

# Reaching beyond our borders

a twinning guide for hemophilia organizations



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

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This guide is also available as a PDF file.

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# Introduction



A boy with hemophilia from Nepal.

**H**emophilia affects about 400,000 people worldwide. Seventy-five percent 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. National hemophilia organizations are key partners of the WFH. In many countries they play a major role in improving care.

The WFH works to strengthen emerging hemophilia organizations. One of the ways we do this is through our twinning program. Twinning is a formal, two-way collaboration or partnership between emerging and established patient associations.

As hemophilia organizations 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 organizations that want to get more involved in international work through twinning. A twinning workshop was held in July 2000 with existing WFH twins to better understand issues and benefits. 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 organization 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 organization twinning (HOT) and medical centre twinning. Other WFH programs and services include healthcare development programs, humanitarian aid, data collection, public affairs, and the production of publications and materials.

Hemophilia organization twinning can play a critical role in a country. Regular support and coaching through twinning helps a patient organization become a driving force for change and progress. National hemophilia organizations promote access to hemophilia care. They work to maintain or improve the quality of care. They are a powerful voice representing the interests of people with hemophilia. However, the range and complexity of challenges facing hemophilia organizations are growing. Such challenges will continue to grow in the future.

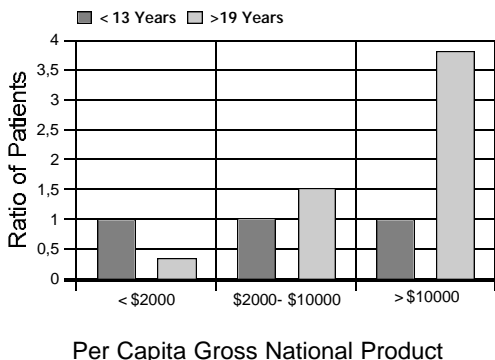
The WFH has training programs and guidelines to help leaders develop the skills they need to create strong and effective hemophilia organizations. We also help national hemophilia organizations negotiate with government. The WFH, side by side with national organizations, has met with health ministers of many countries to promote the goals of the society in that country.

The WFH Hemophilia Organization Twinning (HOT) program helps emerging hemophilia organizations develop partnerships with well-established, knowledgeable, and experienced societies. The HOT program also benefits established societies by presenting them with new challenges. A new challenge can invigorate an organization. It is a chance to increase experience and expertise.

National hemophilia organizations must develop national policies and goals, understand the realities of their regions, and appreciate the global reality for people with hemophilia. The hemophilia community is worldwide and can work together to reach mutual goals.

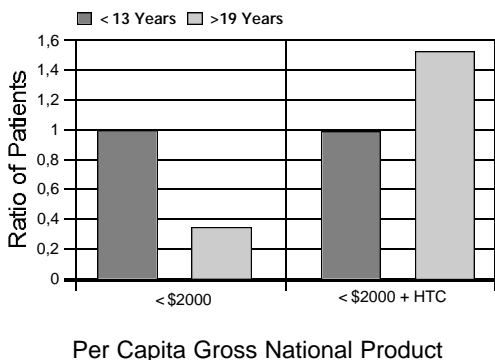
# 1. Twinning and the WFH

**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 shows 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 national hemophilia organizations, healthcare providers, 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 strengthens the ability of emerging societies to work towards this goal.

# 2. All about twinning

*“When you meet the people of the Nepal Hemophilia Society you feel very privileged to be a part of the family spirit they have created. In Sweden, we haven’t been able to create this environment. I think we can learn from this.”*

Patrik Östberg, Sweden  
Sweden – Nepal twins

*“Our institution has been able to perform with greater efficiency due to the nourishment we have received from our ‘big brother’.”*

Douglas Piquinela, Uruguay Argentina  
– Uruguay twins

*“Our skill in providing services to our own Spanish-speaking clients has improved due to our twinning partnership with a Spanish-speaking country.”*

Jeff Cornett, U.S.A.  
Georgia, U.S.A. – Chile twins

## 2.1 What is twinning?

Twinning is a **formal, two-way collaboration or partnership between two organizations.**

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



Official launch of the twinning partnership between the Hemophilia Association of the Philippines (HAPLOS) and the Victoria chapter of Haemophilia Foundation Australia.

