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GENERAL INFORMATION

The Hemophilia Treatment Centre (HTC) Twinning Program of the WFH encourages a network of cooperation between hemophilia treatment centres around the world. Hemophilia treatment centres are categorized by the WFH as either established or emerging, depending on their level of experience. Most often, the established centre is based in a developed country, while the emerging centre is based in a developing country, but there are exceptions. Established HTCs have knowledge, experience and resources, and the transfer of these can be used to help emerging hemophilia treatment centres reach a level of performance that directly benefits people with bleeding disorders.

PROGRAM OBJECTIVE

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

POSSIBLE ACTIVITIES

Twins usually meet face-to-face once per year, with the majority of visits and activities taking place in the emerging country. In between visits, twins keep in touch regularly via email or telephone calls/Skype/social media.

Activities undertaken by twins may include:

- Arranging specialized training programs for medical professionals
- Providing medical advice on complex cases or in emergency situations
- Exchanging information such as publications or materials for doctors and/or patients
- Creating a patient registry
- Outreach activities
- Planning conferences
- Organizing medical workshops

SELECTION CRITERIA

To become a twin, hemophilia treatment centres must have:

- The willingness to give time and energy to the twinning partnership
- A clear sense of why they are beginning a twinning partnership – i.e., what the centre thinks it can contribute to and learn from twinning
- Key contact person(s) working at the HTC who is available to coordinate and communicate with the twinning partner and the WFH
- A strong team commitment to undertake a twinning partnership
- Approval of your hospital administration and HTC director
- A willingness to respect the reporting requirements of the WFH
WFH SUPPORT

WFH support to twins includes:

+ Assisting treatment centres in finding a suitable partner
+ Financially supporting the partnerships through funding for assessment visits and grants
+ Supplying WFH educational materials
+ Facilitating the sharing of experiences between twinning partnerships, including twinning meetings
+ Providing guidance to twinning partnerships on an individual basis by WFH regional program managers and program coordinator, including possibly accompanying twinning partners on assessment visits
+ Complimentary online subscription for emerging HTC twins to Haemophilia journal for the duration of the twinning
+ Complimentary enrollment in the WFH IEQAS Program as of second year of twinning for emerging HTC twins until one year after the twinning ends

APPLICATION PROCEDURE

For details on the application procedure, treatment centres should contact the program coordinator or regional program manager.

The first step is to complete a background questionnaire that will help the WFH understand the treatment centre and its priorities, assess their capacity to take on a twinning project, and find a suitable partner. Once a potential partner has been identified, an assessment visit will take place (see assessment visit guidelines document and assessment visit funding application form for further details). Towards the end of the assessment visit, if both potential partners are in agreement to pursue a twinning, they will complete an application form and submit it to the WFH. The Hemophilia Treatment Centre Twinning Committee meets by conference call in October of every year to review the applications of potential new twins. Twins are informed of the committee decision in November and if approved are required to submit an action plan in December and officially begin twinning in January.

REPORTING REQUIREMENTS

Twins must submit an annual progress report. This report comprises a financial account and full review of the activities that were planned and an explanation of the outcomes of those activities. If the twinning is to continue for another year, an action plan must be submitted. Financial assistance for twinning is dependent on available funding and the timely receipt of both these forms.

FUNDING

The WFH provides annual grants to twins between 2,000 USD and 8,000 USD. Funding is transferred during the month of February or March of each year, and must be spent on the activities approved by the committees as outlined in the funding letter sent to twins.
**DURATION**

Twins can be recognized and supported financially by the WFH for a maximum of four years. After this time, partners are free to continue their partnership, but funding from the WFH will not be provided. Once the twinning has ended, twins are required to submit a **closure questionnaire** to the WFH.

**TWINS OF THE YEAR AWARD**

Each year, the HTC Twinning Committee grants an award in the form of a plaque to the most active and productive partnership based on the annual progress reports. There is no formal nomination procedure, and all twins are automatically considered for the award.

**SPONSOR**

The WFH is grateful to Pfizer for its exclusive sponsorship of the Twinning Program.

**JOIN US!**

If you are interested in learning more about the Twinning Program, please visit the WFH web site or contact the Twinning program coordinator at spineda@wfh.org.
ASSESSMENT VISIT GUIDELINES

The WFH believes strongly in assessment visits as they allow potential twins to meet face-to-face and appreciate firsthand what questionnaires, emails and telephone calls cannot convey. An assessment visit is when 2 representatives from the established HTC visit their potential twinning partner in the emerging country. Before the WFH officially recognizes and funds a twinning partnership, an assessment visit must take place to allow both parties to decide if beginning this relationship is in their best interests and to familiarize the established partner with the local situation. Most assessment visits are between 2 and 4 days in duration. Whenever possible, the WFH regional program manager or program coordinator will accompany the potential twins on the assessment visit and help with the planning process and help with understanding of cultural, economic and social norms.

