Table of Contents

A. GENERAL INFORMATION ................................................................................................................................. 3
   PROGRAM OBJECTIVE ............................................................................................................................... 3
   SELECTION CRITERIA ................................................................................................................................. 3
   WFH SUPPORT ........................................................................................................................................... 4
   APPLICATION PROCEDURE ....................................................................................................................... 4
   REPORTING REQUIREMENTS .................................................................................................................... 4
   FUNDING ...................................................................................................................................................... 4
   DURATION ...................................................................................................................................................... 5
   TWINS OF THE YEAR AWARD .................................................................................................................. 5
   SPONSOR ...................................................................................................................................................... 5

B. ASSESSMENT VISIT GUIDELINES ................................................................................................................ 6
   OVERALL OBJECTIVE ............................................................................................................................... 6
   PRE-VISIT PREPARATION ......................................................................................................................... 6
   ON-SITE TIPS FOR ESTABLISHED ORGANIZATION REPRESENTATIVES ........................................... 7
   CONCLUSION .............................................................................................................................................. 8
   SUGGESTED ASSESSMENT VISIT ACTIVITIES ...................................................................................... 9
   NEXT STEPS .............................................................................................................................................. 9

C. WFH TWINNING PROGRAM GUIDELINES ................................................................................................. 10

D. WFH TWINNING PROGRAM ACTIVITIES ................................................................................................. 12

E. APPENDIX ..................................................................................................................................................... 15

F. ASSESSMENT VISIT FUNDING APPLICATION FORM ............................................................................. 16

G. SWOT ANALYSIS ......................................................................................................................................... 18

H. BACKGROUND QUESTIONNAIRE – EMERGING ...................................................................................... 20

I. BACKGROUND QUESTIONNAIRE – ESTABLISHED .............................................................................. 23

J. TWINNING APPLICATION FORM ............................................................................................................ 26

K. SAMPLE ANNUAL PROGRESS REPORT ................................................................................................. 28

L. SAMPLE ACTION PLAN ............................................................................................................................. 31

M. CLOSURE QUESTIONNAIRE – EMERGING ............................................................................................ 34

N. CLOSURE QUESTIONNAIRE – ESTABLISHED .................................................................................... 35
GENERAL INFORMATION

The Hemophilia Organization (HOT) Twinning Program of the WFH encourages a network of cooperation between hemophilia patient societies, or National Member Organizations (NMOs) around the world. Patient organizations are categorized by the WFH as either established or emerging, depending on their level of experience. Most often, the established organization is based in a developed country, while the emerging organization is based in a developing country, but there are exceptions. Established organizations have knowledge, experience and resources, and the transfer of these can be used to help emerging organizations reach a level of performance that directly benefits people with bleeding disorders.

PROGRAM OBJECTIVE

The objective of the program is to help emerging patient organization strengthen their organization and improve their services to patients and their families. The program encourages the transfer of expertise and knowledge between established and emerging patient organizations in the areas of good governance, strategic planning, fundraising, support groups, patient education and volunteer management, among others.

POSSIBLE ACTIVITIES

Twins usually meet face-to-face once per year, with most 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:
+ Training for board of directors
+ Educational activities for patients and their families
+ Development of a strategic plan or action planning
+ Organizing annual general meetings
+ Organizing summer camps
+ Creating a support group for mothers, youth etc.
+ Planning World Hemophilia Day activities
+ Outreach activities

HOT twins should not organize medical workshops or trainings.

SELECTION CRITERIA

To become a twin, patient organizations 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 organization thinks it can contribute to and learn from twinning
+ Key contact person(s) at the patient organization who is available to coordinate and communicate with the twinning partner and the WFH
A strong team commitment to undertake a twinning partnership
- Support from the patient organization board of directors or other key volunteers
- A willingness to respect the reporting requirements of the WFH

**WFH SUPPORT**

WFH support to twins includes:

- Assisting patient organizations 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

**APPLICATION PROCEDURE**

For details on the application procedure, patient organizations should contact the WFH program coordinator or regional manager. The first step is to complete a background questionnaire form that will help the WFH learn more about the patient organization 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 agree to pursue a twinning project, they will complete an application form and submit it to the WFH. The Hemophilia Organization 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 relationship, 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 HOT 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 website or contact the Twinning program coordinator, Stephanie Pineda, 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 organization 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 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 youth group and its activities. Learn about the challenges faced by the emerging youth group and its NMOs, youth engagement, and the local culture.