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

## 2.2 Hemophilia Organization Twinning (HOT) Program

The Hemophilia Organization Twinning (HOT) Program of the WFH encourages a network of cooperation between national hemophilia organizations around the world. Established national hemophilia organizations have knowledge, experience, and resources. Transfer of these can be used to help emerging national societies reach a level of performance that directly benefits people with hemophilia.

## 2. All about twinning

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Types of

### Twinning activities

- ✓ Visiting
- ✓ Training
- ✓ Exchanging information
- ✓ Networking
- ✓ Supplying equipment
- ✓ Supplying factor concentrate
- ✓ Working together on special projects

*“The assessment visit ... taught us a lot about life and customs in Senegal. It gave us the chance to make friends with wonderfully warm, welcoming people who are easy to work with.”*

François Laroche, Canada Quebec,  
Canada – Senegal twins

### Program objective

The objective of the HOT Program is to strengthen emerging hemophilia societies for the improvement of hemophilia care. The program enhances the transfer of skills and knowledge between established and emerging hemophilia societies. Skills transferred may relate to patient advocacy, management, fundraising, and public relations. Through cooperation and partnership hemophilia organizations are strengthened.

### 2.3 Types of twinning activities

Twinning activities can be based on something twins have in common, such as a shared language or culture. 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** your twin to meet them, collect information, and assess a situation is called an **assessment visit**. Assessment visits are a way to exchange information and ideas. 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 about fundraising, membership, volunteer and board development, government relations, publications, policy making, or strategic planning.

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### Denmark – India twins: an example of training

*The main reason for the twinning between Denmark and India was to improve management techniques, administrative structures, and systems.*

*The general secretary of Hemophilia Federation India (HFI) went to Denmark to assist with a training workshop on strategic planning. Later a Danish management consultant offered a training session to the HFI secretariat in New Delhi, India. The entire executive took part. Danish consultants also trained people in lobbying and fundraising. Twice-yearly monitoring visits to India and yearly visits of Indian staff to Denmark kept this project on track.*

*Twinning helped HFI improve its infrastructure and cooperation between its chapters and head office so they could do fundraising and lobbying together. HFI was able to identify more people with hemophilia and set up a national hemophilia registry.*

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## 2. All about twinning

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*“The Hemophilia Foundation of Minnesota and the Dakotas set up a pen-pal program with the hemophilia community in the Republic of Georgia. We also provided updated medical information for translation into Georgian.”*

Shirley Wilson, U.S.A.  
Minnesota/Dakotas, U.S.A. – Republic  
of Georgia twins



Shirley Wilson (U.S.A.) and Temuri Golidjashvili (Republic of Georgia) work on an action plan.

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

- **Exchanging information** such as publications or materials for doctors and/or patients. You could also share information by telephone, fax, or e-mail. Sharing information should happen regularly and communication should be two-way.

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

**A**rgentina 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 organizations and the other is between treatment centres. Past WFH experience shows that double twinning increases the effectiveness and impact of both programs.

*This twinning partnership is successful largely because information is exchanged regularly. Publications and/or materials for doctors and/or 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 on medical and organizational issues for the National Meeting on Hemophilia in Uruguay.*

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## 2. All about twinning

*“As expected, the summer camp was a great way for both the Indian and the Danish boys to learn something about living with hemophilia in another country. It was more striking to learn about the conditions in India which are very unlike conditions in Denmark. This made the young people see hemophilia from a different perspective.”*

Terkel Andersen, Denmark  
– India twins

*“The first National Hemophilia Workshop was held in Nicaragua. 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 twins

- **Networking** through a “friendship and exchange” or pen-pal program between two hemophilia communities.
- **Supplying equipment** to your twin, such as computers, medical equipment, or office supplies.
- **Supplying factor concentrates** to your twin for emergencies or specific activities such as a summer camp. Supplying factor concentrates 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 local supply of factor concentrates is a more sustainable solution.
- **Working together on special projects** such as summer camps, workshops, outreach, and conferences is a great way to achieve success.



Boys from Argentina participated in a summer camp in Uruguay, organized by the Argentinean association's twin.