The WFH covers the majority of costs associated with the assessment visit. Please see the assessment visit funding application form for more details on WFH funding.

OVERALL OBJECTIVE

1. **Collect information**
   Learn more about the HTC and the services offered to patients.

2. **Determine if the match is appropriate**
   Are the needs of the emerging HTC something that the established HTC feels able to assist with? Is there an understanding and a willingness to cooperate between the potential partners? Are cultural or linguistic obstacles surmountable?

3. **Develop an action plan for the twinning**
   If both partners agree to pursue a twinning, they should use the final day of the assessment visit to determine what areas the twinning should focus on and jointly fill-out the application form that will be submitted to the WFH.

PRE-VISIT PREPARATION

In cooperation with the WFH regional program manager or program coordinator, potential partners will work together to determine an appropriate itinerary for the visit. Most assessment visits take several months to plan via exchange of emails or conference calls. Flights and hotels should be booked well in advance in order to secure the best prices.

1. **Itinerary Planning**
   WFH staff is happy to assist in the development of an itinerary for the visit. Organizers should arrange meetings with the following key players (for introductory meetings, if appropriate):
   
   + Comprehensive care team (hematologists, orthopedists, dentists, psychologists, social workers, laboratory technicians, nurses, physiotherapists, etc.)
   + Hospital administrators
   + Blood bank representatives
   + National Member Organization (patient society) board and key volunteers
2. Other Issues
   + The established HTC visitors must find out about the country they are assessing by reading about the general economic and political issues in the country. If possible, visitors should arrive half a day or a day before the meetings to establish their bearings and overcome jet lag.
   + Visits to government officials are not recommended during an assessment visit. It is better to wait until a formal relationship has been established and the established HTC representatives are more familiar with the emerging HTC and country.
   + Set aside time during the visit to rest, think, and write reports.
   + At least half a day should be set aside at the end of the visit to work on the application form if it is mutually agreed to pursue a twinning.

3. Reference Documents
   Before the visit, we recommend reviewing:
   + Information and correspondence with the potential partners (including background questionnaire)
   + WFH data on country to be visited (provided by WFH staff)
   + Web site travel pages
   + Your government's foreign affairs web site on the emerging country
   + WFH twinning guidebook
   + World Bank data

ON-SITE TIPS FOR ESTABLISHED HTC REPRESENTATIVES

1. Assess the environment
   Observe for opportunities and obstacles to program implementation (socio-cultural, political/legal, technological, economic, demographic).

2. Questions to guide the visit

   I. Organization of care
      + How many treatment centres are in the country?
      + Who is responsible for hemophilia care?
      + Who is responsible for diagnosis?
      + What are the blood transfusion services?
      + Who pays for treatment?
      + How do social security (or equivalent) policies affect PWH?
      + Is there a registry of PWH? How are the census and registry maintained/developed?
      + Does care differ for children and adults?
II. Treatment products
+ What products are available?
+ Does the government purchase treatment products?
+ Who prescribes treatment products?
+ Who is responsible for choosing the product used?
+ How do they buy?
+ Who pays? What price per unit?
+ Is there an administrative body that regulates treatment products, sets standards and provides regular safety updates?
+ Is cryoprecipitate made? If so, how is it made, and in what quantities?
+ What was the usage of concentrates last year? For the country, by PWH?
+ Is the HTC in communication with the Ministry of Health?

III. Medical expertise
+ Is there a comprehensive hemophilia care team? Are they full time or part time?
+ What is the diagnosis capability? How are PWH diagnosed?
+ Have hemophilia specialists received training? If so, who, when, and where?
+ What is the total number of PWH being treated?
+ Is there a treatment protocol? How was it developed?

IV. Patients
+ What are the main activities of the patient organization?
+ How does the patient organization collaborate with the HTCs?

CONCLUSION
Are you ready to start a twinning?
Your assessment visit should give you enough information to know if you want to start a twinning partnership. Among other things, you should be thinking about whether this collaboration would be successful. Will this be a win-win situation for both treatment centres? Remember that participating in twinning program will take up a significant amount of time and energy, and therefore this is not a decision that should be taken lightly. Twinning is a major commitment of time and resources. The collaboration of many team members will be required.

