



# Patient Outreach Guide for Hemophilia and Other Bleeding Disorders

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## **Dedication**

To the memory of Line Robillard, who opened the door for me to the world of hemophilia.

## **Acknowledgements**

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# Introduction

Hemophilia affects about 400,000 people worldwide and the prevalence of other bleeding disorders ranges from about 1 in 1,000 to 1 in 1 million. With treatment and proper care, people with bleeding disorders can live healthy and productive lives. Without treatment, bleeding disorders, particularly hemophilia, can cause crippling pain, severe joint damage, and life-threatening internal bleeding. Sadly, only about 30% of people with hemophilia have been identified worldwide, and the percentage is far lower for other bleeding disorders. Even fewer still receive adequate care.

Identifying people with bleeding disorders through outreach is the first step in treatment and is essential for improving care. Without diagnosis, people cannot receive the treatment they need, and without an accurate number of the people affected, governments are much less likely to provide funding for treatment and research to find better treatments or a cure.

Since 1998, the World Federation of Hemophilia (WFH) has collected data on the global hemophilia population annually. In recent years, the WFH survey has also gathered global data on people living with von Willebrand disease, other rare factor deficiencies, and inherited platelet disorders. The 2006 survey identified 208,006 people with bleeding disorders globally, but this is only a fraction of the actual number. For example, there were 48,276 people with von Willebrand disease identified in the 2006 survey, but it is estimated that the disorder affects about 1 in 1,000 people.

Outreach is vital to gain accurate demographic knowledge about bleeding disorders within a population. However, national hemophilia organizations, physicians, and health authorities often lack the necessary information and/or resources for effective patient outreach. Having a plan and breaking the process down into smaller steps makes an outreach campaign more manageable.

This guide is a practical tool to help national hemophilia organizations plan and carry out an outreach campaign to find new patients with hemophilia or other inherited bleeding disorders who have not been diagnosed or are underserved by healthcare services. The guide explains what patient outreach is, describes key steps as well as common challenges to patient outreach, and outlines strategies for effective campaigns. Case studies from different countries illustrate various approaches, the successes and shortcomings of these initiatives, and lessons learned. The approaches in this guide can be adapted to national and/or cultural contexts or to suit particular objectives.

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“In order to allow for the proper planning and development of health services, the establishment of a national registry of people with hemophilia is essential.

It is therefore a recommendation that priority be given to identification and diagnosis of affected people and their families and to the central registration of individuals with hemophilia and related disorders.”

Report of a Joint WHO/WFH Meeting on the Control of Haemophilia:  
Haemophilia Care in Developing Countries. Geneva, 16-17 June 1997.  
WHO: Geneva, Switzerland. 1998.

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# Section 1

## About patient outreach

### What is patient outreach?

Patient outreach involves identifying individuals with hemophilia or other bleeding disorders who have not yet been diagnosed or whose health needs are not being met by healthcare services. Patients can be identified through awareness-raising and education activities or by actively seeking out patients for diagnosis.

Patient outreach focuses on a targeted population, in this case people with hemophilia, von Willebrand disease or other hereditary bleeding disorder, with the aim of identifying them and providing them with proper treatment and healthcare services. Finding potential patients and arranging for diagnosis is usually done by organizing a patient outreach campaign within a specific community, country, or region.

An outreach campaign may include:

- Contacting known patients to find out if they may have relatives with a bleeding disorder who have not been diagnosed and referring them to a treatment centre for testing;
- Organizing a testing day in one or several cities or regions where people suspected of having a bleeding disorder can come for diagnosis;
- Conducting a workshop to educate specific physician groups (such as general practitioners, emergency room doctors, obstetrician/gynecologists) about the symptoms of hemophilia, von Willebrand disease, or other bleeding disorders and to encourage them to refer patients suspected of a bleeding disorder to a hemophilia treatment centre.
- Organizing an education or information session for women and men in the general population to raise awareness about bleeding disorders and their signs and symptoms.

