

# PLANNING AND INITIATING PROJECTS **A GUIDE FOR EMERGENT NMOs**



**WFH**

WORLD FEDERATION OF HEMOPHILIA

Published by the World Federation of Hemophilia (WFH)

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**World Federation of Hemophilia**

1425 René Lévesque Boulevard West, Suite 1010

Montréal, Québec H3G 1T7

CANADA

Tel.: (514) 875-7944

Fax: (514) 875-8916

E-mail: wfh@wfh.org

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## ■ INTRODUCTION

Your hemophilia patient organization has been accredited by the World Federation of Hemophilia (WFH) – congratulations on obtaining the status of an official National Member Organization (NMO)!

But, now what? There are so many exciting and challenging projects your members want to address, how can you coordinate your team's energies to be the most effective? This guide provides strategies for team priority setting and concrete examples of achievable projects that hemophilia patient organizations commonly initiate.

## ■ START BY AGREEING ON YOUR PRIORITIES

Volunteer team members, and their beneficiaries, often have differing opinions on what projects should be of highest priority for the organization. It is essential to reach agreement on your priorities in a relatively quick and efficient manner. In time, you can execute many different projects, but you should start with those that are of most importance to the most members. Making a plan for the year that is centred around these provides focus and direction for your efforts.

Best practice is to use the first few meetings of your organization each year for this planning process. Setting your priorities for a specific period of time (e.g. one year) will help you concentrate on the identified needs and not get sidetracked by spontaneous projects, which could consume a lot of time and resources. Some of these new projects will represent great opportunities, and your organization may choose to change plans to capitalize upon them, especially when they align with your stated objectives. Just remember, that if you add something to your plan for the year you may have to remove something else, unless you can recruit more people and resources.

A diplomatic moderator, who encourages dialogue and fosters reflection, is essential to successful planning meetings. Recruit someone with experience running team meetings, and ask them to lead your team through this simple group planning exercise:



### Group planning exercise

- 1 Ask each member to name two specific issues, related to bleeding disorders, which they have faced in their personal or professional lives. Write their suggestions on a board for all to see.
- 2 If several people identify very similar issues, these can be combined into one, in order to avoid repetition and focus the discussion.
- 3 Ask everyone to consider the list they have made together and vote for the two issues that they feel most urgently need to be addressed.
- 4 Identify the three or four issues that received the most votes, and make these your first priorities for the coming year.
- 5 Do not discard the remaining list of issues; note them for the following yearly planning session. You might even be able to start working on some of them this year if you have made better progress than expected on your main projects. Use the last two or three meetings of the year to review progress and start planning for the next year.

### Related WFH Resources

- Clarke G. *Action planning. Hemophilia Organization Development #2*, WFH, 2010.
- Nazzaro AM, Strazzabosco, J. *Group dynamics and team building. Hemophilia Organization Development #4*, WFH, 2009.
- Hemophilia patient organization self-assessment*, WFH, 2015.

## ■ SAMPLE PROJECTS FOR EMERGENT NMOs

Now that you have set your priorities, you will need to choose, as an organization, the concrete projects that will allow you to address them. Below are several examples of projects that meet objectives commonly identified as priorities by NMOs. These are just suggestions to get you started, work together to identify the projects that can best meet your objectives with the resources you have available. Be realistic about factors that may be beyond your control when defining your projects. For example, while you may have identified achieving affordable access to treatment factor for everyone as a top priority, your government may not have the resources to supply treatment for all citizens this year. But you may be able to work with them towards interim goals this year, and build on these successes next year to reach your ultimate goal in the future.

### 1. Educate your community



Educating members, their families, and the larger community about bleeding disorders is a high priority for many NMOs.

The WFH offers numerous educational resources for people with bleeding disorders and their families, which can be downloaded for free, or ordered as print copies for a nominal fee,

in several languages ([www.wfh.org/publications](http://www.wfh.org/publications)). They provide clear and accurate information on the realities of living with a bleeding disorder, diagnosis, and management. The treatment guidelines available in your country, as well as the [Guidelines for the Management of Hemophilia](#) prepared by the WFH, are other important resources.

While these resources may be widely available, people do not always read them, for a variety of reasons. Reading in a group, with the assistance of an expert clinician if possible, fosters collaboration and shared understanding, helping members to become expert patients and caregivers.

The next step in this initiative is to organize information sessions, educational workshops, etc. for the broader community.

### 2. Build a collaborative relationship with clinicians and authorities at treatment centres

NMOs may identify a need for closer collaboration with treatment centres.

Clinicians and local health authorities can play a key role in improving access to care for people with bleeding disorders, and the quality of care they receive. Keep clinicians informed of your organization's objectives, the work you are doing, and the progress you make. Take the initiative to communicate with them frequently, in person or in writing.



Clearly explaining the objectives established by your team to clinicians and health professionals signals your desire to collaborate with them. When you share your short, medium, and long term goals, you can identify ways to work together to your mutual benefit. Call and visit frequently to keep them up-to-date. Initiate a discussion about how you can help them improve the level of care people with bleeding disorders in your country receive. Reflect upon, and consider accepting, their recommendations on how to achieve the results prioritized by your organization. You will probably find that you share many priorities and objectives.

### 3. Present your projects to decision makers



Influencing policy and health decisions that impact the bleeding disorders community is a priority for many NMOs.