2. Determine if the match is appropriate
   Are the needs of the emerging youth group something that the established youth group 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 application form for the twinning
   If both partners agree to pursue a twinning, they should use the final day of the assessment visit to determine the objectives and priorities 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 manager and 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 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):
   - Hemophilia organization board of directors/executive committee
+ Youth members and leaders
+ Patients and families
+ Key medical professionals at HTC (if possible)

2. Other Issues
+ The representatives of the established youth group 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 rest and overcome jet lag
+ 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 such as:
+ Information and correspondence with the potential partners
+ 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
+ World Bank data
+ WFH twinning guidebook

ON-SITE TIPS FOR ESTABLISHED ORGANIZATION 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. How developed is the youth group?
+ How many members are active on a regular basis?
+ Is there an official membership list or registry?
+ What are the main activities of the youth members?
+ What are the ongoing projects/current goals of the youth group?
+ Is there an elected executive committee or leadership positions? How often do they meet?
+ Are there chapters?
+ How does the youth group communicate with members?
II. How is care organized?
+ Who is responsible for hemophilia care?
+ How many HTCs are there?
+ 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?
+ What treatment products are available?
+ What was the usage of concentrates last year? For the country, by PWH?
+ What is the level of medical expertise in the country?
+ Is there a comprehensive hemophilia care team?
+ What is the diagnosis capability? How are PWH diagnosed?
+ What is the total number of PWH being treated?
+ Is there a good relationship between medical professionals and the patient organization?
+ Are there treatment protocols?

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 productive. Will this be a win-win situation for both patient organizations? Remember that participating in twinning program will take up a large 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 NMOs can complete the exercise of identifying the elements of their NMOs that fall under each category, but much of the time should be spent focusing on the SWOT of the emerging NMO. 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 NMO 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.

**SUGGESTED ASSESSMENT VISIT ACTIVITIES**

- Time for the established youth group representatives arrive in country and rest
- Initial meeting between patient organizations and youth groups
- Presentations by each patient organization and WFH (if participating in visit)
- Meeting with Executive Committee /Board of emerging patient organization
- Meeting with group of patients and families
- Visit to HTC/hospital and meeting with key medical professionals
- 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 manager or program coordinator and submit the application form, if applicable. The HOT 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.
**WFH TWINNING PROGRAM GUIDELINES**

**Answers to frequently asked questions**

<table>
<thead>
<tr>
<th>Sponsorship recognition</th>
<th>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.</th>
</tr>
</thead>
</table>
| 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 |
<p>| 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. |</p>
<table>
<thead>
<tr>
<th>Treatment product donations</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rotation of volunteers</td>
<td>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.</td>
</tr>
</tbody>
</table>
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>
<tr>
<td>Psychosocial related activities</td>
<td>Genetic counseling</td>
<td>Development of materials (brochure, posters, publications, etc.)</td>
</tr>
<tr>
<td>Home treatment workshop</td>
<td>Clinics</td>
<td>Patient registry and membership lists</td>
</tr>
<tr>
<td>Chapter development activities</td>
<td>Clinical papers and posters</td>
<td>Advocacy initiatives</td>
</tr>
</tbody>
</table>

**Patient logbooks**

**Outreach activities**

**Patient education workshop**

**Awareness-building activities**

**World Hemophilia Day Activities**
### Poster for WFH World Congress

### Hemophilia symposium

### Sharing of publications and other materials

### Professional translation of materials (brochure, posters, publications)

### ID card/bracelet for patients

## 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>Rent for office/facilities</td>
<td></td>
</tr>
<tr>
<td>Funding of treatment of individual PWH (factor concentrates, surgery, etc.)</td>
<td>Scholarships for PWH</td>
<td></td>
</tr>
<tr>
<td>Establishment of additional HTC in region</td>
<td>Participation in WFH congresses and non-WFH congresses (EHC, ISTH, etc.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reimbursement of previous years’ activities/overspending</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employment cooperative for PWH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health insurance program for PWH</td>
<td></td>
</tr>
</tbody>
</table>

## Special rules

<table>
<thead>
<tr>
<th>Hemophilia Organization Twinnings</th>
<th>Hemophilia Treatment Centre Twinnings</th>
</tr>
</thead>
<tbody>
<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>
</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>
</tr>
<tr>
<td>-------------------------------------------------</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>
</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>
</tr>
</tbody>
</table>
WFH HEMOPHILIA ORGANIZATION TWINNING PROGRAM

Assessment Visit Funding Application Form

The WFH provides:

- 2 round-trip economy flights for the established partner to visit the emerging partner.
  - 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 or the program coordinator.