Final meeting of assessment visit
If you have mutually agreed to pursue a twinning partnership, it is recommended that you spend some time completing a SWOT exercise. SWOT is an acronym for Strengths, Weakness, Opportunities and Threats. In a joint meeting, both HTCs can complete the exercise of identifying the elements of their HTCs that fall under each category, but the majority of the time should be spent focusing on the SWOT of the emerging HTC. Please contact Stephanie Pineda (spineda@wfh.org) if you would like to see a SWOT example.

After the SWOT is completed, it is recommended that the priority areas for the potential twinning be identified. The priority areas do not necessarily need to be the top priorities of the emerging
HTC in general, but rather the priority areas that the potential partners mutually agree can realistically address through a 4-year twinning project. After the top priority areas are identified, you can then move on to the application form.

The application form can then be filled-in. Please note that the WFH understands that plans can change over time so you will not be obliged to follow the plan exactly as written. The application form simply serves as a basic outline of what the twins hope to achieve. The action plans that are subsequently submitted by twins annually are where the real details and concrete plans are explained.

**SAMPLE ITINERARY**

+ Established HTC representatives arrive in country and rest
+ Initial meeting between potential partners
+ Presentations by each HTC and the WFH (if participating in visit)
+ Visit to HTC and tour of hospital (lab, physiotherapy, hematology departments (adult and children, if appropriate)
+ Meeting with key medical professionals
+ Meeting with hospital administration
+ Meeting with group of patients and key NMO leaders
+ Visit to blood bank
+ Meeting to determine if twinning should be pursued, and if so:
  - SWOT exercise
  - Rank priority areas for twinning
  - Develop application form

**NEXT STEPS**

After the assessment visit, please report back to the regional program manager or program coordinator and submit the application form, if applicable. The HTC Twinning Committee meets every October via conference call to review the applications of potential new twins. All application forms must be received by the WFH by October 1 to be considered for approval to start twinning the following year. You will be informed of the committee decision in November and if approved, asked to submit an **Action Plan** for the following year, which is your opportunity to request WFH funding to support your planned activities.
| Sponsorship recognition | The exclusive sponsor of the Twinning Program is Pfizer. This means that in addition to the annual funding given to twins, Pfizer supports the operational management of the program (all program related expenses at the WFH), as well as the assessment visits for potential twins. Twins are welcome to solicit funds from other non-pharmaceutical sources (including hospital/university/charitable foundation) for their twinning activities, but if additional funds are obtained, Pfizer’s sponsorship must be recognized first and foremost. For example, if another company sponsored a specific funding event and an article is written about this event, please mention in the article that Pfizer is the exclusive sponsor of the Twinning Program, and X event was sponsored with additional funds from X company. Twins should not seek additional funding for their Twinning activities from another pharmaceutical company. |
| How many twinnings at a time | An HTC or NMO may only participate in one twinning partnership at a time.  
+ Exception: Chapters of established NMOs may simultaneously participate in the program |
| Waiting period between partnerships | For established partners, there is no required waiting period in between twinning partnerships. For emerging partners, there is a 3-year waiting period in between twinning partnerships. The reasons for this is to allow for the knowledge and skills learned from the first partnership to be consolidated, and to allow other potential twins on the waiting list to have the chance to find a partner and join the program. |
| Extensions | Twinning partnerships may last up to a maximum of 4 years. A one-year extension may only be considered by the twinning committees for reasons that prevented planned activities from taking place such as:  
+ Political upheaval in one of the participating countries  
+ Natural disaster in one of the participating countries  
+ Significant leadership change in the emerging or established NMO or HTC |
| Destination of funds | The WFH sends the annual grant to the established partner unless the twins mutually agree to otherwise (option provided on the Action Plan form). Due to high administrative costs, the WFH will not split funds between partners. Partners are welcome to split the funds at their own discretion once the WFH has sent the funds to one partner. |
Treatment product donations

Established twins may wish to donate treatment products to their emerging partner. This is permitted but subject to the rules and regulations of the emerging country. Donations should not become the focus of a twinning partnership since they are not sustainable.

Rotation of volunteers

Established twins are encouraged to involve different team members to participate in the on-site implementation of twinning activities. Volunteers should be selected based on their expertise with the area of focus for the particular visit. Though continuity is important, so is offering a broad spectrum of expertise and allowing other team members to contribute to and learn from the partnership.