Once patients have been found, it is important that the relevant information about each of them be recorded and maintained in a centralized database or registry. A registry is a key tool for tracking the number and diagnosis of people with bleeding disorders and monitoring their health, for long-term planning for hemophilia organizations, and for priority setting for health care. Having a national patient registry allows organizations to answer fundamental questions about the patient population and advocate for improved care. Without an accurate number of the people affected, governments are much less likely to provide funding for treatment and research. For more information on registries, see the WFH's *Guide to Developing a National Patient Registry*.

# The benefits of patient outreach

## **Identifies underserved or undiagnosed patients**

Identification is the first step in treatment. The greatest benefit of patient outreach is identifying patients whose needs have not been met.

## **Provides an accurate number of how many people are affected**

Patient outreach, followed by documentation of their medical condition and treatment in a patient registry, provides precise data on the number of people within a population who are living with bleeding disorders.

## **Supports advocacy for treatment and services**

Accurate information on how many people are affected in a given region is important for persuading governments and health authorities in that area to provide funding and services for their diagnosis, treatment, and organization of care.

## **Provides an opportunity to educate newly identified patients**

Outreach is a key opportunity to help newly diagnosed patients learn more about their bleeding disorder, its inheritance, treatment and care, and resources and strategies for maintaining good health.

## **Builds patient community support and advocacy networks**

Patient outreach promotes awareness of a national hemophilia organization and gives the patient association an important role in the community. By providing outreach and support to people living with bleeding disorders, the association fills a need and creates a sense of community.

## **Builds collaborative relationships with the medical community**

Working with the medical community to identify and diagnose patients can create a strong relationship between the patient association and treaters. Strong collaboration between the two groups is a key element for improving care.

## **Raises awareness of bleeding disorders and the patient organization**

Patient outreach campaigns can raise the profile of bleeding disorders and the patient organization in the general population.

## Section 2

# Organizing a patient outreach campaign

Organizing an effective patient outreach campaign can be broken down into 10 steps:

1. Establish your goal
2. Define your target population
3. Form a project team
4. Gain the support of the bleeding disorders community
5. Build alliances
6. Determine your strategy
7. Develop an action plan
8. Implement the plan
9. Follow up
10. Evaluate the outcome

These steps were developed from a review of publications on public health and patient outreach strategies, case studies from a number of countries with different levels of care for people with bleeding disorders, and interviews with leaders of national hemophilia organizations and World Federation of Hemophilia regional programs staff.

These steps provide the basic framework for organizing a campaign, but the campaign itself—the goal, the target population, the strategy, and the activities—will depend on the unique situation of the country or region involved. Different resources and different healthcare and cultural contexts must be considered. It is therefore important to adapt the campaign to the reality of the community where it will be carried out.

### Step 1: Establish your goal

It is important to clearly define the goal, or desired result, of the campaign. When tackling a large project, it is easy to lose sight of the goal and try to solve all the problems faced by a country's hemophilia population at once. Your goal may focus on:

- diagnosing new patients;
- building a national registry;
- finding an underserved population;
- raising awareness among general practitioners.

Your goal should be specific and measurable. It is also important to have a clear, realistic vision of what is achievable.

You may also have secondary objectives that will come about because of the campaign. These could be, for example, increasing collaboration with physicians, educating patients, or motivating individuals to become involved in the organization's work. The success of an outreach campaign is not demonstrated solely by the number of new patients identified, but by the growth of the organization.

***Example:** The Venezuelan Association for Hemophilia began its outreach project with the goal of gathering basic patient information and developing a national patient registry for hemophilia. The secondary goal of the campaign was to consolidate the country's hemophilia community.*

## Step 2: Define your target population

Determine not only how many people but also who you are trying to reach. It may be people with hemophilia, von Willebrand disease, other rare factor deficiencies, platelet disorders, carriers, and/or women with bleeding disorders. Also, be specific about the geographic area you want the campaign to focus on.

### How many new patients can you expect to identify?

If you are planning a campaign to test and diagnose patients, you need to determine how many new patients you can identify. This will depend on a number of factors: the expected number of people living with the disorder (called prevalence), the level of care in the country, the size of the country, and the distribution of the population.

#### Calculating prevalence of hemophilia

Without a registry, it is very difficult to know the exact number of people with hemophilia in the country. Although the proportion of people born with hemophilia (incidence) is usually the same globally, the proportion of people living with the disease (prevalence) varies from country to country depending on the level of care available. This is because without proper care, many people with hemophilia die young.