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 patient organization:

Established patient organization:

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 patient organization will participate in the assessment visit, and why?

FUNDING

*Please list all costs in US dollars.*

<table>
<thead>
<tr>
<th>Airfare</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Amount</td>
</tr>
<tr>
<td>----------------------------------</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>Total cost</td>
<td></td>
</tr>
<tr>
<td>Total contributions from sources other than the WFH (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

**Total requested from the WFH**

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, patient organization and title):
Date:

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

*Please submit this form to: 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>
</tr>
<tr>
<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>- Only NMO in country</td>
<td>- Increase brand recognition</td>
</tr>
<tr>
<td>- Registry and database</td>
<td>- Public awareness campaigns</td>
</tr>
<tr>
<td>- Medical – lay collaboration in capital city and outside of capital city</td>
<td>- Increase awareness in hospitals outside of capital city</td>
</tr>
<tr>
<td>- Strong physiotherapy</td>
<td>- Target local businesses for donations</td>
</tr>
<tr>
<td>- Newsletter and Web site</td>
<td>- Structure fundraising efforts</td>
</tr>
<tr>
<td>- Dedication of volunteers and community</td>
<td>- Training for board members</td>
</tr>
<tr>
<td>- Good relationship with WFH</td>
<td>- Education of patients and families</td>
</tr>
<tr>
<td>- High level of expertise on medical issues and skills</td>
<td>- Education/raise awareness of health care professionals</td>
</tr>
<tr>
<td>- Good publications and educational materials</td>
<td>- Increase outreach efforts</td>
</tr>
<tr>
<td>- Good relationship with blood banks</td>
<td>- Provide services outside of capital city</td>
</tr>
<tr>
<td>- Able to access treatment products in emergencies</td>
<td>- Lobbying policymakers</td>
</tr>
<tr>
<td>- Patient-driven organization</td>
<td>- Media relations</td>
</tr>
<tr>
<td>- Well-structured organization with good governance practices</td>
<td>- Increase network with other NMOs in region</td>
</tr>
<tr>
<td>- Collaboration with other NMOs in region</td>
<td>- Help patients have hope for their futures</td>
</tr>
<tr>
<td></td>
<td>- Development of chapters</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weaknesses:</th>
<th>Threats:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- No paid staff</td>
<td>- Limited resources</td>
</tr>
<tr>
<td>- Difficulty communicating with members</td>
<td>- Lack of support from outside of immediate hemophilia community</td>
</tr>
<tr>
<td>- High illiteracy of population</td>
<td>- Difficult to reach patients in remote areas</td>
</tr>
<tr>
<td>- Lack of evaluation tools</td>
<td>- Distance/travel makes it difficult for patients outside of capital city to participate in activities</td>
</tr>
<tr>
<td>- No government purchase of CFCs</td>
<td>- Hard for patients to pay annual membership fees, pay for transport to participate in activities</td>
</tr>
<tr>
<td>- High cost of treatment products, treatment products (FFP and cryo) inaccessible to most patients</td>
<td>- Patients who can afford treatment are not members of NMO</td>
</tr>
<tr>
<td>- Lack of volunteers</td>
<td>- Cultural norms, high value of marriage, and dishonor of being sick contributes to social stigma</td>
</tr>
<tr>
<td>- Culture of charity</td>
<td>- Fundraising skills</td>
</tr>
<tr>
<td>- Social stigma (some do not go to school because of condition, feel like a burden to family)</td>
<td>- Inadequate funds (no government, corporate or pharma funding)</td>
</tr>
<tr>
<td>- Low awareness in general public</td>
<td>- Unstructured fundraising practices</td>
</tr>
<tr>
<td>- Low awareness among healthcare professionals, especially outside of capital city</td>
<td>- Low number of identified patients</td>
</tr>
<tr>
<td>- Fundraising skills</td>
<td>- Lack of strategic plan</td>
</tr>
<tr>
<td>- Inadequate funds (no government, corporate or pharma funding)</td>
<td></td>
</tr>
</tbody>
</table>
HEMOPHILIA ORGANIZATION TWINNING PROGRAM

Background Questionnaire – Emerging

Name of hemophilia organization:
Mailing Address:
General email address of hemophilia organization:
Name and title of main contact(s) for potential twinning:
Email address of main contact(s) for potential twinning:
Date form submitted to WFH:

Information about your hemophilia organization

Is your organization registered with the government? □Yes □ No

Is there a medical registry of people with bleeding disorders in your country? □Yes □ No

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

Does your organization have membership list (people with bleeding disorders, family, friends, etc.)? □Yes □ No

If yes, how many members does your organization have?

