Table of Contents

A. GENERAL INFORMATION .................................................................................................................. 3
   PROGRAM OBJECTIVE ................................................................................................................. 3
   WFH SUPPORT ............................................................................................................................. 3
   APPLICATION PROCEDURE ......................................................................................................... 4
   REPORTING REQUIREMENTS ...................................................................................................... 4
   FUNDING ...................................................................................................................................... 4
   DURATION ..................................................................................................................................... 5
   YOUTH GROUP 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 YOUTH GROUP REPRESENTATIVES ............................... 7
   CONCLUSION .............................................................................................................................. 8
   SUGGESTED ASSESSMENT VISIT ACTIVITIES ....................................................................... 9
   NEXT STEPS ................................................................................................................................ 9

C. WFH YOUTH GROUP TWINNING PROGRAM GUIDELINES .................................................... 10

D. WFH YOUTH GROUP TWINNING PROGRAM ACTIVITIES ..................................................... 11

E. APPENDIX ....................................................................................................................................... 13

F. WFH YOUTH GROUP TWINNING PROGRAM ASSESSMENT VISIT FUNDING
   APPLICATION FORM .................................................................................................................... 14
   GENERAL QUESTIONS ................................................................................................................ 14
   FUNDING ...................................................................................................................................... 15

G. YOUTH GROUP TWINNING PILOT PROJECT APPLICATION FORM ........................................ 16

H. WFH YOUTH GROUP TWINNING PILOT PROJECT SAMPLE ACTION PLAN .......................... 18
   ACTIVITIES AND OUTCOMES ................................................................................................. 18
   FINANCES ................................................................................................................................... 19
   GENERAL COMMENTS .............................................................................................................. 20

I. WFH YOUTH GROUP TWINNING PROGRAM SAMPLE PROGRESS REPORT ....................... 21
   ACTIVITIES AND OUTCOMES ................................................................................................. 21
   GENERAL COMMENTS .............................................................................................................. 22
GENERAL INFORMATION
The youth group twinning component of the WFH Twinning Program encourages a network of cooperation between youth group members of hemophilia patient societies, or National Member Organizations (NMOs) around the world. Youth group twins are categorized by the WFH as either established or emerging, depending on their level of experience. Most often, the established youth group is based in a developed country, while the emerging youth group is based in a developing country, but there are exceptions. Established youth groups have knowledge, experience and resources, and the transfer of these can be used to help emerging youth groups reach a level of performance that directly benefits patients with bleeding disorders.

PROGRAM OBJECTIVE
The objective of the Youth Group Twinning Program is to help emerging youth groups strengthen their membership and empower young members of the NMO. The program encourages the transfer of expertise and knowledge between established and emerging youth groups in the areas of leadership training, good governance of youth groups, fundraising, peer support groups, patient education, among others.

POSSIBLE ACTIVITIES
Twins usually meet face-to-face once per year, with most visits and activities taking place in the emerging developing country. In between visits, twins keep in touch regularly via email, mobile texts, Skype, Facebook, WhatsApp and other social media tools.

Activities undertaken by youth group twins may include:
+ Leadership and social media trainings (for i.e. effective communication, public speaking, etc.);
+ Educational activities for other patients and their families;
+ Organizing annual general meetings (including voting on youth leadership positions, etc.)
+ Good governance of youth groups (organizing annual and other meetings, effective communication, voting on leadership positions, relations with NMO leadership, etc.);
+ Action planning;
+ Organizing summer camps;
+ Creating a support group for youth members;
+ Planning World Hemophilia Day activities;
+ Advocacy initiatives;
+ Outreach activities.

Youth group twins should not organize medical workshops or trainings.

WFH SUPPORT
WFH support to youth group twins includes:
+ Assisting youth groups in finding a suitable partner;
+ Financially supporting the partnerships through funding for assessment visits and annual grant funding;
+ 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 Managers/Coordinators and Twinning Program Coordinator, including possibly accompanying twinning partners on assessment visits.

**APPLICATION PROCEDURE**

For details on the application procedure, patient organizations and/or youth groups should contact the WFH Twinning Program Coordinator or Regional Manager/Coordinator.

The first step is to complete an *Expression of Interest* form that will help the WFH learn more about the patient organization youth group 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* section 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 (HOT) Committee meets by conference call in October of every year to review the applications of potential new youth group twins. Twins are informed of the Committee’s decision in November and if approved are required to submit an *Action Plan* in December and officially begin twinning in January.

**REPORTING REQUIREMENTS**

Youth group 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, a new *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 funding grants to youth group 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 HOT Twinning Committee as outlined in the *Funding Agreement Letter* sent to twins.

