

# Improving care beyond our borders

*A twinning guide for hemophilia treatment centres*



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACION MUNDIAL DE HEMOFILIA

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This guide is also available as a PDF file.

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# Introduction

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A boy with hemophilia from Nepal.

**H**emophilia affects about 400,000 people worldwide. Seventy-five percent of them receive little or no treatment. With treatment products and proper care people with hemophilia can live perfectly healthy lives. Without treatment, hemophilia can cause crippling pain, severe joint damage, disability, and death.

The World Federation of Hemophilia (WFH) is an international not-for-profit organization working to introduce, improve, and maintain care for people with hemophilia and related bleeding disorders around the world.

Through a network of committed volunteers and stakeholders, the WFH works to bring about change. Hemophilia treatment centres are key partners in this network. They play a major role in improving care for people with hemophilia.

The WFH works to strengthen hemophilia treatment centres in developing countries. One of the ways we do this is through our treatment centre twinning program. Twinning is a formal, two-way collaboration or partnership between emerging and established treatment centres.

As hemophilia treatment centres in developed countries learn more about the plight of people living with hemophilia in developing countries they often want to offer help. With time, they realize how much they can also benefit from this work. WFH staff felt that a guide to twinning would be useful for hemophilia treatment centres that want to make a global difference. A twinning meeting was held in May 2002 with existing WFH twins, and their feedback was used to create this guide.

**Are you thinking about twinning?** This guide helps you learn about the benefits of twinning, the types of twinning activities, and the WFH support provided to twins. It is also a useful tool for new twins. Use it to plan your twinning projects and activities. It will enhance your partnership with a hemophilia treatment centre in another country.

# 1. Twinning and the WFH

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*“One country’s experience, expertise, and resources, once shared, can allow another country to move forward with its own improvements in hemophilia care. How can such helpful information be transferred? One major way is through the WFH twinning program.”*

Brian O’Mahony, President  
World Federation of Hemophilia

## 1.1 Twinning and WFH hemophilia care programs

The goal of the WFH is that everyone with hemophilia or a related bleeding disorder receives quality health care. To achieve this goal, many people need to work together: health officials, treaters, patients, and parents.

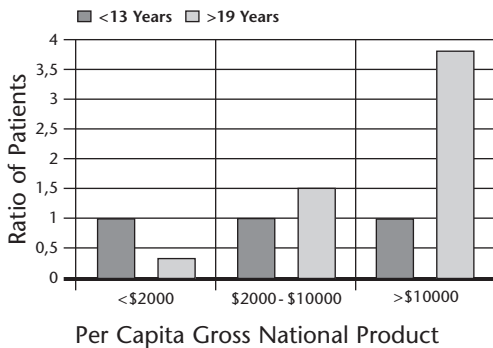
Twinning is one of many WFH programs and services designed to improve hemophilia care. There are two types of twinning, hemophilia treatment centre twinning and hemophilia organization twinning (HOT). Other WFH programs and services include healthcare development programs, humanitarian aid, data collection, public policy, and the production of publications and information materials.

The WFH Hemophilia Treatment Centre Twinning Program helps emerging hemophilia treatment centres develop partnerships with well-established, knowledgeable, and experienced centres. The treatment centre twinning program also benefits established centres by giving them the opportunity to share their expertise and make a global difference.

Treatment centre twinning can play a critical role in changing and improving treatment. Through coaching, training, and transfer of expertise, twinning can improve diagnosis and care delivery, and minimize complications associated with hemophilia, ultimately leading to improved quality of life for patients.

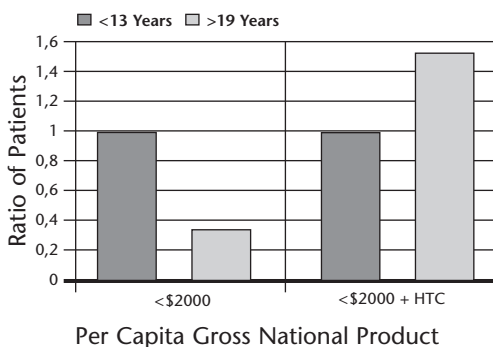
# 1. Twinning and the WFH

**Chart 1.** Relationship between economics (GNP) and the number of adult hemophilia patients\*



\* Data from 17 randomly selected countries  
Evatt and Robillard, *Haemophilia*

**Chart 2.** Effect of hemophilia programs and economics (GNP) on the number of patients\*



\* Data from randomly selected countries  
Evatt and Robillard, *Haemophilia*

## 1.2 Why twinning works

Hemophilia is a chronic disease and managing it is both complex and costly. National hemophilia care programs have been proven to increase the life expectancy of people with hemophilia. Twinning is one way the WFH helps emerging organizations set up and strengthen elements of a national hemophilia care program.

Chart 1 outlines how life expectancy of a person with hemophilia and the economy of a country are related. As you can see, people with hemophilia in countries with higher gross national product (GNP) have almost normal life expectancies. However, in countries with lower GNP, people with hemophilia often do not live beyond childhood.

This does not have to be the case. Data collected by the WFH show that people with hemophilia in countries with lower GNP have higher life expectancies if there is a national hemophilia care program (hemophilia treatment centres, or HTCs). This is shown in Chart 2.

The WFH works with healthcare providers, national hemophilia organizations, and government officials to assess the needs of each country and form a coordinated plan for hemophilia care. Appendix A outlines the steps needed for developing national hemophilia care programs. Twinning is an important WFH tool that helps emerging centres work towards this goal.

# 2. All about twinning

*“Our experience in Moscow was enlightening and educational, and we learnt a great deal about how these dedicated medical professionals care for their patients, with relatively limited resources.”*

Dr. Paula Bolton – Maggs,  
Liverpool, U.K.  
Moscow – Liverpool twins

*“This twinning partnership has made an overwhelming difference to the lives of people with hemophilia in Romania. The number of objectives achieved, the generosity of the assistance, the continuity of activity, and the principle of ‘helping Romanians to help themselves’ have meant that by the end of each objective, the Romanian centre was self-supporting.”*

Dr. Margit Serban, Timisoara,  
Romania  
Timisoara – Munich twins

## 2.1 What is twinning?

Twinning refers to a **formal, two-way collaboration or partnership between two hemophilia treatment centres.**

Twinning is **formal** because treatment centres must arrange a verbal or written agreement about the twinning project or activity. Twinning is not one centre giving to another in need. It is **two-way** because twinned centres work together, share information, and are both better off as a result. Twinning fosters this **collaboration and partnership.**



Dr. Vladimir Vdodin (left) and staff from the Moscow Children's Hematology Centre in Russia visit their twin in Liverpool, U.K.

Both partners must gain for twinning to be a success. Partnerships where the established centre views itself as the “expert” are at risk of being unbalanced.

## 2.2 The Hemophilia Treatment Centre Twinning Program

The Hemophilia Treatment Centre Twinning Program of the WFH encourages a network of cooperation between hemophilia centres around the world. Established centres have knowledge, experience, and resources. Transfer of these can be used to help emerging centres improve treatment and care that directly benefits patients.

### Program objective

The objective of the Treatment Centre Twinning Program is to help emerging centres improve hemophilia treatment and diagnosis. The program encourages the transfer of expertise between established and emerging treatment centres in the areas of diagnosis, treatment, management of complications, and comprehensive care and support.