The WFH uses the following formula to calculate the estimated number of potential patients:

$$\text{Prevalence} = \left( \frac{\text{population}}{2,000,000} \right) \times 133$$

For example, in a country with 30 million residents, the estimated number of people with hemophilia would be about 1,995 individuals.

Based on the estimated prevalence in your country, set an attainable and realistic target number. It is unrealistic to think that all patients will be found. Keep in mind that the more difficult the living situation and inadequate the treatment, the lower the life expectancy of patients. Also, it is very difficult to find mild cases, because these patients rarely or never have bleeding problems. Therefore, the target number should not be too ambitious.

**Example:** When the Hemophilia Association of New Jersey (HANJ) started its registry project to identify women with bleeding disorders, there were 4 million women in New Jersey. The prevalence of bleeding disorders among women was estimated to be approximately 2%, or at least 40,000 women. If 10% of these women had a severe bleeding disorder, there would be an estimated 4,000 women with serious bleeding problems who remained undiagnosed. HANJ set its target population at 4,000 women with bleeding disorders.

### **Reaching underserved populations**

In some countries, the majority of people with hemophilia or other hereditary bleeding disorders have already been diagnosed, but there are still some communities or populations that are underdiagnosed or undertreated. This could be the case in areas that are far from large cities, where access to comprehensive hemophilia care is more difficult, or for members of a particular religious community or ethnic group that is rather isolated and is known to have undiagnosed or underserved individuals. Usually hemophilia treatment centres can help in identifying underserved communities or areas that should be targeted in the patient outreach campaign. This requires comparing the estimated number of people with hemophilia in the general population and the estimated number of patients in a particular area or who are of a particular ethnicity.

**Example:** While the U.S. is building a more comprehensive national patient registry and has a high level of care, a 1998 study by the U.S. Centers for Disease Control and Prevention (CDC) found that certain ethnic and cultural groups were not as well served as others. The National Hemophilia Foundation launched a Multicultural Task Force to help identify and reach these underserved populations. This led to an outreach campaign in Native American communities.

### **Determining the geographic area**

A countrywide outreach campaign encompassing the whole population and territory covered by national healthcare services is the best approach to get an accurate description of the number of people with hemophilia, von Willebrand disease, or other bleeding disorder. However, it is difficult to conduct a patient outreach campaign throughout an entire country at once, especially in a large country. Therefore, it is practical to divide the country into several regions and tackle them one by one. A national goal should be established, but the campaign can then be subdivided by region, province, state, or city.

There is a greater chance of success in areas with larger populations, because the more people you reach, the more people with bleeding disorders you will identify. Starting an outreach project in an urban area will bring better results.

A map is a very valuable tool for determining the regions in which to concentrate outreach efforts and for an overall understanding of the situation in a given country. The estimated and known number of patients in each region can be written on the map. This helps gauge how many patients remain to be found and determine the areas where the needs and the chance for success are the greatest.

**Example:** In Mexico, the Hemophilia Federation of the Mexican Republic (FHRM) began its outreach project in one region, Jalisco, because it had a well-structured patient association and a large urban population. After the success of this project, the FHRM is now doing a second outreach project in the national capital region, which has a high population density and the five largest national medical centres in the country for the treatment of hemophilia.

### Step 3: Form a project team

A patient outreach campaign is a major project that requires a great deal of time and effort. To lead the campaign, you'll need a strong project coordinator and a team that is dynamic, available, and ready to work. This team will be the core of the project. The strengths of each member must be utilized and tasks assigned according to each member's interests and skills, be it coordination, communications, education, medical knowledge, administration, logistics, etc. The project team should include members of the national patient organization and qualified health care providers.

All project team members should have basic knowledge of hemophilia and other target bleeding disorders, as well as political, cultural, or socio-economic awareness of the target population. Specific knowledge and expertise on medical issues, public health, advocacy, community outreach, communications, and administration are also needed. If the team members do not have all the knowledge or skills required for the work, you may want to organize workshops or information sessions and/or distribute relevant educational materials on the bleeding disorder(s), the state of care in the target community compared to elsewhere, patient outreach, public health, case studies, etc.