**WFH TWINNING PROGRAM ACTIVITIES**

What follows is a non-exhaustive list of activities that are generally considered to be appropriate to be funded with WFH twinning funds, not appropriate to fund, and activities with special rules to be considered. Twins receiving funds from alternate sources (ex. additional fundraising activities) are welcome to spend those funds however they mutually agree to. All final WFH funding decisions are made by the WFH HOT and HTC Twinning Committees.

**APPROPRIATE TO FUND (WITH COMMITTEE APPROVAL)**

<table>
<thead>
<tr>
<th>Hemophilia Organization Twinnings</th>
<th>Hemophilia Treatment Centre Twinnings</th>
<th>Both programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training of board members</td>
<td>Education and training of medical professionals</td>
<td>International travel expenses (flights, accommodation, visa)</td>
</tr>
<tr>
<td>Workshops/trainings (ex. strategic planning, fundraising, constitution, leadership)</td>
<td>Short-term off-site training of medical professionals (fellowships that are not part of IHTC program)</td>
<td>Local travel expenses and transportation</td>
</tr>
<tr>
<td>Development of communication tools (ex. web site, newsletter)</td>
<td>Cooperative activities with blood bank or other key stakeholders (ex. Ministry of Health, universities, other local HTCs)</td>
<td>Meals during activities</td>
</tr>
<tr>
<td>Peer support groups (ex. mothers, youth)</td>
<td>Development of treatment protocols and Standard Operating Procedures</td>
<td>Social event (ex. group dinner)</td>
</tr>
<tr>
<td>Physiotherapy related activities</td>
<td>Development of comprehensive care team</td>
<td>Communications expenses between partners</td>
</tr>
</tbody>
</table>
| Psychosocial related activities | Genetic counseling | Development of materials (brochure,
<table>
<thead>
<tr>
<th>Home treatment workshop</th>
<th>Clinics</th>
<th>posters, publications, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter development activities</td>
<td>Clinical papers and posters</td>
<td>Advocacy initiatives</td>
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<tr>
<td></td>
<td></td>
<td>Patient logbooks</td>
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<tr>
<td></td>
<td></td>
<td>Outreach activities</td>
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<td></td>
<td></td>
<td>Patient education workshop</td>
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<tr>
<td></td>
<td></td>
<td>Awareness-building activities</td>
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<tr>
<td></td>
<td></td>
<td>World Hemophilia Day Activities</td>
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<tr>
<td></td>
<td></td>
<td>Poster for WFH World Congress</td>
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<tr>
<td></td>
<td></td>
<td>Hemophilia symposium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sharing of publications and other materials</td>
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<tr>
<td></td>
<td></td>
<td>Professional translation of materials (brochure, posters, publications)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ID card/bracelet for patients</td>
</tr>
</tbody>
</table>

**NOT APPROPRIATE TO FUND**

<table>
<thead>
<tr>
<th>Hemophilia Organization Twinnings</th>
<th>Hemophilia Treatment Centre Twinnings</th>
<th>Both programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and training of medical professionals</td>
<td>Purchase of factor concentrates</td>
<td>Staff salaries or honorariums for volunteers</td>
</tr>
<tr>
<td>Diagnostic testing of emerging samples in established country</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding of treatment of individual PWH (factor concentrates, surgery, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Establishment of additional HTC in region</td>
<td></td>
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<tr>
<td>Participation in WFH congresses and non-WFH congresses (EHC, ISTH, etc.)</td>
<td></td>
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<tr>
<td>Reimbursement of previous years’ activities/overspending</td>
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</tr>
<tr>
<td>Employment cooperative for PWH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance program for PWH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemophilia Organization Twinnings</td>
<td>Hemophilia Treatment Centre Twinnings</td>
<td></td>
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<td>----------------------------------</td>
<td>--------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Summer camp in emerging country may only be funded once per twinning</td>
<td>Research project funding will be examined on a case by case basis to determine what is appropriate to fund or not</td>
<td></td>
</tr>
<tr>
<td>Participation of emerging youth in summer camp in established country may only be funded once per twinning</td>
<td>Purchase of reagents may only be funded up to a maximum of 5,000 USD (total over the duration of the twinning)</td>
<td></td>
</tr>
<tr>
<td>Purchase of key office equipment (ex. computer, printer, software, etc.) may only be funded once per twinning</td>
<td>Use of telemedicine program may be funded, but the establishment of the program cannot be funded</td>
<td></td>
</tr>
<tr>
<td>Travel to the established country for twinning activities may only be funded once per twinning. Special approval from the committee is required for additional travel to the established country.</td>
<td>Purchase of medical equipment will be evaluated by the committee on a case by case basis</td>
<td></td>
</tr>
</tbody>
</table>
WFH HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Assessment Visit Funding Application Form