## 2. All about twinning

### Twinning

- ✓ Improves diagnosis
- ✓ Improves treatment
- ✓ Improves the management of hemophilia complications
- ✓ Builds capacity
- ✓ Raises the profile of the emerging treatment centre
- ✓ Allows sharing of best practices
- ✓ Encourages collaboration
- ✓ Builds relationships
- ✓ Builds a global movement

*“After the mutual evaluation of the Egyptian situation of hemophilia care, our twinned centre suggested a protocol for the basic management of hemophilia for Egypt. It would assure a common protocol would be applied nationally and cover our points of deficiency. The protocol was therefore distributed to the different treatment centres in Egypt.”*

Dr. Magdy El Ekiaby,  
Cairo, Egypt  
Cairo – Tennessee twins



Dr Luke from Ottawa, Canada, examines an X-ray of a patient in Guangzhou, China.

### 2.3 Benefits of twinning

There are many **benefits** to twinning, some of which are outlined here.

#### Improves diagnosis

Correct diagnosis is essential for appropriate treatment. Establishing or helping to maintain laboratory performance can be achieved by providing laboratory training, assessing lab facilities and equipment, reviewing methodology and standard operating procedures, introducing reference materials, and encouraging participation in an external quality assurance program.

Once patients have been correctly diagnosed, a registry provides a record of identified patients and can record treatment monitoring and follow-up.

#### Improves treatment

Twinning can improve hemophilia treatment by providing specialized training on treatment issues to members of the care team or developing treatment protocols. Educating doctors and other healthcare professionals on the dos and don'ts of hemophilia care can make a big difference.

## 2. All about twinning

*“Thanks to the ongoing technical support from our twin in Utrecht, Holland, there is far greater awareness amongst the orthopedic surgeons, physiotherapists, and persons with hemophilia about the role of physiotherapy in the management of hemophilia.”*

Dr. A.S. Chughtai, Lahore,  
Pakistan  
Lahore – Utrecht twins

*“Major goals of the twinning partnership have been to provide staff with training on comprehensive care, provide medical consultation, and assist with developing materials in Chinese for patient education.”*

Dr. Man-Chiu Poon,  
Calgary, Canada  
Tianjin – Calgary twins

*“The creation of a database will help us upgrade records, make presentations and, with the press of a button, provide the treating doctor with the patient’s record.”*

Dr. Anil Lalwani, Pune, India  
Pune – Bradford twins



Dr. Paul Giangrande (right) from Oxford Haemophilia Centre, U.K., which is twinned with the Durban treatment centre in South Africa, participates in the official launch of a national hemophilia program in South Africa, the result of years of hard work by the treatment centres and the national hemophilia association.

### **Improves the management of hemophilia complications**

Twinning activities can bring about great improvements in areas such as prevention, education, or genetic counselling. Well-trained clinical and paramedical staff can make a significant difference in the management of hemophilia complications. For example, educating physiotherapists about exercises to maintain healthy muscles and joints can help increase or restore muscle and joint function.

### **Builds capacity**

Capacity building is about transferring skills and knowledge. This leads to a more capable treatment centre that is better able to provide hemophilia services.

### **Raises the profile of the emerging treatment centre**

Being twinned with a treatment centre in another country gives international recognition and importance to the emerging twin. The twinning partnership can be a valuable tool to help raise awareness of the emerging centre among government officials and the media.

## 2. All about twinning

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*“By supporting the national hemophilia centre in Bratislava, our twin has supported the progress of hemophilia care in all Slovakia.*

*Twinning helped us to improve communications with all the centres of our country, helping coordinate consultation services on hemophilia treatment. Now, if a product shortage occurs in any of the treatment centres, we can ensure access to treatment to all patients by getting factor from another centre.”*

Dr. Angelika Batorova,  
Bratislava, Slovakia  
Bratislava – Tel-Hashomer twins

### **Allows sharing of best practices**

Best practices are methods and strategies that have been used by others and were found to be effective. Twinning is a way to share techniques and interventions that have been shown to work well in other areas. Learning about these best practice approaches can save time and effort.

### **Encourages collaboration**

Collaboration is about working together. Twinning allows medical centres to work together on a project that interests them both.

### **Builds relationships**

Twinning helps build strong relationships among hemophilia centres. These relationships become important when a medical centre has a need. People from one centre can turn to their twin for help or they can work together on a specific issue.

### **Builds a global movement**

More and more, global events influence hemophilia healthcare policy, funding, and development. Twinning is a way to build a successful global hemophilia network that includes everyone.

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### *Slovakia – Israel: An example of using twinning to increase visibility*

**O**ne of the WFH's earliest twinning success stories was the partnership between treatment centres in Tel-Hashomer and Bratislava. Much of its success was due to raising the profile of the treatment centre in the eyes of the Slovak government. To do so, the Tel-Hashomer centre contacted the Israeli embassy and got its support for the twinning project. Embassy officials attended official functions linked to the twinning. This forced the Slovak authorities to also send a government official to these functions, which raised the profile of the events even more and resulted in a lot of media coverage. This was a major factor in the government's recognition of the Bratislava centre as the national hemophilia treatment centre in Slovakia.

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## 2. All about twinning

### Types of twinning activities

- ✓ Visiting
- ✓ Training
- ✓ Providing medical advice
- ✓ Exchanging information
- ✓ Supplying equipment
- ✓ Supplying factor concentrates/reagents
- ✓ Working together on special projects
- ✓ Conducting research

*“The Argentinean centre has trained two gastroenterologists and a dentist in Uruguay. The three professionals are taking care of young people with hemophilia in the Hospital Pereira Rossell at the moment, and as a result all of the children have had a full dental consultation and evaluation.”*

Dr. Alicia Pereira,  
Montevideo, Uruguay  
Montevideo – Buenos Aires twins



Dr. Jugutis from Lithuania consults with Dr. Claes Pettersson from Sweden.

### 2.4 Types of twinning activities

Twinning activities can be based on something twins have in common, such as a shared interest. Activities can also be chosen based on the strength of one twin or the needs of another.

Some of the main types of twinning activities are outlined here.

- **Visiting** a twin to meet them, collect information, and assess the situation is called an assessment visit. Assessment visits are a way to exchange information and gather specific data. Training does not take place. Detailed guidelines for assessment visits are available from the WFH.
- **Training** is a way to pass on knowledge, values, and skills. Training can be formal or it can be an informal exchange of knowledge to medical and paramedical professionals, including hematologists, nurses, physiotherapists, orthopedists, social workers, psychologists, laboratory technologists, dentists, and other specialists.

Training can be held on-site or via exchange visits. On-site training is when staff from one twin trains others at the site of their partner. Exchange visits are when both twins send people to visit the other centre so both partners become familiar with each other’s situation.

Making sure that the skills learned through training will be useful given the situation of the emerging centre is an issue that needs to be considered. For example, is laboratory training relevant if there is no access to reagents and other testing materials at the emerging laboratory centre?

## 2. All about twinning

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*“We have obtained assistance regarding appropriate management of clinical problems through consultations with the Oxford Centre.”*

Dr. Vis Poovalingam,  
Durban, South Africa  
Durban – Oxford twins

*“The twinning program has included joint discussion and assessment of isolated problematic cases.*

*One patient from Klaipeda was referred to Malmo for radioactive synovectomy, a procedure to be introduced in Klaipeda.”*

Dr. Eric Berntorp,  
Malmo, Sweden  
Klaipeda – Malmo twins

- **Providing medical advice** to your twin on complex cases or in emergency situations. It is important to agree and establish an efficient communication system between twins for advice to be timely and effective.