Of those members, how many are active volunteers who are regularly available to help with projects and attend meetings?

Does your organization have regional chapters? □Yes □ No
If yes, list them?

Does your organization have a board of directors/executive committee? □Yes □ No
Are they elected? □Yes □ No
If yes, how often are elections held?

Does your organization have any paid staff? □Yes □ No
If yes, how many staff and are they full or part time?

Does your organization hold regular meetings? □Yes □ No
If yes, how many times per year are the meetings?
Does your organization keep minutes of the meetings?

Does your organization have an established office space? □ Yes □ No

What are the main sources of funding for your organization? Please select all that apply:

- □ Government
- □ Pharmaceutical company/ies
- □ Grant
- □ Membership fees
- □ Private donors
- □ Fundraising activities
- □ Other (please specify):

What is the main language of communication of the organization?

Are any key volunteers able to communicate in additional languages? Please specify.

Does your organization have access to the following tools?

- Computer □ Yes □ No
- Photocopier □ Yes □ No
- Fax □ Yes □ No
- Internet □ Yes □ No

---

**Hemophilia organization services**

Does your organization…

- Plan workshops or conferences? □ Yes □ No
- Produce a newsletter? □ Yes □ No
- If yes, how many issues per year, and is it printed or digital?
- Have an online presence (web site, Facebook page, etc.)? □ Yes □ No
- Provide education about bleeding disorders to members? □ Yes □ No
- Produce educational materials? □ Yes □ No
- Use the media to inform the general public about issues related to bleeding disorders (awareness building)? □ Yes □ No
- Conduct fundraising activities? □ Yes □ No
- Organize youth activities? □ Yes □ No
- Lobby the government? □ Yes □ No
- Have contact with hemophilia treatment centers? □ Yes □ No
- Offer counseling to patients? □ Yes □ No
Have an action plan? ☐ Yes  ☐ No
If yes, please send a copy along with this questionnaire.

**Why twinning?**

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

What are the top three key aspects of your organization that you want to improve during a twinning partnership?
1)  
2)  
3)  

Has the board of directors/executive committee of your organization discussed and approved the possibility of twinning?
☐ Yes  ☐ No
Please describe the response:

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

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

Please provide any additional comments:

Thank you for your interest in the WFH Twinning Program.

*Please submit this form to: spineda@wfh.org*
HEMOPHILIA ORGANIZATION TWINNING PROGRAM

Background Questionnaire – Established

Name of hemophilia organization:
Mailing address:
General email address of hemophilia organization:
Name and title of main contact(s) for potential twinning:
Email address of main contact(s) for potential twinning:
Date form submitted to WFH:

Information about your hemophilia organization

Is your organization registered with the government? ☐ Yes ☐ No

Is there a medical registry of people with bleeding disorders in your country? ☐ Yes ☐ No

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

Does your organization have membership list (people with bleeding disorders, family, friends, etc.)? ☐ Yes ☐ No

If yes, how many members does your organization have?

Of those members, how many are active volunteers who are regularly available to help with projects and attend meetings?

Does your organization have regional chapters? ☐ Yes ☐ No
If yes, list them?

Does your organization have a board of directors/executive committee? ☐ Yes ☐ No
Are they elected? ☐ Yes ☐ No
If yes, how often are elections held?

Does your organization have any paid staff? ☐ Yes ☐ No
If yes, how many staff and are they full or part time?

Does your organization have regular meetings? ☐ Yes ☐ No
If yes, how many times per year are the meetings?
Does your organization keep minutes of the meetings?
Does your organization have an established office space? □ Yes □ No

What are the main sources of funding for your organization? Please select all that apply:

□ Government □ Pharmaceutical company/ies
□ Grant □ Membership fees
□ Private donors □ Fundraising activities
□ Other (please specify):

What is the main language of communication of the organization?

Are any key volunteers able to communicate in additional languages? Please specify.

Does your organization have access to the following facilities?

Computer □ Yes □ No
Photocopier □ Yes □ No
Fax □ Yes □ No
Internet □ Yes □ No

Hemophilia organization services

Does your organization…

Plan workshops or conferences? □ Yes □ No

Produce a newsletter? □ Yes □ No
If yes, how many issues per year, and is it printed or digital?