The funding will be sent to the developed youth group partner since generally most of the annual funding is used for travel expenses. Any transfers to the developing partner must be coordinated by the twins and not by the WFH. The WFH will not split the funds between partners.
DURATION
Youth group twins can be recognized and supported financially by the WFH for up to two years. If both partners wish to continue at the end of their two years, they will be invited to formally apply to renew their partnership on an annual basis, for a maximum of two additional years. In summary, a Youth Group Twinning can last between two and four years. After this time, partners are free to continue their relationship, but funding from the WFH will not be provided. Once the youth group twinning has ended, twins are required to submit a Closure questionnaire to the WFH.

YOUTH GROUP 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. The award has no financial value. Its objective is to share best practices, experiences and lessons-learned with others. The award is presented every two years at the WFH World Congress. The first Youth Group Twins of the Year Award will be awarded in 2020.

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 and the Youth Group Twinning Program, please visit the WFH web site or contact the Twinning Program Coordinator, Stephanie Pineda, at spineda@wfh.org.
ASSESSMENT VISIT GUIDELINES

The assessment visit is an important component of all WFH Twinning Program partnerships. 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.

Prior to applying to formally join the Youth Group Twinning Program, the WFH funds an assessment visit whereby the developed partner visits the developing partner. This is an opportunity for the youth groups to meet face-to-face for the first time, to assess whether committing to a twinning partnership is in the best interest of both youth groups, and to familiarize the established partner with the local situation. Whenever possible, the WFH Regional Manager/Coordinator or Twinning Program Coordinator will accompany the potential twins on the assessment visit and help with the planning process and with the understanding of cultural, economic and social norms. At the end of the assessment visit, if a twinning partnership is mutually agreed to be pursued, the partners will jointly complete a formal Twinning Application Form to join the program.

The WFH covers the majority of costs associated with the youth group twinning 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 the services/activities offered to youth patients by each youth group. Learn about the challenges faced by the emerging youth group, how bleeding disorders are managed, 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 youth group twinning should focus on and jointly fill-out the Twinning Application Form that will be submitted to the WFH.

PRE-VISIT PREPARATION

In cooperation with the WFH Regional Manager/Coordinator and Twinning 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. Representatives of the established youth group should arrange meetings with the following key players (for introductory meetings, if appropriate) in the developing country:

- Hemophilia organization board of directors/executive committee
- Youth group members, group of patients and families

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, as well as the situation of bleeding disorders 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 by the youth group partners to work on the Application Form if it is mutually agreed to pursue a twinning.

3. **Reference Documents**
Before the start of the visit, we recommend reviewing information such as:

- 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;
- World Bank data;
- WFH twinning guidebook.

**ON-SITE TIPS FOR ESTABLISHED YOUTH GROUP 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**

   1. How developed is the youth group?
      - How many youth are active on a regular basis in the youth group?
      - Is there an official membership list or registry?
      - What are the main activities of the youth group?
      - What are the ongoing projects/current goals of the youth group?
      - Is there an elected youth group executive committee? How often do they meet?
Is there a Terms of Reference /Constitution for the youth group?
How does the youth group communicate with its members?

II. How is care organized?
+ Who is responsible for bleeding disorders care?
+ How many HTCs are there?
+ Who pays for treatment?
+ How do social security (or equivalent) policies affect PWBD?
+ Is there a registry of PWBD? 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 PWBD?
+ 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, the patient organization and the youth group?
+ 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 youth group 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 youth groups? 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 youth representatives will be required.

Final meeting of assessment visit
If you have mutually agreed to pursue a youth group 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 youth groups can complete the exercise of identifying the elements of their youth group that fall under each category, but much of the time should be spent focusing on the SWOT of the emerging youth group. 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 youth group twinning be identified. The priority areas do not necessarily need to be the top priorities.
of the emerging youth group in general, but rather the priority areas that the potential partners mutually agree can realistically address through a 2-year twinning project. If both partners wish to continue at the end of their two years, they will be invited to formally apply to renew their partnership on an annual basis, for a maximum of two additional years.