While twinning can be a powerful tool to improve the medical situation in a given centre, it is important to keep in mind that doctors and paramedical professionals from established centres should only have an advisory role when visiting an emerging centre. They cannot practice medicine as they would in their own country. Twins from established centres must ensure that their personal medical malpractice insurance extends to cover them for work associated with the WFH. It is WFH policy that surgical interventions are not performed without prior approval by the WFH.

- **Exchanging information** such as publications or materials for doctors and/or patients (i.e., treatment protocols, journal articles, patient education tools, etc.). You could also share information by telephone, fax, or e-mail. Sharing information should happen regularly and communication should be two-way.
- **Supplying equipment** to your twin, such as laboratory equipment, medical equipment, or computers. If medical equipment is donated, its usefulness over the next few years should be evaluated. For example, are the replacement equipment parts available in the emerging country and how much do they cost? What is the estimated life of the equipment and what is the cost/benefit for the twin?

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### *Argentina – Uruguay: an example of information exchange*

Argentina and Uruguay enjoy a special relationship because they are close geographically, culturally, and through trade. There are two twinning partnerships between Argentina and Uruguay: one is between hemophilia treatment centres and the other is between national organizations. Past WFH experience shows that double twinning of centres and hemophilia organizations in the two countries increases the effectiveness and impact of both programs.

This twinning partnership between Argentina and Uruguay is successful largely because information is exchanged regularly. Publications and other materials for doctors and patients are shared. The twins communicate regularly by telephone, e-mail, and in person. Communication is made easier because the twins share a common language and are close to each other (the capital cities are only 200 kilometres apart). This helped them work together to organize the National Meeting on Hemophilia in Uruguay.

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## 2. All about twinning

*“The first National Hemophilia Workshop was held in Nicaragua in 2001. We took advantage of our twinning with Venezuela to build an international team of workshop leaders. Many important topics about hemophilia were covered in these workshops. There was also time to discuss WFH programs, living with hemophilia, and the perspectives of some members of the association.”*

Yader Velásquez, Nicaragua  
Venezuela – Nicaragua  
hemophilia organization twins

*“We have collaborated on a research project looking at levels of von Willebrand factor in various ethnic groups in Durban, South Africa. An abstract relating to this work was presented at the WFH 2002 Hemophilia World Congress.”*

Dr. Paul Giangrande,  
Oxford, U.K.  
Oxford – Durban twins

- **Supplying factor concentrates and/or reagents** to your twin for emergencies or specific activities. Supplying factor concentrates and/or reagents should not be a priority in twinning partnerships because it is not a sustainable activity. Working with a twin so they can get a regular supply of factor concentrates and/or reagents is a more sustainable solution.
- Working together on **special projects** such as creating a patient registry, doing outreach, organizing training workshops, and planning conferences is a great way to achieve success. Advocacy work with the central or regional government can also be part of a twinning partnership.
- **Conducting research** that can be beneficial to the emerging twin should be encouraged. Such studies can provide data and information that can be used to increase the efficiency of the emerging centre. Research projects can also give credit and recognition to the twinning partners. However, the WFH strongly suggests that research should not be the sole focus of a twinning partnership.



The Milan hemophilia treatment centre in Italy participated a workshop on psychosocial aspects of hemophilia organized by its twin in Iran.

## 2. All about twinning

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WFH

### Support to twins

- ✓ Finding a twin
- ✓ Financial support
- ✓ Supplying WFH material
- ✓ Sharing experience
- ✓ Guidance and coaching

## 2.5 WFH support to twins

### Finding a twin

Are you interested in twinning? The WFH will help match your treatment centre with a centre in an emerging country. Let us know where in the world you'd like to twin. Think about the language of the staff and volunteers of your centre, or your contact with emerging countries.

### Financial support

The WFH gives U.S.\$1,500 yearly towards the expenses of each twinning partnership, and provides grants for specific twinning projects. The WFH also offers funding for the first assessment visit to your twinning partner.

### Supplying WFH material

The WFH gives you publications and other materials to help with twinning activities. These include a twinning data questionnaire, funding applications and guidelines, and evaluation forms.

### Sharing experience

We value what has been learned through past twinning projects. Sharing this information and experience can benefit future twinning ventures. WFH summary reports and twinning meetings help get this information to you.

### Guidance and coaching

The WFH can help each twinning partnership. Our regional program officers keep in touch with you and provide follow-up support as needed. When possible, we can travel with you on an assessment visit to your twin's centre.

## 2. All about twinning

Does

**your group have the**

- ✓ Commitment
- ✓ Vision
- ✓ Capacity
- ✓ Values
- ✓ Funding

### 2.6 Are you ready for twinning?

How do you know if your treatment centre is ready to take on a twinning project? Use the following checklist to find out.

- Commitment: Is there a strong desire within your hospital administration to take on a twinning project?**  
Before starting, you need support from all levels of your treatment centre: staff, administration, and volunteers. People must be willing to learn and to share. Ideally, sharing experience is already a central part of your centre's mission. Your twinning project may take time, effort, and resources – is everyone on board?
- Vision: Are you clear about why you want to twin?**  
What can you give? How do you hope to benefit? For example, you may feel that twinning will expose you to new ideas about care and prevention interventions, or you may want to share your experience in this area with others.
- Capacity: Do you have the capacity to take on a twinning project?**  
If you are stretched to the limit now, you need to decide how you can add the extra work of a twinning project. You must be able to devote the time needed to make twinning work. There is no quick and easy way for success.
- Values: Can your treatment centre value this twinning project?**  
Take a good look at the current spirit of your group. What are the current internal politics of your centre? Are you able to welcome others? Can you empathize with the problems of another centre?
- Funding: Can you afford a twinning project?**  
Core funding is covered by the WFH through annual twinning payments, assessment visit funding, and grants. However, it's helpful if you can find some additional funding from inside or outside your centre.



# 3. Steps for improved diagnosis and care

*“The determination of the two teams has paid off in results.*

*Comprehensive diagnosis and inhibitor screening are now available at the Tartu centre, and treatment with concentrates is becoming more and more commonplace in Estonia.”*

Dr. Sam Schulman, Stockholm, Sweden  
Tartu – Stockholm twins



Dr. Lily Heijnen from the Netherlands helps with a patient consultation at her centre's twin in Pakistan.

**H**emophilia treatment centres have many functions. Some of these evolve or change over time with advances in diagnosis, treatment, and care in a particular country. The basic functions are diagnosis and evaluation, treatment, coordination of care, education (of parents, patients, other medical providers, community-based organizations, schools, etc.), data collection, research, and advocacy.

The objective of treatment centres in emerging countries should be to develop appropriate diagnosis and treatment, taking into account the initial level of care available. This cannot be done overnight but, with the help of twins and the WFH, improvements can be made gradually.

This chapter outlines the basic steps treatment centre twins can focus on to improve diagnosis and medical expertise in the emerging country. It also gives a summary of the comprehensive care model, which represents the optimal level of hemophilia care. Comprehensive care is available in the established centres involved in the twinning program. However, emerging centres often do not follow the comprehensive care model simply because they do not have the resources. However, through twinning, even with limited resources, there are many things that can be done to work towards establishing a core comprehensive care team, including the hematologist, nurse, physiotherapist, and orthopedist.

## 3.1 Steps for developing medical expertise

The WFH has developed a model for improving hemophilia care on a step-by-step basis, starting from the most basic level with the comprehensive care model being the optimal level (see Appendix A – “Developing national hemophilia care programs”). The process is divided into two phases. All steps in Phase I can be achieved at relatively low cost and using local resources, but the results – in terms of life expectancy of patients – are dramatic.