## 2. All about twinning

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### The benefits of **Twinning**

- ✓ Builds capacity
- ✓ Allows sharing of best practices
- ✓ Encourages collaboration
- ✓ Builds relationships
- ✓ Promotes solidarity
- ✓ Broadens horizons
- ✓ Builds a global movement
- ✓ Offers new challenges

*“We do not feel alone now.”*

Suman Dhungana, Nepal  
Sweden – Nepal twins

*“The 13th annual meeting of the European Haemophilia Consortium took place in Timisoara, Romania.*

*The Romanian society pulled together a comprehensive program of events. As twins, we worked closely together to organize this regional conference. Ministers of Health from both countries attended. This shows the benefits of the collaboration made possible through twinning.”*

Hubert Hartl, Austria  
Austria – Romania twins

## 2.4 The benefits of twinning

There are many possible benefits to twinning. Some of these benefits are outlined here.

### **Builds capacity**

**Capacity building** is about transferring skills and knowledge. This leads to more capable organizations that are better able to provide hemophilia services. Strong patient organizations are a driving force for change and progress.

### **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 groups time and effort.

### **Encourages collaboration**

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

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### **United Kingdom – Russia: an example of capacity building**

**R**ussia’s main objective was to reach more people with hemophilia in Russia and the Commonwealth of Independent States. Russia and the United Kingdom shared their experience to develop a communication centre. The U.K. Haemophilia Society took part in the Russian Hemophilia Society’s workshops and conferences. Ongoing communication, assessments, and monitoring visits ensured support and consultation.

*The Russian organization improved their strategic planning abilities and worked with greater confidence. They expanded from a nucleus of patients in Moscow and St. Petersburg to a truly national organization with 56 chapters. They are now able to conduct regional outreach, lobbying, and fundraising. The Russian Hemophilia Society became a structured nationwide organization as a direct result of twinning with the United Kingdom.*

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## 2. All about twinning



Jeff Cornett, from Hemophilia of Georgia (U.S.A.), works with Luis Gonzalez, of the Chilean Hemophilia Society, to teach patients about hemophilia.

*“Our organization has learned much about the many needs of a developing organization and how to work cooperatively with the association, government officials, patients, and families.”*

Rita Gonzales, U.S.A.  
Texas, U.S.A. – Monterrey  
Mexico, twins

### **Builds relationships**

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

### **Offers new challenges**

Twinning offers new challenges to established organizations. A new challenge can energize an organization and offer a chance to increase experience and expertise.

### **Promotes solidarity**

Twinning helps to create a feeling of belonging to a larger community, a worldwide family. It is also a way to be inspired by others. Inspiration empowers people to work for rights and services for the hemophilia community.

### **Broadens horizons**

Twinning helps you reach out to others, break down barriers, and learn about other cultures. It broadens your horizons to see how hemophilia affects people in other parts of the world.

### **Builds a global movement**

Twinning is a way to build a successful global hemophilia network that includes everyone. This is important because hemophilia affects people all over the world. As well, global events influence hemophilia healthcare policy, funding, and development.

## 2. All about twinning

WFH

### Support to twins

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

*“HOT twins gained a lot by sharing their experiences at the HOT twinning meeting in July 2000 as part of the first WFH Global NMO Training Workshop. Lots of creative problem-solving ideas were generated. Solutions varied based on the needs of each country. Every twinning can have problems and these problems are often similar.”*

Brian O’Mahony, President  
World Federation of Hemophilia

## 2.5 WFH support to twins

The WFH provides a range of support to twins, including:

### Finding a twin

Are you interested in twinning? The WFH will help match your organization with an emerging organization. Let us know where in the world you’d like to twin. Think about the language of the staff and volunteers of your organization, or your existing contact with emerging countries. We keep a list of countries looking for twins.

### Financial support

The WFH gives U.S.\$1,500 yearly towards the expenses of each twinning partnership. We offer 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 funding applications and guidelines, information on action planning, 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 individually. Our regional program officers keep in touch with you and provide follow-up support as needed. When possible, we travel with you on an assessment visit to your twinning partner. The WFH also organizes regional twinning meetings.

## 2. All about twinning

Does

### Your group have the

- ✓ Commitment
- ✓ Vision
- ✓ Capacity
- ✓ Culture
- ✓ Funding

## 2.6 Are you ready for twinning?

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

**Commitment: Is there a strong desire within your organization to take on a twinning project?**

Before starting, you need support from all levels of your organization: board of directors, staff, and volunteers. People must be willing to learn and to share. Ideally, sharing experience is already a central part of your organization'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 for care and prevention interventions or that you would like 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 do the extra work of a twinning project. You must be able to devote the time needed to make the project work. There is no quick and easy way for success.