After the top priority areas are identified, 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 to arrive in country and rest
+ Initial meeting between youth groups
+ Presentations by each youth group and the WFH (if a WFH staff is participating in assessment visit)
+ Meeting with Executive Committee/Board of the emerging youth group
+ Meeting with youth group members; should time permit consider meeting with group of patients and families as well
+ Meeting to determine if twinning should be pursued, and if so:
  o SWOT exercise
  o Rank priority areas for youth group twinning
  o Complete Application Form

NEXT STEPS

After the assessment visit, please report back to the Regional Manager/Coordinator or Twinning Program Coordinator and submit the application form, if applicable. The Hemophilia Organization Twinning (HOT) Twinning Committee meets every October via conference call to review the applications of potential new youth group twins. All application forms must be received by the WFH by October 1st to be considered for approval to start twinning the following year. You will be informed of the Committee’s 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 YOUTH GROUP TWINNING PROGRAM GUIDELINES**

**Answers to frequently asked questions**

<table>
<thead>
<tr>
<th>Sponsorship recognition</th>
<th>The exclusive sponsor of the Twinning Program and Youth Group 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 youth group twins. Twins are welcome to solicit funds from other sources (including other pharmaceutical companies), 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.</th>
</tr>
</thead>
</table>
| How many twinnings at a time | A youth group may only participate in one twinning partnership at a time.  
• Exception: Youth 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 | A youth group twinning partnerships is designed to last up to 2 years. If both partners wish to continue at the end of their two years, they will be invited to formally apply to renew their partnership on an annual basis, for a maximum of two additional years. In summary, a youth group twinning can last between two to four years. |
| Destination of funds | The WFH sends the annual funding grant to the established youth group 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. |
| Rotation of volunteers | Established twins are encouraged to involve different youth 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 YOUTH GROUP TWINNING PROGRAM ACTIVITIES

What follows is a non-exhaustive list of activities that are generally considered to be appropriate to be funded with WFH youth group twinning funds, not appropriate to fund, and activities with special rules to be considered. Youth group 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 Twinning Committee.

<table>
<thead>
<tr>
<th>Appropriate to fund (with committee approval)</th>
<th>International travel expenses (flights, accommodation, visa)</th>
<th>Awareness-building activities or campaigns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training of youth leaders</td>
<td>Meals during activities</td>
<td>World Hemophilia Day Activities</td>
</tr>
<tr>
<td>Workshops/trainings of youth members (ex. Leadership training, social media, advocacy, patient education, etc.)</td>
<td>Local travel expenses and transportation</td>
<td></td>
</tr>
<tr>
<td>Development of communication tools (ex. web site, blog, newsletter)</td>
<td>Social event (ex. group dinner)</td>
<td></td>
</tr>
<tr>
<td>Peer support groups</td>
<td>Patient education workshop</td>
<td></td>
</tr>
<tr>
<td>Youth chapter development activities</td>
<td>Development of educational materials (brochure, posters, publications, videos, etc.)</td>
<td></td>
</tr>
<tr>
<td>Professional translation of materials (brochure, posters, publications)</td>
<td>Advocacy initiatives</td>
<td></td>
</tr>
<tr>
<td>Summer camps</td>
<td>Outreach activities</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not appropriate to fund</th>
<th>Scholarships for PWBD</th>
<th>Rent for office/facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and training of medical professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purchase of factor concentrates</td>
<td>Participation in WFH congresses and non-WFH congresses (EHC, ISTH, etc.)</td>
<td>Any youth-related activities that are already included in the Action Plan of the NMO HOT Twinning (should the organization be participating in one)</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Diagnostic testing of emerging samples in established country</td>
<td>Reimbursement of previous years’ activities/overspending</td>
<td></td>
</tr>
<tr>
<td>Funding of treatment of individual PWBD (factor concentrates, surgery, etc.)</td>
<td>Employment cooperative for PWBD</td>
<td></td>
</tr>
<tr>
<td>Staff salaries or honorariums for volunteers</td>
<td>Health insurance program for PWBD</td>
<td></td>
</tr>
</tbody>
</table>

**Special rules**

- Participation of emerging youth in summer camp in established country may only be funded once per twinning
- Purchase of key office equipment (ex. computer, printer, software, etc.) may only be funded once per twinning
- Travel to the established country for youth group twinning activities may only be funded once per twinning. Special approval from the HOT Twinning Committee is required for additional travel to the established country
APPENDIX
WFH YOUTH GROUP TWINNING PROGRAM
Assessment Visit Funding Application Form

The WFH provides:
  + Round-trip economy class airfare for up to 2 youth group representatives and 1 senior (adult) youth group supervisor from the established country to travel to the emerging country
    o The WFH must approve the itinerary and cost of the flights before the tickets are purchased
  + Accommodations at a reasonably priced hotel for 2 to 4 nights
  + Cost of a visa (if required)
  + Meals
  + Local transportation expenses (in the emerging country)

The participants (or the NMO/youth group) will be responsible for all other expenses related to the visit (passport fees, vaccinations, transportation to and from home city airport, etc.). 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 youth group 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 youth group and WFH National Member Organization (NMO):**

**Established youth group and WFH National Member Organization (NMO):**

**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 youth group will participate in the assessment visit (1-2 youth group representatives and senior (adult) supervisor), and why?
FUNDING
Please list all costs in US dollars.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></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 transportation</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>
<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 of youth group designated leader/coordinator and title):
Date:

Signature of NMO leadership (name and title – NMO President/ Board of Directors/Executive Committee member):
Date:

Thank you for your interest in the WFH Youth Group Twinning Program

Please submit this form to Stephanie Pineda: spineda@wfh.org
YOUTH GROUP TWINNING PILOT PROJECT
Application form

Name of NMO of emerging youth group:
Address:
Country:
Main youth contact person(s):
Email address 1: Email address 2:
Main NMO leader who will act as a supervisor of the Youth Group Twinning:
Email address:
Telephone(s):

Name of NMO of established youth group:
Address:
Country:
Main youth contact person(s):
Email address 1: Email address 2:
Main NMO leader who will act as a supervisor of the Youth Group Twinning:
Email address:
Telephone(s):

What are the main goals of the planned Youth Group 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>
<td></td>
<td></td>
</tr>
<tr>
<td>Goal</td>
<td>Activities</td>
<td>Anticipated outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goal</td>
<td>Activities</td>
<td>Anticipated outcomes</td>
</tr>
<tr>
<td>------</td>
<td>------------</td>
<td>----------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

When did the assessment visit take place, and who participated in it?

How will the twinning impact the established (developed) youth group?

What challenges do you anticipate facing through the youth group 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 youth leader and senior member (names, titles):
Established NMO youth leader and senior member (names, titles):
Date:

Thank you for your interest in the WFH Twinning Program

Please submit this form to: spineda@wfh.org
WFH Youth Group Twinning Pilot Project

SAMPLE ACTION PLAN

Youth Group Twinning partnership:
Deadline date for submission to WFH: December 1, 2018
Date submitted to WFH:
Report completed by:
Emerging youth group name:
Established youth group 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 measureable outcomes of each activity (ex. summer camp for 25 youths, distribute 100 copies of newsletter, etc.).

Example:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
<th>Anticipated measureable outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth meeting and workshop</td>
<td>June 2018 during 3-day visit</td>
<td>Participation of 30 youth NMO members.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social media workshop on the use of social media tools to engage youth members.</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>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Any additional comments on planned activities and outcomes?

**Finances**

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

*Twins are welcome to apply for funding 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>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**Total funding amount being requested from the WFH:**

Youth group twins will keep all expenditures under the WFH Twinning Program segregated and apart from general NMO expenditures.

The WFH sends the funding to the established youth group unless twins request otherwise. Please select the statement that both groups 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 youth group NMO: ☐
- Please send the funds to the emerging youth group NMO: ☐

Youth group twin partners will complete and submit to the WFH a year-end progress report by December 2018 with copies of all receipts that demonstrate how the funds have been spent. It
is expressly understood that future funding under the WFH Youth Group Twinning Program cannot be made until the twins have submitted a year-end 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>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Any additional comments on finances?

**General Comments**
In what ways will your planned 2018 activities be important to hemophilia youths and the bleeding disorders 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
WFH Youth Group Twinning Program
SAMPLE PROGRESS REPORT

Youth Group Twinning Partners:
Deadline date for submission to WFH: November 16, 2018
Date submitted to WFH:
Report completed by
- Emerging youth group name:
- Established youth group name:

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 2018 Action Plan. It is important to specify measurable outcomes for each activity (ex. summer camp for 25 youths, newsletter distributed to 100 youths, etc.).

If additional activities were accomplished that were not included in your 2018 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>
<tbody>
<tr>
<td>Youth meeting and workshop</td>
<td>Fully accomplished. Original plan was for 30 participants to attend, but due to miscommunication regarding the date, in the end 20 participants attended. Full program was executed, including games for youth, meeting representatives of different chapters, and psychosocial workshop.</td>
<td>3 youth patients new to the NMO attended and were enthusiastic to participate in future events. Youths discussed possibility of forming a youth executive committee. Youths agreed to set-up a WhatsApp group and create a Facebook page. Social media workshop on the use of social media tools to engage youth members.</td>
</tr>
</tbody>
</table>
Activity | Was the activity fully, partially, not accomplished or modified? Please explain | Measureable outcome(s) of activity
--- | --- | ---
| | | 
| | | 
| | | 
| | | 
| | | 
| | | 

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. This table must be completed in **US dollars**. Thank you for your cooperation.*

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

Final balance

<table>
<thead>
<tr>
<th>Twinning funding given by WFH</th>
<th>USD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amount spent this year</td>
<td></td>
</tr>
<tr>
<td>Balance</td>
<td></td>
</tr>
</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>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Any additional comments on finances?

GENERAL COMMENTS

What were the challenges encountered with your Youth Group 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 to: spineda@wfh.org