## 3. Steps for improved diagnosis and care



Drs. Man-Chui Poon and Brian Luke from Canada helped their twins in China organize a regional workshop on hemophilia care.

### Phase I

In Phase I, medical expertise can be gradually improved, to ensure a basic diagnostic capability and basic management. This can be achieved with the following twinning activities:

- 1- Provide basic training to the doctor(s) and laboratory technologist(s), either locally or at the established twin's centre.
- 2- Encourage hospital administration to assign a specially trained hematologist to hemophilia care.
- 3- Advise on the creation of a **patient registry** for existing (or known) patients.
- 4- Develop **treatment protocols** adapted to the situation of the emerging country/centre. These treatment protocols need to be approved and a system established to ensure they are used by medical and paramedical staff.

### Phase II

Phase II focuses on developing a comprehensive care team with specialized knowledge in the different disciplines that are involved in the treatment of hemophilia: orthopedics, dentistry, nursing, physiotherapy, etc. It is important to make sure that all members work together as a team, by encouraging constant collaboration and meetings. The following twinning activities can help build a comprehensive care team:

- 1- Provide specialized training in hemophilia for the hematologist in charge of hemophilia care.
- 2- Provide training to the core group: nurse, physiotherapist, and orthopedist.
- 3- Provide training to a social worker/psychologist and dentist.
- 4- Encourage the laboratory's participation in an external quality assurance (EQA) program, and provide advanced training to a specialized laboratory professional (i.e., inhibitors, von Willebrand disease).

## 3.2 The comprehensive care model

Comprehensive care is a system of care that uses a team to provide optimal care for the patient in one or several designated treatment centres. The team consists of professionals from several disciplines: doctors, nurses, social workers, psychologists, physiotherapists, orthopedists, genetic counsellors, dentists, and other specialists. All efforts of the comprehensive care team are focused on people with hemophilia and their families. All members of the team work with them to develop individual plans and coordinate the complex medical services needed.

### 3. Steps for improved diagnosis and care

*“The University Hospital in Geneva has extensive expertise in multi-disciplinary consultations, surgical interventions, physiotherapy, dental problems, and laboratory. Some of the main aspects that we need to work on in our Beirut centre are precisely our joint multidisciplinary consultations, the training of personnel including orthopedic surgeons and physiotherapists, and improving our physiotherapy and diagnostic material. This means that the Geneva centre is easily able to share their particular skills, knowledge, and experiences to improve these aspects of our hemophilia centre.”*

Dr. Ali Taher,  
Beirut, Lebanon  
Beirut – Geneva twins



Angus McCraw from London, U.K., provides training to lab technologists in India.

Participating in a comprehensive care system can benefit people with hemophilia for many reasons. Hemophilia is a relatively rare disorder. Most medical providers in the community may have little experience with its diagnosis and treatment. They may not know about the newest trends in preventing complications. In a hemophilia treatment centre, there is a team of trained medical providers, whose members have special training and experience in hemophilia, and they know about its complications and current treatment options. Other benefits of a comprehensive care approach include:

- Increased efficiency
- Cost-effectiveness
- Improved availability of specialized services
- Improved access to home care (when applicable) and community-based services
- Early identification of potential problems and development of specific treatment
- Decreased complications of bleeding
- Decreased mortality
- Improved employment rates
- Increased school and work attendance
- Educated parents play an active role in managing their children’s care

Today, comprehensive care centres can successfully improve the physical, mental, and social health of people with hemophilia.

### 3. Steps for improved diagnosis and care

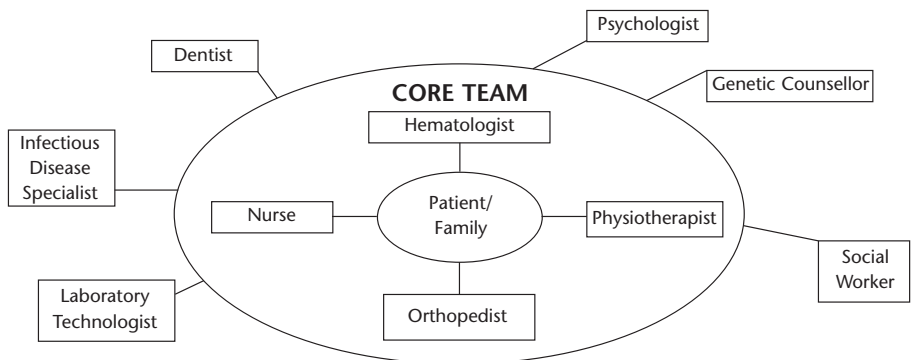
*“It’s unusual to have an orthopedic surgeon as the founder of a new hemophilia program, as is the case with our twin in Bogota. Many people with hemophilia in Colombia have orthopedic problems because clotting factor treatment in past years was minimal. Dr. Llinas has been able to arouse interest in the orthopedic problems of people with hemophilia. He has held outreach clinics in other towns, including orthopedic diagnosis and, on several occasions, performed radionuclide synovectomies where needed.”*

Dr. Carol Kasper  
Bogota – Los Angeles twins

### 3.3 The comprehensive care team

Who is on the comprehensive care team? Comprehensive care teams include patients, their families, and a core group of health professionals – usually a nurse, hematologist, orthopedist, and physiotherapist. Additional team members may come from such areas as psychology, genetics, infectious disease, social work, dentistry, and nutrition. Even though they do not directly treat patients, laboratory technologists in charge of diagnosis are an essential resource for the comprehensive care team.

The illustration below shows a typical comprehensive care team. The core team members are inside the circle, with additional team members outside.



### 3. Steps for improved diagnosis and care



Nurse Graciela Perini teaches a mother good clinical practices regarding venepuncture and concentrate preparation and administration at the treatment centre in Bogota, Colombia.

The following table describes some of the responsibilities of the core members of the comprehensive team.

Team member	Potential responsibilities
Person with hemophilia and family	All efforts of the comprehensive care team are focused on people with hemophilia and their families. All members of the team interact with them and consider their needs, goals, and beliefs before beginning any therapy.
Hematologist (pediatric or adult)	Medical evaluation Diagnosis, treatment recommendations Individual/family education Professional education Communication with primary doctor and other specialists as needed Program planning Research, both laboratory and clinical
Nurse	Individual/family education Assessment and treatment of bleeding episodes Professional education (hospital staff, nursing) Coordination of team; link with other services, community agencies Home treatment preparation and supervision Case management of clinical care Participate in/coordinate clinical research studies
Physiotherapist	Routine evaluation of joint status, muscle strength Rehabilitation of musculoskeletal problems which cause disabilities (i.e., after bleeding, chronic synovitis or arthropathy) Strengthening before surgery and rehabilitation after surgery Early detection of possible problems Education with recommendations for physical activities, fitness, and sports Assessment of bleeds and recommendations on a course of treatment Participation in clinical research
Orthopedist <sup>1</sup>	Evaluation of the musculoskeletal system (including joints, muscles, and peripheral nerve status) Management of orthopedic problems Prevention of musculoskeletal problems Professional education of physiotherapists, nurses, and colleagues Advice on shoe adaptations, orthotics, and prosthetics Surgical treatment (based on own expertise in other patient groups and only if sufficient clotting factor is available)
In some countries, the psychologist/social worker is part of the core team.	
Psychologist/ social worker	Individual/family education Public education Psychosocial counselling; development/educational testing Assessment of quality of life or family functioning Referral for community-based services; follow-up Crisis intervention Professional education; individual/family, schools, employers, public Empowerment of families to contact resources Outreach

<sup>1</sup> The physiotherapist can also fulfil this role except for surgical treatment.