**Values: Can your organization value this twinning project?**

Take a good look at the current spirit of your group. What are the current internal politics of your organization? Are you able to welcome others? Can you empathize with the problems of others?

**Funding: Can you afford a twinning project?**

Core funding is covered by the WFH through annual twinning payments, assessment visit funding, and capacity building grants. However, it's helpful if you can find some additional funding from inside or outside your organization.

# 3. Steps for twinning success

Steps to

## Explore the idea

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

*“Our twinning was strengthened by the historic links and trade and cultural exchanges between the Baltic and Scandinavian communities. This made our twinning a natural choice.”*

Nils Tore Olsen, Norway  
Norway – Lithuania twins



François Laroche, of the Quebec chapter of the Canadian Hemophilia Society, shakes hands with twinning partner Anta Sar Sy, of the Senegalese Hemophilia Association.

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

## 3.1 Explore the idea

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

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

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 organization’s capacity to set a realistic goal. 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 directions.

### 3. Steps for twinning success

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*“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, U.S.A. Minnesota/Dakotas, U.S.A. – Republic of Georgia twins. Hemophilia centres in Minnesota and Georgia are also twinned through the WFH’s twinning program for medical centres.

#### **Step 3. Check your level of commitment**

Make sure that your organization is clear and feels strongly 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 organizations often guide the best projects.

Who will help and support the leader? Share the tasks between several people in both organizations. 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 or board member.

#### **Step 5. Identify potential twinning partners**

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

Keep these factors in mind when choosing a partner:

- **Compatibility** – Make sure your cultures are compatible. Consider what languages people in your organization can speak. Look at the historical, economic, and trade links between your two countries.
- **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 an organization and a treatment centre** – Double partnerships in the same country work well. This means hemophilia organizations and hemophilia treatment centres in both countries are twinned. Double partnerships can have a greater impact and output, making them more effective.
- **Needs** – There must be a good match between the needs and capacities of your two organizations.

### 3. Steps for twinning success

*“The Zimbabwe Hemophilia Association made us feel very welcome. I feel better informed about all aspects of hemophilia care in Zimbabwe after visiting. We have a clearer picture of how we can help.”*

Jill Smith, Australia: Western Australia  
– Zimbabwe twins

Steps to

#### Make a plan

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

#### Step 6. 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.

#### Step 7. Select a partner and agree to proceed

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

### 3.2 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 organization to have a good understanding of a potential partner organization: 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 organization 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.



### 3. Steps for twinning success

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*“One goal of the Georgia, U.S.A. – Chile twinning has been to educate people with hemophilia and their families in Chile. It is also to improve the fundraising abilities of the Chilean Hemophilia Association. These goals were based directly on needs identified by the Chilean association. These also happen to be two of the main strengths of Hemophilia of Georgia. This greatly facilitated the learning process, as it was easy to provide a specialist to train Chileans on those subjects.”*

Jeff Cornett, U.S.A.: Georgia  
U.S.A. – Chile twins

*“Our first assessment visit changed my idea of what is possible within the framework of our twinning partnership.”*

Gordon Clarke, U.K.  
United Kingdom – Russia twins

#### **Step 2. Outline your proposed project**

Your general outline should include a realistic project goal; project objectives; and a brief description of the activities, time frames, and estimated costs. It is helpful to make a list of the resources each organization will bring to the twinning partnership. This includes the people that will be involved. Look at “Steps for developing national hemophilia care programs” in Appendix A as a planning tool.

#### **Step 3. Make a detailed action plan**

Prepare a detailed action plan together with your partner organization. Use the action plan outline and application form available from the WFH to guide you. The WFH has published a monograph on action planning which you may find helpful (Gordon Clarke, *Action Planning*, Hemophilia Organization Development Monograph Series, No. 2).

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 organizations. Be exact about the role of each organization 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, board, and volunteer members 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.

### 3. Steps for twinning success

*“Together with members of the Nepal Hemophilia Society we discussed the future role of the society. We outlined the steps needed to make it even stronger.”*

Patrik Östberg, Sweden:  
Sweden – Nepal twins

#### Step 4. Approve the project action plan

Both organizations 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 organizations have agreed on the general outline.



Karin Pappenheim of the U.K. Haemophilia Society works with twins Yuri Zhulyov and Nadya Motsygina, of the Russian Hemophilia Society, during a WFH skills training workshop on action planning.