The WFH provides:

+ 2 round-trip economy flights for the established partner to visit the emerging partner.
  o The WFH must approve the itinerary and cost of the flights before the tickets are purchased
+ Reasonable hotel accommodations for the 2 participants (2-4 nights)
+ Cost of a visa (if required)
+ Meals
+ Local travel costs (in the emerging country)

All other expenses are not covered by the WFH. If you have any questions or concerns about what items are covered/not covered, please consult a Regional Manager/Coordinator or the Program Coordinator (spineda@wfh.org).

Potential twins may request 1 reimbursement to cover the costs of the assessment visit, or may request 2 reimbursements (1 prior to the visit for flights, and 1 upon return for hotel, meals, local travel and visa).

---

Emerging HTC:
Established HTC:
Anticipated date of visit:

---

GENERAL QUESTIONS

What is the anticipated visit schedule for the assessment visit? Attach a separate document if you prefer.

Who from the established HTC will participate in the assessment visit, and why?
**FUNDING**

*Please list all costs in US dollars.*

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airfare</td>
<td></td>
</tr>
<tr>
<td>Visa</td>
<td></td>
</tr>
<tr>
<td>Hotel</td>
<td></td>
</tr>
<tr>
<td>Meals</td>
<td></td>
</tr>
<tr>
<td>Local travel</td>
<td></td>
</tr>
<tr>
<td><strong>Total cost</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Total contributions from sources other than the WFH (please specify)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Total requested from the WFH</strong></td>
<td></td>
</tr>
</tbody>
</table>

Are you requesting 1 reimbursement or 2 (please see top of page 1)? Please explain below and if 2 reimbursements are requested, detail the approximate amount and timing for each.

Do you agree to submit receipts for all expenses being covered by the WFH (if requested by the WFH)?

Yes [ ]
No [ ]

Is there any other information that you wish to share with the WFH?

Form completed by (name, HTC and title):

Date:

*Thank you for your interest in the WFH Twinning Program*

*Please submit this form to Stephanie Pineda: spineda@wfh.org*
SWOT ANALYSIS

A SWOT Analysis is the process of examining the internal Strengths and Weaknesses, and the external Opportunities and Threats that affect an organization’s ability to meet its objectives.

Assessment visit location:
Date:
Emerging organization involved:
Established organization involved:

<table>
<thead>
<tr>
<th>Internal Forces</th>
<th>External Forces</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths:</strong></td>
<td><strong>Opportunities:</strong></td>
</tr>
<tr>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td><strong>Weaknesses:</strong></td>
<td><strong>Threats:</strong></td>
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<td>•</td>
<td>•</td>
</tr>
</tbody>
</table>

See reverse page for a sample analysis
# EXAMPLE OF A SWOT ANALYSIS

<table>
<thead>
<tr>
<th>Internal Forces</th>
<th>External Forces</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths:</strong></td>
<td><strong>Opportunities:</strong></td>
</tr>
<tr>
<td>▪ Support of hospital administration</td>
<td>▪ Identify nurse to work with HTC</td>
</tr>
<tr>
<td>▪ Good cooperation with blood bank</td>
<td>▪ Identify social worker to work with HTC</td>
</tr>
<tr>
<td>▪ Motivated hematologist with international training</td>
<td>▪ Identify dentist to cooperate with HTC</td>
</tr>
<tr>
<td>▪ Skilled laboratory technician</td>
<td>▪ Further training for physiotherapist–consider WFH IHTC fellowship</td>
</tr>
<tr>
<td>▪ Good cooperation with patient organization</td>
<td>▪ Upcoming WFH regional laboratory training workshop</td>
</tr>
<tr>
<td>▪ Physiotherapy program in development</td>
<td>▪ Support patient organization to lobby government for purchase of factor concentrates</td>
</tr>
<tr>
<td>▪ Patient registry</td>
<td>▪ Identify patients outside of major cities</td>
</tr>
<tr>
<td>▪ Medical Director and Lab staff have sufficient coagulation backgrounds</td>
<td>▪ Develop educational materials for patients</td>
</tr>
<tr>
<td><strong>Weaknesses:</strong></td>
<td><strong>Threats:</strong></td>
</tr>
<tr>
<td>▪ No dedicated nursing staff</td>
<td>▪ Humanitarian aid is the only source of factor concentrates</td>
</tr>
<tr>
<td>▪ No dedicated social worker</td>
<td>▪ HTC team is small, no succession plan in place</td>
</tr>
<tr>
<td>▪ No dentist identified to work with patients</td>
<td>▪ Bleeding disorders is a small fraction of all blood diseases – not a priority for medical professionals or government</td>
</tr>
<tr>
<td>▪ Laboratory equipment difficult to maintain</td>
<td></td>
</tr>
<tr>
<td>▪ Supply of reagents unreliable</td>
<td></td>
</tr>
<tr>
<td>▪ Government does not purchase factor concentrates, reliance on humanitarian aid</td>
<td></td>
</tr>
</tbody>
</table>
HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Background Questionnaire – Emerging