### 3. Steps for improved diagnosis and care

*“I was so happy when the results of my performance in the quality assurance scheme showed that my results compared favourably to the rest of the world.”*

Manjeed Mahendiratta,  
Delhi, India  
Delhi – London twins

It is important to note that medical systems differ from country to country, and that the specific situation can affect the responsibilities of the members of the comprehensive care team. For example, in most emerging countries, the orthopedist and physiotherapist have a major role because joint damage in people with hemophilia is more frequent. In some countries, there are no social workers or genetic counsellors. The role of the nurse within the comprehensive care team can also vary greatly; it can range from being a support technician to being the comprehensive care team coordinator.

#### 3.4 Laboratory diagnosis

Correct diagnosis is the key to appropriate hemophilia treatment and the role of the laboratory is fundamental to achieving this. Laboratory personnel conduct diagnostic tests and assays to correctly identify a variety of bleeding disorders. To ensure the reliability of laboratory testing and reporting, a number of quality assurance measures are taken. The emerging twin should be introduced to internal quality control and the use of reference materials. Also, they should be encouraged to participate in an external quality assurance (EQA) program. The WFH does have an EQA scheme, which has been specifically designed for this purpose. Further information or advice can be obtained from the WFH.

Team member	Potential responsibilities
Laboratory technologist	Performance of a range of coagulation tests Accurate diagnosis of bleeding disorders Accurate monitoring of treatment Maintenance of quality assurance through the use of standard operating procedures Reference materials Participation in an external quality assurance program

The WFH laboratory manual, entitled *Diagnosis of Haemophilia and Other Bleeding Disorders*, is a comprehensive guide to assist laboratory technologists. It details the various tests to establish an accurate diagnosis of hemophilia and other bleeding disorders. The manual contains step-by-step instructions on sample preparation, screening tests, factor assays, inhibitor detection, and the assays of von Willebrand factor, and is intended to be used as a reference for laboratory practice within centres diagnosing and monitoring treatment of bleeding disorders. It also reviews the equipment needed within a laboratory, such as reliable refrigerators and freezers, and the importance of the continuity of supply of consumables and reagents. Copies of the laboratory manual can be obtained from the WFH.

# 4. Steps for twinning success

## Steps to Explore the idea

1. Assess the capacity of your centre
2. Set a clear, realistic goal
3. Check your level of commitment
4. Decide who will be involved
5. Contact the WFH
6. Identify potential twinning partners
7. Contact potential partners
8. Select a partner and agree to proceed

*“During our first assessment visit to Panama, we had the opportunity to visit the children’s hospital and the adults’ hospital. We held different meetings with them concerning the laboratory, hematology clinic, nursing, and rehabilitation. We also held meetings with members of the Panamanian Association of Hemophilia. We jointly carried out clinical visits with patients suffering from hemophilia A and B. All of this has allowed us to have a better understanding of the current situation of patients in Panama.”*

Dr. Jose Aznar, Valencia, Spain  
Panama City – Valencia twins



Staff from the Bradford hemophilia treatment centre in the U.K. participate in the launch of a new comprehensive care centre in Pune, India, built with the help of funds raised by the Bradford centre.

**W**hat makes twinning projects successful? Experience from past twinning projects shows that following these steps and suggestions leads to success.

## 4.1 Explore the idea

Take the time to do some research. Talk with other twinned treatment centres. Consider cultural diversity and the strengths of your centre. Preparation is the foundation for success.

### Step 1. Assess the capacity of your centre

Identify the strengths of your group. What skills and resources can you share with others? What are your needs?

### Step 2. Set a clear, realistic goal

Use the assessment of your centre’s capacity to set a realistic goal for a twinning project. The goal should be a clear statement about the purpose of your twinning project. Use it to express what you hope to gain and what you can give. It is important to keep expectations in check. The activities included in the twinning project should be achievable with available resources and within agreed upon time frames. Set your goal early in the process. You can always alter it later if needed. Examine the “Steps for developing national hemophilia care programs” in Appendix A for strategic direction.

### Step 3. Check your level of commitment

Make sure that your treatment centre feels strongly and is clear about why it wants to take on a twinning project. Ask people to commit to the goal.

### Step 4. Decide who will be involved

Who will take the lead on this project? Twinning projects are more successful when people take the lead. Committed people from both centres often guide the best projects.

## 4. Steps for twinning success

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*“Owing to the geographical position on either side of the Baltic Sea, it was eminently fitting that the Klaipeda treatment centre in Lithuania and the Malmo centre in Sweden should be twinned.”*

Dr. Romualdas Jurgutis,  
Klaipeda, Lithuania  
Klaipeda – Malmo twins

*“The double twinning of organization and centre twins is an efficient and effective way to maximize results. Both work together on projects. This encourages good communication between healthcare providers and patients. Patients and physicians work together to improve the lives of people with hemophilia.”*

Shirley Wilson,  
Minnesota, U.S.A.  
Republic of Georgia –  
Minnesota/Dakotas, U.S.A. twins.  
Hemophilia treatment centres  
in Minnesota and Georgia are  
also twinned.

Who will help and support the leader? Share the tasks between several people in both treatment centres. This will create a sense of connection with your twin. This will also make sure the twinning program will continue over time. You do not want your program to stop because of a change of staff.

### **Step 5. Contact the WFH**

At this point, you should contact the WFH to inform us of your interest in twinning and ask for advice on next steps. The WFH can also provide up-to-date information on the current developments of the twinning program.

The WFH will do a comprehensive assessment of your organization by collecting basic information on the services provided at your centre. This will give us a better idea of your treatment centre’s overall structure and activity. We will also explore with you the reasons why you want to get involved in a twinning partnership.

### **Step 6. Identify potential twinning partners**

You may already have a treatment centre in mind as your twinning partner. If not, identify potential partners. This can be done with the help of the WFH.

Keep these factors in mind when choosing a partner:

- **Compatibility** – Make sure your cultures are compatible. Consider what languages people in your centre can speak. Look at the historical, economic, and trade links between your two countries.
- **Needs** - There must be a good match between the needs and capacities of your two treatment centres.
- **Synergy** – Synergy happens when working together has a greater effect than if each partner worked alone. Your chances of success are much greater if there is good synergy between twins. To ensure good synergy there should be an interest in sharing experiences, concerns, interests, approaches, and activities. There should also be mutual trust.
- **Partner with a centre and an organization** – Double partnerships between hemophilia centres and hemophilia organizations in the same countries work. They can have a greater impact and output, making them more effective.

### **Step 7. Contact potential partners**

Explore the possibility of twinning with potential partners on your list. Are they interested? Exchange information about needs and strengths to make the best match. You are assessing the interest and commitment for building a partnership.



## 4. Steps for twinning success

### Steps to Make a plan

1. Make an assessment visit
2. Collect data
3. Make a detailed action plan
4. Approve the project action plan
5. Get funding if needed

### Step 8. Select a partner and agree to proceed

Select your partner treatment centre. Agree in principle to proceed with your twinning project. Tell the other potential partners you approached about your decision.

### 4.2 Make a plan

This is the time to get specific. Visit your twin and then together write out and agree on the plan for your project. You must be able to complete the activities on time with the resources you have at hand.