Have an online presence (web site, Facebook page, etc.)? □ Yes □ No

Provide education about bleeding disorders to members? □ Yes □ No

Produce educational materials? □ Yes □ No

Use the media to inform the general public about issues related to bleeding disorders (awareness building)? □ Yes □ No

Conduct fundraising activities? □ Yes □ No

Organize youth activities? □ Yes □ No

Lobby the government? □ Yes □ No

Have contact with hemophilia treatment centers? □ Yes □ No

Offer counseling to patients? □ Yes □ No

Have an action plan? □ Yes □ No
If yes, please send a copy along with this questionnaire.
Why twinning?

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

What are the top three key areas of expertise your organization could contribute to a twinning partnership?

1) 
2) 
3) 

Has the board of directors/executive committee of your organization discussed and approved the possibility of twinning?

☐ Yes   ☐ No

Please describe the response:

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

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

Please provide any additional comments:

Thank you for your interest in the WFH Twinning Program.

Please submit this form to: spineda@wfh.org
HEMOPHILIA ORGANIZATION TWINNING PROGRAM

Twinning Application form

Emerging patient organization:
Mailing Address:
Main contact person(s):
Email address 1: Email address 2:
Telephone(s):

Established patient organization:
Mailing Address:
Main contact person(s):
Email address 1: Email address 2:
Telephone(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.

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

How will the twinning impact the established (developed) patient organization?

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

Do you anticipate seeking financial support from another source (company, charity 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 NMO (name, title):
Established NMO (name, title):
Date:

Thank you for your interest in the WFH Twinning Program

Please submit this form to: spineda@wfh.org
WFH Hemophilia Organization Twinning Program

2017 Progress Report

Twinning:

Deadline date for submission to WFH: November 30, 2017

Date submitted to WFH:

Report completed by  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 measureable outcomes for each activity (ex. summer camp for 25 youths, newsletter distributed to 100 families, new elections procedure adopted and included in constitution of NMO).

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>Measureable outcome(s) of activity</th>
</tr>
</thead>
</table>
| Family Day     | Fully accomplished.  
Original plan was for 50 participants to attend, but due to miscommunication regarding the date, in the end 40 participants attended. Full program was executed, including games for youth, meeting of mother’s group, and psychosocial workshop. | 2 families new to the NMO attended and were enthusiastic about the support of the NMO.  
Youths discussed possibility of forming a youth committee of NMO.  
Mothers group shared experiences with one another.  
Psychosocial workshop on the challenges of gaining and retaining employment for PWH. |
<table>
<thead>
<tr>
<th>Activity</th>
<th>Was the activity fully, partially, not accomplished or modified? Please explain</th>
<th>Measureable outcome(s) of activity</th>
</tr>
</thead>
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</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>
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</table>
**Final balance**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Funding Source</th>
<th>Cost in US dollars</th>
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<tbody>
<tr>
<td>WFH Funding</td>
<td>$8,000 USD</td>
<td></td>
</tr>
<tr>
<td>Amount spent this year</td>
<td></td>
<td></td>
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<tr>
<td>Balance</td>
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</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>
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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 indicated above to: spineda@wfh.org*
WFH Hemophilia Organization Twinning Program

2018 Action Plan

Twinning Partners:
Deadline date for submission to WFH: **November 30, 2017**
Date submitted to WFH:
Report completed by: Emerging partner representative:

Established partner representative:

### 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. summer camp for 25 youths, distribute 100 copies of newsletter, develop new electoral guidelines in constitution).*

**Example:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
<th>Anticipated measurable outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Day</td>
<td>August 2018 during 5-day visit</td>
<td>Participation of 50 NMO members.</td>
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<tr>
<td></td>
<td></td>
<td>Psychosocial workshop for all participants on employment-related challenges for PWH. Meeting of Mother’s Group.</td>
</tr>
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</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 measurable outcome(s)</th>
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</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.*

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<thead>
<tr>
<th>Activity</th>
<th>Cost in US dollars</th>
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<th>Travel expenses</th>
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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 2018 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 [ ]
HTC Twinning partners will complete and submit to the WFH an annual progress report with copies of all receipts that demonstrate how the funds have been spent. It is expressly understood that future funding under the WFH HTC Twinning Program cannot be made until the twins have submitted an annual progress report.

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>
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Any additional comments on finances?

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**General Comments**

In what ways will your planned 2018 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 ORGANIZATION TWINNING PROGRAM

Closure Questionnaire – Emerging

Name of NMO:

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 organization 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 interest in the WFH Twinning Program.

Please submit this form to: spineda@wfh.org
HEMOPHILIA ORGANIZATION TWINNING PROGRAM

Closure Questionnaire – Established

Name of NMO:

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 organization 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: spineda@wfh.org