

# THE WFH HAEMOPHILIA CENTRE TWINNING PROGRAMME: TEN YEARS OF GROWTH, 1993-2003

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# The WFH Haemophilia Centre Twinning Programme: Ten Years of Growth, 1993-2003

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## Summary

The WFH Twinning Programme celebrates its tenth anniversary this year. Twinning is one of several international WFH programmes designed to improve haemophilia care at a global level. There are two types of twinning, and the haemophilia treatment centre twinning programme should be distinguished from the WFH haemophilia organization twinning (HOT) involving national member organisations (NMO's). The WFH Haemophilia Treatment Centre Twinning Programme helps emerging haemophilia treatment centres develop partnerships with well-established and experienced centres. Twinning can improve diagnosis and clinical care through coaching, training, and transfer of expertise, ultimately leading to improved quality of life for patients. Twinning can also enhance the profile and recognition of treatment centres in emerging countries, which can be valuable in raising awareness among politicians and the media. Examples of activities include consultation on the management of specific cases, clinical and laboratory training, donation of equipment and publications as well as research projects. The centre twinning program also benefits centres in developed countries by giving them the opportunity to gain exposure to clinical problems no longer encountered in their own countries, as well as experience of new cultures. Currently, a total of 22 treatment centres around the world are linked through the twinning programme and applications for new partnerships are welcome. Twinning links are not permanent, but are reviewed on an annual basis and typically remain in place for periods of 3-5 years. Limited financial support from WFH is available to twinned centres in the form of money for an initial assessment visit, as well as regular annual grants to established partners and the possibility of applying for additional funding to support specific projects. In addition, continuing support and advice are available from the WFH regional programme officers.

**Keywords:** WFH, haemophilia, twinning, comprehensive care

## The Development of the Programme

The goals of treatment of haemophilia can be summarised succinctly as follows: "to minimise disability and prolong life, to facilitate general social and physical well-being and to help each patient achieve full potential, whilst causing no harm" [1]. Whilst much has already been achieved in wealthier countries, the outlook for people with haemophilia in poorer countries remains bleak. The WFH estimates on the basis of recent global surveys that approximately 70% of people with haemophilia around the world remain undiagnosed and therefore receive no treatment. The WFH Decade Plan, published in 1992, recognised the paramount importance of fostering the development of haemophilia care in developing countries [2]. This principal goal of this ambitious strategy is to encourage and foster the highest possible levels of diagnosis and comprehensive care for people with haemophilia and related disorders throughout the world, and to establish programmes which address the local issues which restrict access to comprehensive care for people with haemophilia in the developing world. It was appreciated that one way of achieving these goals was to encourage the creation of strong ties between professionals working in haemophilia centres in developed and developing countries. The concept of a twinning programme was thus proposed by Prof. Guglielmo Mariani. The scheme was subsequently approved by the WFH Council in October 1993 and Prof. Mariani was appointed as the first chairman of the twinning committee. In the early years of the programme, those centres already designated by the WFH as International Haemophilia Training Centres (IHTC) were primarily involved and forged the first formal partnerships [3]. These were often based on pre-existing informal partnerships

which were usually cemented by historical, linguistic, cultural and/or political links. Since then, many other centres have become involved in the programme as it has expanded and evolved and designation as an IHTC is certainly no longer a prerequisite for involvement in the scheme.

## Aims of the Twinning Programme

The WFH Haemophilia Treatment Centre Twinning Programme promotes the development of a collaborative network of haemophilia centres around the world. Established centres with the necessary knowledge, experience and resources can help emerging centres improve treatment and directly improve the level of care to patients by sharing and transferring these skills. WFH has developed a step-by-step model for development of haemophilia care, and one of the main aims of the twinning programme is to foster the model of comprehensive care for people with haemophilia, involving teams of professionals from several disciplines.

Examples of some of the principal types of twinning activities include:

1. **Providing medical advice** on the management of clinical problems and complex cases. Good communication links, using e-mail or fax, need to be established and maintained.
2. **Training** to pass on knowledge and skills. This can be achieved by exchange visits, so both partners become familiar with each other's situation, or on-site when staff from one site train others at the site of their partner. For example, good laboratory training helps to ensure correct diagnosis as well as appropriate management of haemophilia and related conditions.
3. **Donation** of laboratory equipment and reagents, and/or coagulation factor concentrates. If donating equipment, some consideration needs to be given to issues such as availability and cost of reagents and spare parts. Participation in external quality assurance schemes for the appropriate laboratory tests is also to be encouraged.
4. Working together on **special projects** such as creating a computerised patient registry, organizing training workshops or conferences. Advocacy work with the central or regional government can also be an important part of the twinning partnership.
5. **Research:** conducting research that can be beneficial to the emerging twin should be encouraged, as such work can provide important data as well as information of genuine clinical benefit. Involvement in such work can also have the added advantage of giving credit and enhancing the recognition of treatment centres. Recent examples of published work resulting from collaborative work between twins include a study of the prevalence and genotypes of rare coagulation disorders in Iran and the plasma levels of von Willebrand factor in various ethnic groups in South Africa. However, research work should not be the sole focus of the link, as this can lead to feelings of exploitation.