#### Step 1. Make an assessment visit

Visit your potential twinning partner in their country and learn on-site about their reality. It is important for your treatment centre to have a good understanding of your potential partner centre: their issues, strategies, techniques, and level of development. It is equally important to understand and value the culture and history of your potential twin. Be realistic about your hopes for the twinning project.

During the visit you could prepare a general outline of the project or even a detailed action plan with your twinning partner. Assessment visit guidelines are available from the WFH and can help you gather useful information from your visit.

The WFH has funding available for assessment visits to potential twinning partners. Application forms for assessment visit funding can be obtained by contacting the WFH.

An assessment visit to your partner centre during the planning stage is the best way to begin. If this is not possible, you can still communicate through e-mail, telephone, and fax. It is useful if the assessment visit takes place within the first year after the start of your twinning partnership.



Uruguay and Argentina treatment centres receiving the WFH Twins of the Year Award in 2000.

## 4. Steps for twinning success

*“One of our twinning goals is to improve the diagnostic capability of the centre and translate it into appropriate care of the hemophilia community and other bleeding disorder groups, specifically to recognize and identify von Willebrand disease from hemophilia, for which our country has no capability at the moment.”*

Dr. Mary Chua, Manila,  
Philippines  
Manila – Melbourne twins

*“The twinning project has stimulated interest in people with hemophilia in Nicaragua: in December 2000, a hemophilia shelter was inaugurated, and in May 2001, we hosted a workshop about hemophilia. Dentists, emergency doctors, physiotherapists, and pediatricians are now interested in receiving specialized training in hemophilia care.”*

Dr. Norma De Bosch,  
Caracas, Venezuela  
Managua – Caracas twins

### Step 2. Collect data

In order to measure results of your centre twinning partnership over the years, it is important to collect data at the very beginning of your partnership. You will want to know, for example, if the emerging treatment centre has a registry, how patients are diagnosed, what medical expertise is available, is a treatment protocol used, etc. Not only will this help you plan your twinning activities, this initial data will also be a reference for your evaluation at the end of your partnership. The WFH twinning data questionnaire and the WFH annual survey are tools you can use to collect the data.

### Step 3. Make a detailed action plan

Prepare a detailed action plan together with your partner treatment centre. Use the action plan outline and application form available from the WFH to guide you. You can also use “Steps for developing national hemophilia care programs” (Appendix A) as a planning tool.

Your action plan should include:

- **Goal and objectives** – start with one goal and a few specific objectives. The focus must be clear and precise because this shows you both have a clear sense of needs and strengths. Write clear and measurable objectives.
- **Roles and responsibilities** of both centres. Be exact about the role of each partner in the twinning project. Who is responsible for what?
- **Activities** – detail the project activities and the time they will take to complete.
- **Detailed budget** – include sources of income and expenses.
- **People involved** – list the staff and volunteers who will work on the project and what their roles will be.
- **Expected outcomes** – clearly state what results you expect. These are your outcomes. Identify ways to measure the success of each outcome that will tell you if you have achieved your objectives.
- **Monitoring and evaluation** – outline a plan to monitor progress. Plan how you will evaluate your project and/or partnership.

### Step 4. Approve the project action plan

Both centres need to approve the detailed project action plan. Then send it to the WFH for official recognition.

### Step 5. Get funding if needed

The WFH gives some funds each year to all twins and offers grants for specific projects. However, if you need more funding for the project, you will need to find it from other sources. Approach funders early in the process, perhaps after the two treatment centres have agreed on the general outline.

## 4. Steps for twinning success

### Tips for successful Implementation

- ✓ Be sensitive to cultural diversity
- ✓ Work at communication
- ✓ Be flexible
- ✓ Network with other twins
- ✓ Monitor and report regularly

### 4.3 Implement the plan

Now that the planning is complete, you are ready to implement your twinning project. Follow your plan and use good project management practices. Past experience shows that cultural sensitivity, networking, flexibility, good communication, and regular monitoring and reporting are keys to success.

#### **Be sensitive to cultural diversity**

Take the time to learn about the culture of your twinned partner. Make sure you tailor your approach, information, and activities to the culture of your twin. Use the tips in Section 4 of this guide to help you approach cultural diversity.

#### **Work at communication**

You need a good flow of information between the two treatment centres for a successful twinning project. See Section 5 for strategies for effective communication.

#### **Be flexible**

You may need to change your plans along the way. A flexible, step-by-step approach to planning and implementation works better than sticking with a fixed plan. This is most important for treatment centres working on their first twinning project.

Sometimes factors beyond your control will affect your ability to reach objectives. Here are some examples of factors beyond your control:

- **Change in leadership or staff**  
When the key contact person or staff changes in either treatment centre you must adjust the original plan.
- **Change in priorities**  
After a twinning project is approved, a new priority can arise. Political instability or organizational restructuring are two examples. These can change the focus of your project or activity.

Most WFH twinning projects have been very successful. However, a few have not reached their full potential or have ended because of difficulties that could not be overcome. Do not get discouraged if your twinning project is not going according to plan. Instead, try to learn from it. The valuable lessons learned by others that have met with challenges through twinning have been included in this guide.

## 4. Steps for twinning success



Prof. Pier Mannucci from Italy meets with a patient and his family at his centre's twin in Iran.

### Network with other twins

Learn from the shared experience and advice of twins from around the world by contacting other twins and at WFH meetings.

### Monitor and report regularly

How do you know if your project is on track? Monitoring can tell you if activities have taken place as planned. Twins should monitor the project often and keep track of results through regular reports.

Monitoring involves:

- Making sure planned activities are being carried out and that there are no serious delays.
- Reviewing the budget so as not to overspend.
- Checking for progress on project objectives and activities.
- Identifying problems as they come up.

Monitoring can help you notice areas of concern, such as falling behind schedule, high costs, implementation issues, or lack of progress. Take action early to overcome these concerns.

**Reporting** is part of the monitoring process. WFH reports are due in the last quarter of each year. Progress reports should be prepared regularly during the twinning project. Your reports must include information on the following areas:

- The status of the action plan;
- The status of the budget;
- Progress made on project goals;
- Problems during project implementation.

### 4.4 Evaluate your work

Evaluation compares what you expected to happen with what really happened on a twinning project or activity. It also looks at **how** things were done.

You probably assess the merit of your work informally without calling it evaluation. You may ask questions, consult partners, get feedback and then use that information to improve your work. When stakes are low, this type of informal evaluation might be enough. When the stakes are higher (when time and money are involved, or when you work with many people) it may make sense to use a formal and visible evaluation. As a general rule at least 15 percent of your time and resources on a project should be spent on evaluation.

## 4. Steps for twinning success

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*“The twinning program has been invaluable to both centres. Not only has it allowed us to learn a great deal from each other, but it has provided us with an opportunity to renew historic links between our two peoples, and to lay the foundation for further cooperative efforts in other medical specialties.”*

Dr. Eric Berntorp,  
Malmo, Sweden  
Klaipeda – Malmo twins

There are two kinds of evaluation: **process** and **outcome**.

Process evaluation measures how well you and your twin are doing things. It looks at the processes used to achieve your project objectives. As well, don't forget that your twinning partnership itself is a main activity. You should evaluate the effectiveness of this partnership. You may want to evaluate processes such as the way you communicate, make decisions, or implement activities.

**Outcome evaluation** measures how well you have achieved your objectives. It looks at the real outcomes or results of your project and compares them to what you hoped would happen.