Name of Hemophilia Treatment Centre/Hospital: [ ]
Mailing address: [ ]
Country: [ ]
General email of HTC: [ ]
Name and title of main contact(s) at HTC: [ ]
Email address of main contact(s) at HTC: [ ]
Date form submitted to WFH: [ ]

Information about your HTC

Where is your HTC based?   Private hospital [ ]
   Government hospital [ ]
   Other (please describe): [ ]

Does your HTC have a patient registry?   Yes [ ] No [ ]

What is the number of people registered with:
   Hemophilia A: [ ]
   Hemophilia B: [ ]
   VWD: [ ]
   Rare bleeding disorders: [ ]

   How are the majority of patients diagnosed?   Clinical symptoms only [ ]
   Clotting screening tests (PT or APPT) [ ]
   Factor assays [ ]

Are reagents available?   Always [ ]
   Sometimes [ ]
   Never [ ]

Does your HTC have regular access to medical professionals in the following areas?

   Hematologist
      Adult   Yes [ ] No [ ] If yes, how many?
      Pediatric   Yes [ ] No [ ] If yes, how many?
   Orthopedist   Yes [ ] No [ ] If yes, how many?
   Nurse   Yes [ ] No [ ] If yes, how many?
   Lab technician   Yes [ ] No [ ] If yes, how many?
   Physiotherapist   Yes [ ] No [ ] If yes, how many?
<table>
<thead>
<tr>
<th>Professional</th>
<th>Yes</th>
<th>No</th>
<th>If yes, how many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dentist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td>How many?</td>
</tr>
</tbody>
</table>

Did any of the above medical professionals receive international training? □ Yes □ No
If yes, please describe (who, what, when, where):

What is the language of communication in your HTC?
Can any medical professionals communicate in a second language? □ Yes □ No
If yes, please describe who and which language:

Do you have a treatment protocol? □ Yes □ No
If yes, please include this document when you submit this form.

What is the availability of the following in your HTC (do not include donations)?

<table>
<thead>
<tr>
<th>Availability</th>
<th>Always</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole blood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plasma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cryoprecipitate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plasma-derived concentrate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recombinant</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Does your HTC have regular contact with the national hemophilia organization (WFH national member organization) in your country? □ Yes □ No
If yes, please describe:

Does your HTC have access to the following facilities?

<table>
<thead>
<tr>
<th>Facilities</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photocopier</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fax</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Why twinning?**

Why does your HTC want to participate in the WFH Twinning Program?

What are the top three key aspects of your HTC that you want to improve during a twinning partnership?

1) 
2) 
3) 

Have all HTC team members agreed to pursue a twinning partnership? □ Yes □ No
Please describe the response:

Is your hospital administration in agreement to pursue a twinning partnership?
☐ Yes  ☐ No

Please describe the response:

Has the possibility of twinning been discussed with the national hemophilia organization (WFH national member organization) in your country?
☐ Yes  ☐ No

Please describe the response:

What kind of support is your HTC expecting from the WFH if you participate in the Twinning Program?

Please list any previous international partnerships your HTC has been involved in:

Please provide any additional comments:

Thank you for your interest in the WFH Twinning Program.

Please submit this form to Stephanie Pineda: spineda@wfh.org
HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Background Questionnaire – Established

Name of Hemophilia Treatment Centre/Hospital:
Mailing address:
Country:
General email of HTC:
Name and title of main contact(s) at HTC:
Email address of main contact(s) at HTC:
Date form submitted to WFH:

Information about your HTC

Where is your HTC based? □ Private hospital
□ Government hospital
□ Other (please describe):

Does your HTC have a patient registry? □ Yes □ No

What is the number of people registered with:
■ Hemophilia A:
■ Hemophilia B:
■ VWD:
■ Rare bleeding disorders:

Does your HTC treat:
□ Adults
□ Children
□ Both adults and children

Does your HTC have regular access to medical professionals in the following areas?

