatment can result in a good increment in patient identification as people come forward for diagnosis.

The UK Haemophilia Centre Doctors’ Organisation (UKHCDO) has a database for the whole UK haemophilia population. This was established in 1968 by those physicians with an interest in haemophilia when it was realised that the average general practitioner would see only one patient with haemophilia in his or her lifetime, and therefore haemophilia care needed to be provided in specialist centres. This database has been approved by the UK Data Protection Agency and it contains named data with the option for patients to refuse participation, but few have taken this option. The database contains information about all new diagnoses and deaths; information about treatment; and adverse events including inhibitors, HIV, hepatitis and risk for variant CJD.

Epidemiologic Research

The UKHCDO database has provided information about the past epidemic of HIV. It recorded 1,246 infections and showed that these patients had seroconverted by the end of 1982. Analysis also demonstrated the good effect of anti-retroviral therapy on survival.

Data from the UKHCDO database shows a survival of 63 years for severe haemophilia and 75 years for non severe haemophilia. So far there are around 6,000 haemophilia patients in the registry.

The number of new inhibitors occurring each year has also been recorded and there has been some evidence that the occurrence of inhibitors may be related to the type of treatment used. It has been shown that the majority of inhibitors occur in children less than 10 years but that there is also an increase in the very elderly, over 70 years.

The information held on this database has been shared with national government to achieve and maintain the best provision of care with an evidence base ensuring that there are not ‘cut-backs’ of care provision.

Prof Christine Lee

“Data are power!
Keep collecting your data
and keep your morale up.
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Dr Zafar and NNHF councillors Prof Lee and Prof Hedner sharing a moment at the Forum.

Dr Truc from Vietnam, presenting his workshop team's ideas.

Pharmacovigilance

Within Europe, EAHAD (European Association for Haemophilia and Allied Disorders) has adopted 10 principles of care. The European Union recognised that in order for these principles of care to be realised, a pharmacovigilance would be needed and therefore funding was provided for EUHASS, the European Union Haemophilia Safety Surveillance.

Orthopaedic treatment in patients with haemophilia

As another aspect of multidisciplinary care, the need for extensive orthopaedic care, including sophisticated orthopaedic surgery to substitute for destroyed joints, due to repeated joint bleedings in haemophilia patients was on the agenda. Dr Horacio Caviglia, department of orthopaedics, Hospital Juan A. Fernández, Buenos Aires, Argentina provided a survey of various orthopaedic treatment options available at his centre in Buenos Aires, stressing that a lot can be done to help haemophilia patients even without access to the most advanced techniques and treatments.

Patients who have access to treatment have few disabling injuries. But this is not the case for patients living in the developing world – they do not have access to treatment and often suffer disabilities. The development of orthopaedic surgery in the developing world is essential for patients to receive treatment for their deformities. Orthopaedic surgeons in charge of those patients are required to be experienced and to apply a holistic approach.

There are three most frequent pathologies in patients with haemophilia: synovitis, joint disease and injury sequelae secondary to soft tissue haematoma. At the clinic in Buenos Aires, when a patient has experi-

enced more than three joint bleeds over less than a six-month period, it is considered that a target joint is present and should be treated as synovitis.

Treating synovitis

Radioactive synoviorthesis is a globally accepted treatment of synovitis. In developing countries, there is often no access to radioactive materials; therefore, chemical synoviorthesis is performed instead, and rifampicine or emicine can be used.

In our hospital, however, the treatment of choice is sinovium angioli- sis. We started using this procedure three years ago. It consists of arterial embolization of synovial vessels – in other words a less invasive procedure that blocks the vessels of the target joint, reducing cartilage damage. This method requires high technology and an experienced inter- ventional radiologist.

As an orthopaedic surgeon, the first thing you should know is that pa- tients with haemophilia have a clinical-radiological dissociation. This means that they experience large radiological joint damage with little pain. When there is no pain or a mild pain level, the patient should not be operated despite the serious radiological damage, except if stiffness or deformities alter his/her social life. Therefore, our motto is to treat patients, not x-rays.

Advanced treatments

Arthropathy treatments range from excision of osteophytes in the joint – when they limit the movement or generate pain – and osteoto- my for deformities that can make sitting or walking difficult. Total joint replacement in hips and knees has shown very good results. This pro- cedure is currently being performed in the ankle area, and long-term results must be expected. In the elbow area, results have not been sat- isfactory.

Haematomas often produce sequelae if not treated properly – claw hand can be developed in the upper limbs, and equinus foot in the lower limbs.



Dr Tahir Shamsi receiving his project completion certificate from Susanne Brandl and Alexandre Alencar.

Looking forward to the BPS Forum 2012

The NNHF BPS Forum 2012 will focus on the importance of exercise and musculoskeletal care. The relevance of these topics reflect the interest of the participants of our BPS Forum 2010, the World Federation of Hemophilia (WFH) congress audience and members of our network.

Sharing knowledge has become more and more important in the work of NNHF as we see the creation of connections between professionals from different specialties and with various experiences from around the world as a huge chance to further sustainable development and change on the ground.

“Our recently started activities in Campinas are great examples of the benefits of international collaboration and learning from others. I have worked in Canada and two of our physiotherapists have studied recently in Italy and India as NNHF fellows. We are very eager to use the gained knowledge in our MSK focused project and share these experiences with others within our field who may benefit,” says Dr Ozelo.

The NNHF BPS Forum 2012 will take place at the WFH congress in Paris. As in Buenos Aires, it will entail a multidisciplinary panel discussion coupled with presentations from international experts and interactions with the participants.

“We already look forward to welcoming our project partners, fellows, engaged individuals and interested experts in the field for this interesting exchange working day,” says Susanne Brandl, general manager at NNHF.



Creating impact through Better Practice Sharing

“I am very proud to have been part of the Desafio Orinoco swimming team and being one of the champions, sharing the great benefits with the congress participants. Having the opportunity now to help transfer the excitement and knowledge to the Mexican team of the Desafio del Caribe 2011/2012, makes me happy.”

Alejandro Garrido

A member of the Desafio Orinoco 2010 swimming team, participating at the meet the champions session on the NNHF booth at WFH congress 2010.