

HEMOPHILIA ORGANIZATION TWINNING PROGRAM

General Information

Background

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.

Program Objective

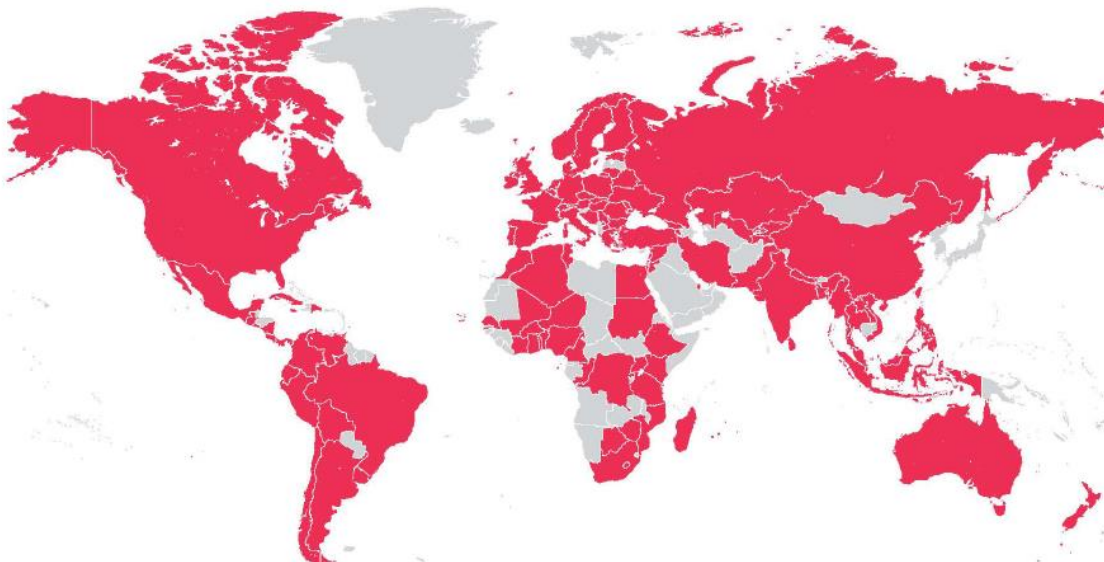
The objective of the program is to help emerging patient organization strengthen their organization and improve their services to patients and their families. The program encourages the **transfer of expertise and knowledge between established and emerging patient organizations** in the areas of good governance, strategic planning, fundraising, support groups, patient education and volunteer management, among others. Twinning activities must focus on **sustainability and capacity-building**. The goal of a twinning partnership is for the emerging partner to be able to maintain, and in the future, increasingly improve the capacity of the patient organization that has been achieved through the partnership. Many established partners find that participating in a twinning offers them new insight on their services offered to patients and their families, and that they learn just as much from their partners as they do from them.

Funding

The WFH provides annual grants to twins to a maximum of 8,000 USD (including any unspent balance from previous years). Funding is transferred during the first quarter 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 up to four years, with the possibility of a one-year extension. 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.



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 commitment to respect the activity and financial 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 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). Following the assessment visit, if both potential partners agree to pursue a twinning project, they will complete an **application using the WFH SurveyMonkey Apply platform** (access will be granted for eligible applicants by the program coordinator). Included in the application, partners will be required to submit their proposed action plan for the first year of activities.

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 their financial information in December and officially begin twinning in January.

Reporting Requirements

Twins must submit an annual progress report using the SurveyMonkey Apply Platform. This report comprises a financial account including back up receipts 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.

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.

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, Zoe Jackson, at zjackson@wfh.org.

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