Hematologist
  □ Yes □ No If yes, how many?
  Adult
  Pediatric
  Orthopedist
  Nurse
  Lab techniciant
  Physiotherapist
  Dentist
  Psychologist
  Social Worker
  Other:

What is the language of communication in your HTC?
Can any medical professionals communicate in a second language? □ Yes □ No
If yes, please describe who and which language:

Do you have a treatment protocol? Yes □ No □
If yes, please include this document when you submit this form.

What is the availability of the following in your HTC?

<table>
<thead>
<tr>
<th>Item</th>
<th>Always</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
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Does your HTC have regular contact with the national hemophilia organization (WFH national member organization) in your country? Yes □ No □
If yes, please describe:

Does your HTC have access to the following facilities?

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<td>Photocopier</td>
<td></td>
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<tr>
<td>Fax</td>
<td></td>
</tr>
<tr>
<td>Internet</td>
<td></td>
</tr>
</tbody>
</table>

Why twinning?

Why does your HTC want to participate in the WFH Twinning Program?

What are three key areas of expertise your HTC could contribute to a twinning partnership?

1)
2)
3)

Have all HTC team members agreed to pursue a twinning partnership?
Yes □ No □
Please describe the response:

Is your hospital administration in agreement to pursue a twinning partnership?
Yes □ No □
Please describe the response:

What kind of support is your HTC expecting from the WFH if you participate in the Twinning Program?
Please list any previous international partnerships your HTC has been involved in:

Please provide any additional comments:

Thank you for your interest in the WFH Twinning Program.

Please submit this form to Stephanie Pineda: spineda@wfh.org
HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Twinning application form

Emerging HTC:
Mailing address:
Main contact person:
Email address:
Phone number(s):

Established HTC:
Mailing address:
Main contact person:
Email address:
Phone number(s):

What are the main goals of the planned twinning? Please list up to 5 in order of priority.
1.
2.
3.
4.
5.

What are the main activities planned to achieve the above listed goals? Please use the table below or a separate document if preferred.

<table>
<thead>
<tr>
<th>Goal</th>
<th>Activities</th>
<th>Anticipated outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

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<tr>
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</table>

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<tr>
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<th>Anticipated outcomes</th>
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</tbody>
</table>
When did the assessment visit take place, and who participated in it?

How will the twinning impact the established (developed) HTC?

What challenges do you anticipate facing through twinning partnership, and how do you anticipate overcoming them?

Do you anticipate seeking financial support from an organization (company, charity, hospital, etc.) other than the WFH to support your twinning activities? If yes, please provide some details.

Is there any other information that you wish to share with the WFH?

---

**Form completed by:**
Emerging HTC (names, titles):
Established HTC (names, titles):
Date:

*Thank you for your interest in the WFH Twinning Program*

*Please submit this form to Stephanie Pineda: spineda@wfh.org*
WFH Hemophilia Treatment Centre Twinning Program

SAMPLE PROGRESS REPORT

Twinning Partners:
Deadline date for submission to WFH: November 30, 2017

Date submitted to WFH:
Report completed by (names): Emerging partner representative:
Established partner representative:

Activities and Outcomes

Please complete the table below and indicate which activities were achieved by your partnership this year. These activities were taken from your 2017 Action Plan. It is important to specify measurable outcomes for each activity (ex. Accurate diagnosis of 12 patients, 1 physiotherapist trained in record-keeping of patients.)

If additional activities were accomplished that were not included in your 2017 Action Plan, please include them in the blank fields below.

Example:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Was the activity fully, partially, not accomplished, or modified? Please explain</th>
<th>Measurable outcome(s) of activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach initiative in 3 neighbouring towns.</td>
<td>Partially accomplished. Initial plan modified after it was determined there was not enough time to accomplish in 1 visit. One town reached this year, and remaining towns will be reached in 2018.</td>
<td>10 new patients identified and NMO is now in contact with them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>Was the activity fully, partially, not accomplished, or modified? Please explain</th>
<th>Measurable outcome(s) of activity</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
Any additional comments on activities and outcomes?