Treatment centres involved in a twinning project should do both process and outcome evaluations. Focus on a practical, ongoing evaluation that involves staff, volunteers, and other stakeholders. This type of evaluation helps you:

- Clarify project plans;
- Improve communication between partners;
- Gather feedback to improve and account for project effectiveness and efficiency.

Think about who will read the evaluation results: your treatment centre staff and administration, your partners, your volunteers, or your funders. Keep this in mind when choosing the scope of your evaluation.

Don't wait too long after the project has been completed to finish your evaluation: it's best to do this while everything is still fresh in your mind and you can still access any information you might need.

Share the results of the evaluation: don't let the report sit on a shelf. Encourage discussion about the project. Talk about what worked and make changes to policies, procedures, and future activities.

Evaluation is a powerful way to separate projects that make a difference from those that don't. It is a driving force for developing effective approaches, improving twinning partnerships, and showing the results of your investment of time and resources. Evaluation can tell you if what you are doing is worth the investment.

# 5. Twinning across cultures

## Developing Cultural awareness

- ✓ Examine your own cultural identity
- ✓ Learn about your twin
- ✓ Keep an open mind
- ✓ Be patient
- ✓ Be honest about cultural biases
- ✓ Ask questions
- ✓ Risk making mistakes



Nurse Jill Smith, from the treatment centre in Perth, Australia, meets children at the hemophilia centre in Harare, Zimbabwe.

## 5.1 What is culture?

**Culture** refers to a group of people with common, shared experiences. This shapes the way they view the world. You can be born into a cultural group by your race, country of birth, gender, class, or religion. You could also become part of a cultural group by moving to a different part of the world or losing your job or your health. People with hemophilia may see themselves as part of a distinct cultural group.

In thinking about our differences, don't forget what you have in common with others around the world. We are all human beings. We all feel compassion, want to learn, have dreams and doubts, and have a vision for a better world.

## 5.2 Why twin with other cultures?

You benefit from partnering with others. Your treatment centre also benefits in ways you may not even expect. These benefits are greater if your partner is from another culture. Cultural groups have strengths and ideas that may be different from your own. You need a wide range of ideas, plans, and wisdom to solve the challenges faced by people with hemophilia worldwide. Partnerships between cultures can create powerful, positive change.

The mission of the WFH is global. To achieve it, people from different cultures need to work together.

## 5.3 Developing cultural awareness

Good partnerships and successful projects take time and effort to create. A key step is to build a genuine relationship with people from another culture. To do this, you and your centre need to become good at working with people from other cultures. You need to develop cultural awareness.

## 5. Twinning across cultures

*“Collaboration between the two pairs of Canadian – Chinese twins will greatly facilitate hemophilia activities not only in the two twinned Chinese centres but also in China in general through better coordination and networking.”*

Dr. Man-Chiu Poon,  
Calgary, Canada  
Tianjin – Calgary twins

This may take time and involve learning new skills. However, the only way for you to design a twinning project that actually works is if you adapt it to the culture of your twin. You may even be rewarded with a partnership that goes beyond your expectations.

Here are some suggestions about developing cultural awareness.

- **Examine your own cultural identity**

One good way to learn about other cultures is by thinking more about your own. Know how your culture shapes the way you do things. This allows you to see how your ways may affect others. If you can talk clearly about your own culture you will be able to listen to others talk about theirs.

What is your culture? This is more than knowing where your family comes from. Culture changes over time. Part of your culture is from your ancestors but your family, your friends, and your community add to it. Groups you identify with are also part of your culture, such as being a parent, an immigrant, a labourer, or a small business owner.

- **Learn about your twin**

Read about the culture and history of your twin and apply what you learn. This shows that you value the culture enough to find out more about it. Research helps you ask questions that make sense. It is also the only way to design an effective, culturally appropriate, and successful project.



Dr. Parapia from Bradford, U.K., receives a traditional welcome from his centre's twin in Pune, India.

## 5. Twinning across cultures



Dr. Wahid Hanna from Knoxville, U.S.A., examines a young boy at the Knoxville centre's twin in Egypt.

- **Keep an open mind**

Don't judge people right away if they think or work differently than you. Take time to learn more about their cultural values. You may even learn new and effective approaches this way! Treatment centres in different cultures may have work expectations and habits different from your own. For example:

The length of time expected for a response can vary. Your version of "immediate response" may be very different from your twin's.

The approach to making decisions can vary. Some twins may work by consensus, others by deferring decisions to others.

Approaches to implementing a project can vary. The person implementing the project may not be the person responsible or accountable for the project.

The type of leadership may vary. The person who seems to be leading a project may not be the person defining the direction of the project.

- **Be patient**

Decide to partner cross-culturally and don't give up. Building relationships with people from another culture takes time and effort.

- **Be honest about cultural biases**

Like it or not, you may be biased about people from different cultures. You may have picked up inaccurate information when you were young, from people around you or from television or movies.

- **Ask questions**

Question people about their culture, customs, and views. People are usually pleased if you show an interest in their lives and culture. If you are sincere and listen well, people will tell you a lot.

- **Risk making mistakes**

You will make mistakes because of cultural differences. If you say or do something that is insensitive, learn from it. Apologize, and then rebuild the partnership. Do not let guilt keep you from reaching your goals.



# 6. Communication

## Tips for Good communication

- ✓ Start early
- ✓ Review often
- ✓ Respect your differences
- ✓ Be flexible and resourceful
- ✓ Assume complexity
- ✓ Tolerate the stress of uncertainty
- ✓ Show respect and empathy



Dr. Carol Kasper, from Los Angeles, U.S.A., visits the hemophilia team at the treatment centre in Bogota, Colombia, which is twinned with Los Angeles Orthopaedic Hospital.

## 6.1 General communication tips

Communication is a key tool for effective twinning. Here are some general tips about good communication across cultures.

### Start early

Decide how you will communicate early in the twinning partnership. Know who your contact person is.

### Review often

Review your system regularly and make changes if needed.

### Respect your differences

Know that both treatment centres may use different communication styles. Keep an open mind. Don't quickly jump to conclusions or pass judgment on others.

### Be flexible and resourceful

Adjust quickly and effectively to changing situations. Know how to quickly get the things you need to respond well to any situation.

### Assume complexity

Know that working cross-culturally will be complex. There may be many diverse ideas and outcomes.

### Tolerate the stress of uncertainty

Don't show your stress due to communication issues. Things may not be clear or easy to understand right away. Becoming frustrated may make it worse. Be patient.

### Show respect and empathy

Show your genuine understanding, honour, and esteem of the person or culture you are dealing with. Imagine yourself as your partner. Empathy is critical.

# Conclusion

*“Both centres have learnt about using resources more effectively. The twinning partnership has been a great morale booster.”*

Dr. Anil Lalwani, Pune, India  
Pune – Bradford twins



A physician and laboratory technologist from Albania receive training from their centre's twin in Vicenza, Italy.

**T**winning can greatly improve hemophilia care at its most basic level. It can reward both partners in ways they may not have thought possible.

Twinning gives emerging hemophilia treatment centres the skills, experience, and determination to face the challenges ahead. But perhaps even more importantly, it gives them support that can lift their sense of isolation and give them hope to carry on.