Tips for successful

#### Implementation

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

### 3.3 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 reality of your twin. Use the tips in Section 4 of this guide to help you approach cultural diversity.

### 3. Steps for twinning success

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*“We need to make sure information and resources are shared. A good way to do this is to jointly write up a detailed yearly timeline on the actions and responsibilities of each organization.”*

Ann Roberts, Australia: Victoria  
Australia – Philippines twins

#### **Work at communication**

You need a good flow of information between two organizations 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 organizations 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**

When the key contact person or the board changes in either organization 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.



Meeting with other twins at events like the WFH world congress can be a great source for advice and ideas.

### 3. Steps for twinning success

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*“I found the WFH global NMO training workshop most interesting since I was able to share issues and concerns with many representatives of national hemophilia organizations. I was able to learn and get new ideas from others, particularly on how to make our own organization better and more relevant to the needs of our members. I gained a lot from attending and now have a much better picture of the hemophilia community throughout the world. I hope to implement new actions and strategies locally as well as try to do a bit more for our HOT twin in Pakistan and others in the ASEAN region.”*

Aris Hashim, Malaysia  
Malaysia – Pakistan twins

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.

#### **Network with other twins**

Learn from the shared experience and advice of twins from around the world.

#### **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 October 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.

### **3.4 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

### 3. Steps for twinning success

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*“India and Denmark believe that the minimum monitoring to promote the sharing of information should be every year, if every six months is not possible. Monitoring proved to be effective in the case of the India – Denmark twinning. Denmark representatives visited India twice a year.”*

Ashok Verma, India  
Denmark – India twins

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.

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.

Organizations 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 organization, your partners, your volunteers, your participants, 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.

# 4. Twinning across cultures

*“We feel proud of the collaboration and solidarity demonstrated.... Our goal will remain the same over time: to help people with hemophilia in El Salvador that have put in so much effort into moving their hemophilia organization forward under very precarious conditions.”*

Otilia Ragull, Catalonia  
Catalonia – El Salvador twins



Members of the Swedish and Nepal Hemophilia Societies have found their partnership to be very rewarding.

## 4.1 What is culture?

**Culture** refers to a group of people with common, shared experiences. It 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.

## 4.2 Why twin with other cultures?

You benefit from partnering with others. Your organization 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.

## 4. 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
- ✓ Care and show caring
- ✓ Risk making mistakes
- ✓ Notice differences in communication styles and values

### 4.3 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 organization need to become good at working with people from other cultures. You need to develop **cultural awareness**.

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.

#### 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! Organizations in different cultures may have work expectations and habits different from your own. For example:

## 4. Twinning across cultures

*“Twinning partnerships cannot be ‘pushed’. Twinning between India and Denmark took two visits and eight months of communication by fax or e-mail to build a relationship of trust. Only then did the twinning start.”*

Ashok Verma, India  
Denmark – India twins

- 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.



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

### **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. This does not make you a “bad” person. You may have picked up inaccurate information when you were young, from people around you or from television or movies.



## 4. Twinning across cultures

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Having some young people from India attend the Danish Haemophilia Society's summer camp taught all participants about living with hemophilia in another country.

### **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.

### **Care and show caring**

Caring about people is what makes a partnership work. Don't let your worry about culture get in the way of your caring.

### **Notice differences in communication styles and values**

Don't assume that your way is the "right" way. Good communication is the key to effective twinning. Listen closely for what is being said rather than for what you want to hear. Adapt the way you communicate to fit the situation.

### **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.

# 5. Communication

Tips for

## Good communication

- ✓ Start early
- ✓ Review often
- ✓ Respect your differences
- ✓ Be aware of problems
- ✓ Get personal
- ✓ Be flexible and resourceful
- ✓ Listen and observe carefully
- ✓ Assume complexity
- ✓ Tolerate the stress of uncertainty
- ✓ Listen to your feelings
- ✓ Keep a sense of humour
- ✓ Show respect and empathy

## 5.1 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 organizations may use different communication styles. Keep an open mind. Don't jump to quick conclusions or pass judgment on others. Use "I" messages instead of "you" messages. For example, say "I respect your opinion but I must add..."

### Be aware of problems

Communicate your communication problems!

### Get personal

Get to know each other. Don't rely entirely on paper as a way to communicate. Express your personal feelings, thoughts, and ideas in a warm and personal way.