Building on the spirit of collaboration established by regular communication with clinicians and health authorities, you may identify an opportunity to influence important decisions

that impact the bleeding disorders community. Some clinicians and health professionals work for associations or treatment centres and may be particularly well positioned to help you. Set up a meeting to discuss a specific collaboration proposal, or the main objectives of your organization, with individuals that you have identified as likely to be interested. After the meeting, follow up with a written summary of the discussion. Policy and decision makers often have very busy schedules and will need a tactful reminder of what was agreed upon with your organization. This clearly identifies, for both parties, who is responsible for each action, and allows you to establish a working plan. Be sure to schedule another in-person meeting before too long, to discuss progress and maintain the positive momentum.

#### Related WFH Resources

Page D. *Making your case effectively. Hemophilia Organization Development #5, WFH, 2004.*

O'Mahony B. *Developing and sustaining an effective lobbying campaign. Hemophilia Organization Development #9, WFH, 2006.*

WFH Advocacy in Action workshop materials, including a variety of advocacy tools, resources, and presentations on specific issues: [www.wfh.org/en/advocacy-in-action](http://www.wfh.org/en/advocacy-in-action) (login required to access workshop materials).

### 4. Initiate a patient registry

Establishing a record of the number of patients with bleeding disorders in your country provides an evidence base that is an important early step in any NMO's advocacy work.

In order for you to effectively make your case to decision makers, you must be able to back up your proposals with evidence. A patient registry is a great place to start. In collaboration with a clinician specializing in bleeding disorders, design a patient registry form. Make it as brief and as simple as possible so that the patient him/herself, or his/her caregivers, can easily fill it out. Include basic identification and location information such as national identification codes, complete address, telephone number, and e-mail address. The diagnosis section should record the patient's bleeding disorder as well as any details on the type of disorder (e.g. hemophilia **A**, von Willebrand disease **type 3**) or laboratory evidence (e.g. coagulation percentage) available. Take special care to respect the confidentiality of the identity of each patient and to keep the collected forms well organized and secure.

These registry forms provide valuable data about the identified patient population. Even if you have a small patient population, you can analyze these data and prepare a brief presentation with graphics outlining which bleeding disorders have been diagnosed, where patients live, and the centres where they receive treatment. This presentation will





be a powerful tool which you will use frequently in your exchanges with collaborators and decision makers.

With these data you can also start to fill out the WFH Annual Global Survey (AGS). Even if you cannot answer all of the questions, any data you can provide for this annual international survey is very helpful to the work of the WFH and to all its members. The results are published every year ([www.wfh.org/en/data-collection](http://www.wfh.org/en/data-collection)) and available in an interactive online tool ([www.wfh.org/en/resources/annual-global-survey](http://www.wfh.org/en/resources/annual-global-survey)) to help you make the graphs for your presentation. You will need to update your files and your presentation periodically, and the AGS is the perfect opportunity to do this. Try to add a bit more information every year (<http://www1.wfh.org/globalsurvey/>).

#### Related WFH Resources

*Benefits of a national patient registry. WFH Fact Sheet #5, WFH, 2007.*

*Quality data collection, WFH Fact Sheet #8, WFH, 2014.*

*Evatt B. Guide to developing a national patient registry, WFH, 2005.*

### 5. Extend your network to other cities or rural areas



Reaching out to other individuals and groups will grow and strengthen your NMO.

Seek out people with bleeding disorders and clinicians who treat them in other cities or rural areas. You can help them to identify their priorities and to develop their own activities.

Make sure that you do not lose

contact with them; your outreach efforts strengthen their development too. Together, a network of organizations can achieve greater results, especially when it can demonstrate strong collaboration and communication between its members.

Finding other patients might seem challenging at first, but you will probably find that patients in your own organization have relatives with bleeding disorders in other cities or regions; this is an excellent way of identifying people outside your local area. Social media also provide means for people with bleeding disorders to connect, even if they live far away from each other.

You have much more in common with other organizations than you might think. They may even have already heard about your organization's activities and be interested in carrying out similar projects in their own region. These alliances can last a lifetime, and together you may initiate projects at a regional or even national level!

#### Related WFH Resource

*Donnelly J. Patient outreach guide for hemophilia and other bleeding disorders, WFH, 2008.*

### ■ CONCLUSION

Your NMO is facing exciting and challenging times. There are a great many issues that you and your members would like to tackle, but also significant challenges of limited resources and time, and differing priorities. Build a strong team dynamic, determine your priorities



together, and embark upon carefully chosen projects that allow you to make an impact with your available resources. With these steps, you will be well on your way to establishing your NMO as a strong advocate for the diagnosis and treatment of bleeding disorders. Your team will be inspired by the success of those initial projects and, together with your new collaborative partners, you will be empowered to aim a little higher every year.

World Federation of Hemophilia  
1425, boul. René-Lévesque O. Bureau 1010  
Montréal, Québec H3G 1T7 Canada

Tel. : (514) 875-7944

Fax : (514) 875-8916

E-mail: [wfh@wfh.org](mailto:wfh@wfh.org)

Internet: [www.wfh.org](http://www.wfh.org)

The bottom half of the page features a solid red background. Overlaid on this background are several large, semi-transparent circles of varying shades of red, creating a pattern of overlapping shapes that resemble a stylized molecular or cellular structure.