Twinning can also help to boost the profile of a treatment facility in an emerging country. Being twinned with a treatment centre can lend prestige and importance as well as international recognition to an institution. This can be valuable in raising awareness of the centre among government officials and the media. Twinning is a two-way collaborative partnership between two haemophilia treatment centres and staff from developed countries can gain valuable experience from exposure to clinical problems no longer encountered in their own countries, such as orthopaedic problems. The programme also affords a unique opportunity to gain exposure to other cultures and customs, broadening personal horizons and breaking barriers. Twinning can lead to lasting personal as well as institutional relationships which in turn help to build a successful global haemophilia network.

The haemophilia centre twinning programme must be distinguished from the WFH

Haemophilia Organization Twinning (HOT), which involves pairing of national member organizations (NMO's) hospital-based institutions. This programme is overseen by a separate WFH committee and provides support and training to the national member organisations (NMO's) in non-clinical matters such issues as patient education, general management, managing budgets, government relations, outreach and fundraising.

Some financial support from WFH is available for twinned partners although it must be appreciated that this is limited and twins from more developed countries usually secure additional funding from other sources to support their activities. The importance attached to the twinning programme is reflected by the growing budget allocated to the scheme by the WFH Executive Committee, which is now approximately US\$ 120,000 per year (5% of the total WFH budget). The programme is supported by generous sponsorship from Wyeth in the form of an unrestricted financial grant amounting to more than US\$ 700,000 over a three-year period. This grant has allowed the programme to expand, both in terms of the numbers of twinned partners but also as regards the financial allocation available to each pair. Funding is offered for an initial assessment visit when a link is planned. Regular annual grants of US\$ 1500 are awarded and there is also the possibility of applying for additional funding to support specific projects. Such additional grants typically amount to US\$ 2000-8000). WFH is also able to offer free subscriptions to the journal "Haemophilia" to twinning partners which would otherwise not be able to afford this journal.

Regular meetings for twinning partners are arranged on an annual basis during WFH and ISTH congresses, and these informal gatherings provide an opportunity to exchange experiences and hear presentations from various twinning partners about their activities. The Centre Twinning Programme is just one of several WFH programmes, and other resources may be tapped if necessary. For example, an application may be made for an IHTC Fellowship for a key member of staff. Various "wet" laboratory workshops are run each year, including an annual "Training the Trainers" course in London, and attendance at such courses may be

deemed appropriate for appropriate laboratory staff. WFH also runs a humanitarian aid programme, through which over 21 million units of coagulation factor concentrates were distributed around the world in 2002. Requests from twins for concentrates for specific purposes will always be considered. WFH also publishes a number of useful publications, such as the WFH register of coagulation factor concentrates, the WFH laboratory manual entitled *Diagnosis of haemophilia and other bleeding disorders* and monographs on many aspects of haemophilia treatment. A full list of publications is available on the WFH internet web site ([www.wfh.org](http://www.wfh.org)), and the full text of many of these can be downloaded in PDF format.

It is important to bear in mind that the World Federation of Haemophilia, like many other international charitable or not-for-profit organisations, does not provide any form of insurance or other indemnity for volunteer workers against malpractice or accident in view of the prohibitive cost this would entail. All health care professionals working away from their own hospitals or countries should therefore limit their role to a purely advisory one, unless their personal medical malpractice or other insurance specifically includes cover for such work. The same caveat applies to donations of any coagulation factor concentrates.

#### **Approved Partnerships:**

Currently, a total of 22 treatment centres around the world are linked through the twinning programme. 7 twinning partnerships have recently closed but a further 10 new applications are currently under active consideration. Lists of current and recently-closed twinning partners are presented in Table 1, together with the year in which the link was established. This is a truly international programme, involving treatment centres in North America, South America, Europe, Middle East, Far East and Australasia.