### Be an active listener

Repeat back what you hear in conversation to check for accuracy. Listen actively by giving verbal clues often, such as "uh huh" or "yes". Ask for clarification if you are not sure you understood properly.

### 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.

### Listen and observe carefully

This helps increase your sensitivity to the whole message and not just what is being said.

## 5. Communication

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*“Most people in the Philippines speak English but cannot read it well. We translated educational materials into Tagalog (a local dialect), but there are a number of other common dialects.”*

Ann Roberts, Australia  
Victoria, Australia – Philippines twins

### **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 understandable right away. Becoming frustrated may make it worse. Be patient.

### **Listen to your feelings**

Take your feelings seriously and keep in touch with how you feel about what the other person is saying in conversation. Manage personal biases and treat others with respect.

### **Keep a sense of humour**

Don't take yourself so seriously that you forget to laugh.

### **Show respect and empathy**

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

## **5.2 Bridging language barriers**

Language issues may get in the way of effective communication. Here are some suggestions that may help bridge language barriers.

- Make sure your objectives and hopes are realistic if you have real language barriers.
- Arrange for bilingual translators for meetings and documents.
- Decide if you will hold meetings in two languages. This is a good option, but remember to double the time or halve the agenda for each meeting.
- Produce all your materials in the language of both partners. Be clear about the target audience for project materials and adapt the languages used as needed.

## 5. Communication

*“The goal of the Quebec-Senegal twinning was to improve public awareness about hemophilia. The partners created a video and a flyer on hemophilia and adapted them to the culture of the area. Choices were made based on language and literacy issues. The video and flyer were translated into Wolof, a local language. Creating a video made sure that people who could not read would still have access to the information.”*

François Laroche, Canada Quebec,  
Canada – Senegal twins

- Keep culture in mind when speaking and writing. Make sure your words cannot be misinterpreted. Use pictures and diagrams to clarify your ideas when possible.
- Avoid jargon, slang, and metaphors from your culture and organization. If you cannot avoid this, include a glossary of commonly used terms. Invite your partner to do the same.
- Know that just because someone can speak the language it does not mean they are culturally aware.



Australia – Philippines twins meet to evaluate progress and set new goals and objectives.

Partnership involves working together with your twin on a project or activity. Effective communication across cultural and language barriers is the bridge that allows twinning partnerships to be successful.

# Conclusion

*“Collaboration leads to the sharing of knowledge, expertise, and good will. This approach educates not only the people with hemophilia in both countries, but also the medical staff and volunteers. The leading role and support of the WFH is indispensable.”*

Bülent Zülfikar, Turkey  
Turkey – Azerbaijan twins



Participants of the first WFH workshop for national hemophilia organizations and twins.

**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 organizations the skills, experience, and determination to face the challenges ahead. But perhaps even more importantly, it gives them emotional support and friendship that can lift their sense of isolation and give them hope to carry on.

Does your organization have access to information, skills, and resources to share with others? Or, are you part of an emerging hemophilia patient organization that would benefit from twinning? If you are interested in reaching 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.: (514) 875-7944

Fax: (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. Phase II steps usually require additional resources. National programs can dramatically increase the life expectancy of people with hemophilia 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.

## 1. Care delivery

The first steps to better **care delivery** include setting up a regular clinic with a patient registry and follow-up plan. Resources are used more efficiently when this clinic is officially recognized and operates as a first reference centre. If the government agrees to a long-term, national plan, then regional treatment 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, dentistry, nursing, physiotherapy, and so on.

## 3. Treatment products

It is possible to improve the quality and quantity of local **treatment products**. Local treatment products range from whole blood to freeze-dried cryoprecipitate. Concentrates are introduced in Phase 2.

## 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. As the organization develops, it works to educate people with hemophilia and members. 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 various regions it becomes a national organization. A national group can work on fundraising and lobbying. 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 organizations
<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.</li> <li>2. A structured and registered organization that 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 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>



## Appendix B

# Glossary

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### **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.

### **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.

### **Factor**

A type of protein found in blood that helps blood clot.

### **Factor concentrate**

A manufactured preparation of individual clotting factors, or groups of factors, which is injected into a vein to provide fast treatment of bleeds.

### **Goal**

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

### **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.

## **Stakeholders**

People who care about an 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 of your twinning activity.

## **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.

## **Twinning**

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

## **World Federation of Hemophilia**

An international, not-for-profit organization working to introduce, improve, and maintain hemophilia care around the world.

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