### Finances

*Please complete the table below and submit copies (by email) of all receipts that demonstrate how WFH Twinning funds were spent. We ask that you kindly indicate the expenditures in **US dollars.** Thank you for your cooperation.*

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cost in US dollars</th>
</tr>
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<tbody>
<tr>
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</tr>
</tbody>
</table>
Final balance

<table>
<thead>
<tr>
<th>Activity</th>
<th>Funding Source</th>
<th>Cost in US dollars</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

If you wish, you may also account for funding that was provided by sources other than the WFH.

Additional funding

<table>
<thead>
<tr>
<th>Activity</th>
<th>Funding Source</th>
<th>Cost in US dollars</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Any additional comments on finances?

General Comments

What were the challenges encountered with your twinning this year? How were these challenges addressed?

Any additional information to share with the WFH?

Thank you for taking the time to submit this report. We appreciate your efforts.

Please send this report before the deadline to: spineda@wfh.org
WFH Hemophilia Treatment Centre Twinning Program

SAMPLE ACTION PLAN

Twinning partners:

Deadline date for submission to WFH: December 5, 2016

Date submitted to WFH:

Report completed by: Emerging partner name: Established partner name:

Activities and Outcomes

Please indicate the activities that you plan to accomplish over the course of next year. It is important to also specify the anticipated measurable outcomes of each activity (ex. 12 new patients added to registry, Physiotherapist trained in record-keeping of patients.)

Example:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
<th>Anticipated measureable outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach initiative to 3 towns</td>
<td>May 2017 during a 5 day visit</td>
<td>Hope for at least 30 new patients to be identified</td>
</tr>
</tbody>
</table>

Please rank your activities in order of priority and note that there is no specific number of required activities per twin per year.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
<th>Anticipated measureable outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<td>4.</td>
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<tr>
<td>5.</td>
<td></td>
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<tr>
<td>6.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
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</tbody>
</table>
Any additional comments on planned activities and outcomes?

**Finances**

*Twins may apply for grants to cover their planned activities listed in the Action Plan. Grants may also include travel as well as general communications, if needed.*

*Twins are welcome to apply for grants up to $8,000 USD. (Please note that the WFH guarantees a minimum of $2,000 USD assuming the activities are deemed appropriate).*

**Please differentiate between activities and travel expenses.**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cost in US dollars</th>
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<tbody>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel expenses</td>
<td>Cost in US dollars</td>
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<td></td>
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<td></td>
<td></td>
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</tbody>
</table>

Total amount being requested from the WFH:

The WFH sends the grant to the established partner unless twins request otherwise. Please select the statement that both partners agree to for your 2017 funding and note that the splitting of funds cannot be coordinated by the WFH.

Pick one:
• Please send the funds to the established partner  □  
• Please send the funds to the emerging partner  □  

Do you agree to submit a financial report (including receipts) for all funding given to you from the WFH?  Yes  □    No  □  

If you plan to seek funding from sources other than the WFH, please describe your plans and specify if these funds are confirmed (guaranteed) or not.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Funding Source</th>
<th>Cost in US dollars</th>
<th>Confirmed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Any additional comments on finances?

________________________________________________________________________________________

**General Comments**

In what ways will your planned 2017 activities be important to the hemophilia community?

Any additional information to share with the WFH?

________________________________________________________________________________________

*Thank you for taking the time to submit this report. We appreciate your efforts.*

*Please send this report to: spineda@wfh.org*
HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Closure Questionnaire – Emerging

Name of Hemophilia Treatment Centre:

Date form submitted to WFH:

What was the most important achievement of this twinning?

What were the major challenges faced during your twinning, and how were these challenges addressed?

How did your HTC benefit from this twinning?

If you could start your twinning over again, what would you do differently?

How was the support you received from the WFH for your twinning?

Do you have any suggestions about how the WFH Twinning Program could be improved?

Thank you for your participation in the WFH Twinning Program

Please submit this form to Stephanie Pineda: spineda@wfh.org
HEMOPHILIA TREATMENT CENTRE TWINNING PROGRAM

Closure Questionnaire – Established

Name of Hemophilia Treatment Centre:

Date form submitted to WFH:

What was the most important achievement of this twinning?

What were the major challenges faced during your twinning, and how were these challenges addressed?

How did your HTC benefit from this twinning?

If you could start your twinning over again, what would you do differently?

How was the support you received from the WFH for your twinning?

Do you have any suggestions about how the WFH Twinning Program could be improved?

Thank you for your participation in the WFH Twinning Program

Please submit this form to Stephanie Pineda: spineda@wfh.org