Does your treatment centre have access to information, skills, and resources to share with others? Or, are you part of an emerging treatment centre that would benefit from twinning? If you are interested in improving care beyond your borders and becoming a twin, contact the WFH at:

## **World Federation of Hemophilia**

1425 René Lévesque Boulevard West, Suite 1010  
Montréal, Québec H3G 1T7  
CANADA

Tel.: +1 (514) 875-7944

Fax: +1 (514) 875-8916

E-mail: [wfh@wfh.org](mailto:wfh@wfh.org)

Web site: [www.wfh.org](http://www.wfh.org)

# Developing national hemophilia care programs

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National hemophilia care programs focus on four target areas:

1. care delivery
2. medical expertise
3. treatment products
4. patient organizations

Hemophilia care improves as you make step-by-step progress in each of these four areas. Table 1 shows the objectives and steps needed to improve in each category. Steps are divided into two phases. Phase I steps can be reached at a low cost using local resources. National programs can dramatically increase the life expectancy of people with hemophilia by following this step-by-step approach. Twins may find Table 1 useful as a guide for choosing projects and activities that would have the greatest impact. Centre twinning focuses mostly on care delivery and medical expertise, but some twins expand their activities into the other areas as well.

## 1. Care delivery

The first steps to improve **care delivery** include setting up a regular clinic with a patient registry and plan for regular follow-up. Resources are used more efficiently when the government officially recognizes the clinic. If the government agrees to a long-term national plan for hemophilia, then regional centres can be planned. Work then begins to develop basic care and comprehensive care teams.

## 2. Medical expertise

**Medical expertise** can also be improved by training doctors and healthcare professionals in the basic diagnosis and management of hemophilia. Further training can focus on specialized areas such as orthopedics, nursing, physiotherapy, dentistry, and so on.

## 3. Treatment products

It is possible to improve the quality and quantity of local **treatment products**. In Phase I, local treatment products range from whole blood to freeze-dried cryoprecipitate. Concentrates are introduced in Phase II.

## 4. Patient organization

A strong **patient organization** is needed to improve and maintain hemophilia care. A national hemophilia organization is often the catalyst for major change. National organizations work with doctors and the government to improve treatment of hemophilia.

# Developing national hemophilia care programs

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The first step to forming a **patient organization** includes setting up a structured and registered group that holds regular meetings in a regional centre. When the group is ready, it does outreach to other regions of the country to identify new patients. These people organize into chapters offering services and support to their local community.

When an organization includes members from other regions it becomes a national organization. It should be a valued partner of the government on hemophilia issues such as creating a national plan for the care and treatment of hemophilia.

## Appendix A

### Table 1. Steps for developing national hemophilia care programs

Care delivery	Medical expertise	Treatment products	Patient organization
<b>Objectives</b>			
<p>To set up a national hemophilia care program within a health system (to have a national plan).</p> <p>To make the organization of hemophilia treatment more efficient.</p>	<p>To provide appropriate diagnosis and treatment.</p>	<p>To obtain the best quality blood products in sufficient quantity.</p>	<p>To develop a strong patient organization for advocacy and education.</p>
<b>Development steps: Phase I</b>			
<ol style="list-style-type: none"> <li>1. Isolated doctor works with no resources.</li> <li>2. Treatment is possible in one hospital, usually in the capital city.</li> <li>3. A regular clinic exists in one hospital. A patient registry is set up and regular care and follow-up are offered.</li> <li>4. Official recognition of the clinic as a hemophilia treatment centre (HTC).</li> <li>5. Official support for a long-term and national hemophilia care program.</li> </ol>	<ol style="list-style-type: none"> <li>1. Basic laboratory diagnostic ability.</li> <li>2. Basic medical expertise in hematology. This includes pediatricians and general practitioners.</li> </ol>	<p><b>Local production of:</b></p> <ol style="list-style-type: none"> <li>1. Whole blood</li> <li>2. Plasma</li> <li>3. Fresh frozen plasma</li> <li>4. Cryoprecipitate</li> <li>5. Freeze-dried cryoprecipitate</li> </ol>	<ol style="list-style-type: none"> <li>1. A nucleus of patients forms the organization.</li> <li>2. Organization is structured and registered and holds regular meetings.</li> <li>3. Organization educates people with hemophilia and families in the capital city.</li> </ol>
<b>Development steps: Phase II</b>			
<ol style="list-style-type: none"> <li>6. Additional treatment centres are set up in large cities.</li> <li>7. Specialized hospitals exist for children and/or adults.</li> <li>8. Comprehensive hemophilia care team is formed in major HTC(s).</li> <li>9. Basic team formed in other areas/regional HTCs.</li> </ol>	<ol style="list-style-type: none"> <li>3. Specialized hematologists work in the system.</li> <li>4. Specialized comprehensive care team includes nurses, orthopedists, dentists, psychologists, social workers, and physiotherapists.</li> </ol>	<p><b>Purchase, contract fractionation, or local production of:</b></p> <ol style="list-style-type: none"> <li>6. Plasma-derived concentrates</li> <li>7. Recombinant concentrates</li> </ol>	<ol style="list-style-type: none"> <li>4. Regional chapters are formed (parent organization becomes a national organization).</li> <li>5. National organization does fundraising and lobbying.</li> <li>6. National organization is a partner in national hemophilia care program.</li> </ol>

**Action plan**

A record of the activities a group has agreed to do to reach its goal.

**Assessment visits**

Visiting a twin or potential twin to collect information and assess the situation in their country.

**Best practices**

Methods and strategies used elsewhere and found to be effective.

**Capacity building**

Teaching skills and providing information to enable people to become more effective.

**Collaboration**

Working together on a project or activity.

**Comprehensive care**

A system of care that uses a multidisciplinary team of medical providers with specialized knowledge to provide optimal care for the person with hemophilia at a hemophilia treatment centre. The team consists of hematologists, nurses, physiotherapists, orthopedists, social workers, psychologists, laboratory technologists, genetic counsellors, dentists, and other specialists.

**Culture**

A group of people who share common experiences. Culture can include language, religion, music, food, and lifestyle.

**Cultural awareness**

Learning more about other cultures and having respect for them.

**Evaluation**

A comparison of what you expect to happen with what really happened during a twinning project or activity. Evaluation can also look at how you did things.

**Goal**

A general statement about the purpose of a project or activity.

**Hemophilia treatment centre**

A specialized medical centre that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders. Ideally, there is a comprehensive care team of trained medical providers, who have special training and experience in hemophilia and know about its complications and current treatment options.

**Monitoring**

Regular tracking of a project as it takes place.

**National Member Organization**

A national hemophilia organization that is a member organization of the World Federation of Hemophilia.

**Objectives**

The specific steps taken to achieve a goal.

**Outcome**

The result of actions taken in a project or activity.

**Outreach**

Identifying and educating people with hemophilia living in outlying areas.

**Partnership**

The relationship between two organizations working toward a common goal. Partnership includes sharing skills, information, and resources.

**Patient registry**

A database or record of identified people with hemophilia or inherited bleeding disorder. A registry includes information on personal details, diagnosis, treatment, and complications.

**Stakeholders**

People who care about an organization or activity. Stakeholders can be people who benefit, people with influence, or supporters. Ask yourself “who cares about this activity?” and “what do they care about?” to find the stakeholders.

**Sustainable**

Making sure that the work or success of a project will continue even after twinning support is gone.

**Synergy**

When working together has a greater effect than if each partner worked alone.

**Treatment protocols**

Guidelines or recommendations on the treatment and management of hemophilia to ensure the quality of care.

**Twinning**

A formal, two-way collaboration or partnership between two centres.

**World Federation of Hemophilia**

An international organization working to introduce, improve, and maintain hemophilia care around the world.

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