**Table 1**

<b>Current WFH Centre Twins (22)</b>
Kingston (Jamaica) - Houston (USA) [1996]
Tianjin (China) - Calgary (Canada) [1997]
Tehran (Iran) - Milan (Italy) [1997]
Montevideo (Uruguay) - Buenos Aires (Argentina) [1998]
Tbilisi (Georgia) - Minneapolis (USA) [1998]
Bangalore (India) - St. Louis (USA) [1999]
Cairo (Egypt) - Knoxville (USA) [1999]
Harare (Zimbabwe) - Perth (Australia) [1999]
Hong Kong (China) - London UK [1999]
Managua (Nicaragua) - Caracas (Venezuela) [1999]
Pune (India) - Bradford (UK) [1999]
Guangzhou (China) - Ottawa (Canada) [2000]
La Havana (Cuba) - Florence (Italy) [2000]
Manila (Philippines) - Melbourne (Australia) [2000]
Moscow (Russia) - Liverpool (UK) [2000]
Tirana (Albania) - Vicenza (Italy) [2000]
Lahore (Pakistan) - Utrecht (Netherlands) [2001]
Panama City (Panama) - Valencia (Spain) [2001]
Algiers (Algeria) - Paris (France) [2002]
Beirut (Lebanon) - Geneva (Switzerland) [2002]
Oxford (UK) - Doha (Qatar) [2002]
Shanghai (China) - Ottawa/Calgary (Canada) [2002]
<b>Recently-Closed WFH Twinning Partnerships (7)</b>
Timisoara (Romania) - Munich (Germany) [1996-2002]
Plovdiv (Bulgaria) - Bonn (Germany) [1998-2002]
St. Petersburg (Russia) - Boston (USA) [1998-2002]
Trivandrum (India) - Detroit (USA) [1998-2002]
Hanoi (Vietnam) - Taipei (Taiwan) [1999-2002]
Oxford (UK) - Durban (South Africa) [1999-2002]
Vellore (India) - Los Angeles (USA) [1999-2002]

Regional programme officers have been appointed by WFH for Latin America [Karine Frisou], Europe [Catherine Hudon], Africa & the Middle East [Dr. Assad Haffar] and Asia [Robert Leung], and part of their duties involve monitoring twinning links in their respective areas and providing support. As a general rule,

a centre may only be twinned with one other partner at a time in order to ensure that efforts are not diluted. Twinning links are not permanent, but are reviewed on an annual basis at the end of the calendar year and typically remain in place for periods of three years although in exceptional cases the duration may be extended for up to five years. It is recognised that many partners continue to maintain close informal links after ending a formal WFH twinning partnership and this helps to foster the spirit of a truly global haemophilia community. Reports from each partner involved in the twinning programme are collated by the clinicians from each participating centre each year and are considered by the WFH Twinning Committee. In this way, progress towards reaching previously-agreed objectives can be monitored and potential problems identified. Each year, an award is made to the twinning partnership judged by the WFH Twinning Committee to have been the most active and achieved the most results. Recent winners of this prestigious WFH "Twin of the Year" Award have included Buenos Aires (Argentina)-Montevideo (Uruguay) in 1999, Bradford (UK)-Pune (India) in 2000, St. Louis (USA)-Bangalore (India) in 2001. The 2002 award was shared by two twins, Liverpool-Moscow and Panama-Valencia. Unfortunately, there is no financial award although each partner is awarded an inscribed plaque which is presented at a major venue such as the opening session of the WFH congress and the award often attracts considerable publicity. For example, the award-winning partnership between Pune and Bradford (UK) was the subject of a BBC documentary programme shown in the UK in October 2002.

### Joining the Twinning Programme

The WFH twinning initiative is an active and growing programme. Expressions of interest are positively welcomed from centres hitherto not involved in this scheme but which have with the necessary experience, skills and resources. Application forms and a copy of the illustrated WFH brochure "*Improving care beyond our borders: a twinning guide for hemophilia treatment centres*" should be obtained from Karine Frisou, Twinning Coordinator at the WFH office in Montreal.



Applications are considered by the WFH twinning committee and evidence will be sought of genuine commitment to the programme, not just on the part of senior medical personnel but also from the multidisciplinary staff of the treatment centre. Clear support from the hospital administration is also desirable. The centre should also have the spare capacity to take on this additional work, including allowing staff time off from usual duties to travel abroad and also to receive visitors from abroad for periods of training. With regard to developed countries, the programme is primarily suitable for larger comprehensive care centres, which offer broad exposure to most aspects of haemophilia care.

If you do not have a potential twinning partner in mind, the WFH staff can help you to identify a suitable match for your centre. Factors such as existing cultural links with your centre or country will be taken into consideration, as well as language skills of your staff. Existing links between the national member organisations (NMO's) may also be deemed relevant. For example, the UK Haemophilia Society is currently twinned with the Russian NMO, and it was therefore thought appropriate to twin the Children's Hospital in Moscow with Alder Hey Children's Hospital in Liverpool (UK). Once a potential twinning partner has been identified, funding for an assessment visit is provided. It is vital for key staff in your treatment centre to have a good understanding of your potential twin, and understand the issues relevant and important to them as well as to assess level of development and treatment available. The WFH will usually be able to supply you with data from the annual surveys, including information on demography, number of diagnosed patients and product/treatment availability. It is equally important to understand and value the culture and history of your potential twin. Such a visit also enables you to set realistic objectives and goals for the partnership over the relatively limited three-year period available. Assessment visit guidelines are available from the WFH and can help you gather useful information from your visit. During the visit you could prepare a general outline of a project or even a detailed action plan with your twinning partner. The action plan submitted with a proposal for twinning will require a clear statement of goals and objectives, with details of the key personnel

involved and a proposed budget. The action plan should also outline plans to monitor progress and outcomes.

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