You may also want to bring in people from outside the organization who have the relevant expertise. This can include hemophilia treaters, laboratory specialists, educators, volunteers with experience in communications, and public health specialists.

As the campaign gains momentum, remaining open to the integration of new members in the team is important in order to build alliances and benefit from more people who can help.

Even though there is a project coordinator, the campaign cannot rest entirely on one person's shoulders. A campaign must be able to rely on the participation of all members of the project team.

If the patient outreach campaign, or a part of it, is conducted in a remote area, a local leader will need to be recruited to take care of logistics (reserving event space, coordinating snacks and refreshments, organizing transportation for patients, etc.), local media relations, and budget administration, since some things cannot be efficiently taken care of from a distance.

### Step 4: Gain support of the bleeding disorders community

It is important to obtain the support and help of key organizations that represent the bleeding disorders community—patient and medical—before launching a project on patient outreach. Without their support effective outreach will be difficult and it will be hard to make changes to improve care for people with bleeding disorders. Key partners in patient outreach are:

- Patient organizations for people with bleeding disorders
- Hemophilia treaters and treatment centres
- Health authorities and public health agencies

Other supporters may include other government agencies, blood collection agencies, pharmaceutical companies, etc.

In order to persuade stakeholders to support and participate in your campaign, the goal and benefits must be clearly communicated, as must the roles and responsibilities you would like each of them to take. Without the support of key partners, it will be difficult to complete the campaign. Once involved, all partners must be informed regularly of outreach activities, campaign progress, and results.

It is essential to share information on the campaign with the medical community involved in bleeding disorders, since they will be responsible for screening individuals identified through outreach. Their future workload will also be affected as more patients with bleeding disorders are found. Collaboration between the hemophilia organization and medical community is a major factor in successful patient outreach.

***Example:** In Venezuela, the Venezuelan Association for Hemophilia worked very closely with the physicians at the National Hemophilia Centre in Caracas when they started their outreach projects. The physicians not only provided information on any known patients, but also reviewed completed patient questionnaires, and accompanied the patient association on visits to regional hospitals to establish contact with local physicians and help encourage laboratory personnel and other healthcare professionals to participate in the activities. The National Hemophilia Centre was responsible for coordinating the medical and laboratory aspects of the campaign.*

Government authorities (namely the Health Department) should be kept informed of the campaign, since they will also be interested in the data that will be collected. They can sometimes help by providing resources (financial, human, and/or informational), encouraging hospitals and physicians to participate, or assigning civil servants to help ensure an effective campaign.

## Step 5: Build alliances

For a successful campaign, it is important to identify and build alliances with the groups, organizations, and individuals who have thorough knowledge of the target population. These include:

- Local physicians and hospitals
- Religious groups
- Charitable organizations
- Community organizations
- Red Cross/Red Crescent Societies
- Other organizations working in preventive health

It is important to develop alliances in the local medical community, including with physicians and hospital medical staff, in the region targeted by the outreach campaign. The local hospital can provide key support in the outreach campaign. For example, it could help publicize the campaign and provide space, equipment, and staff for diagnosis activities. There must be good coordination with the physician in charge and the rest of the medical staff.

Alliances with other community or patient groups are also valuable, and can be a great source of support for the campaign. The more that is known about a community, the easier it will be to understand its needs and norms. For example, cooperation could be sought from support groups, religious groups, charitable organizations, or non-governmental organizations working in preventive health.

Once these groups are identified, their leaders must be convinced of the importance of the patient outreach project. In order to obtain their support and participation, it is important to properly communicate the goal and benefits of the campaign and explain exactly how you would like them to help. Given their knowledge of the community, their involvement will increase your ability to reach target populations and help you identify people who could assist in the campaign.

***Example:** When the Hemophilia Foundation of Minnesota/Dakotas (HFMD) set out to identify people with hemophilia in Native American communities, the tribal elders played a key role. To build alliances with Native American communities, the HFMD created a Native American advisory committee for the project. The advisory committee made recommendations to the HFMD on the best outreach methods to use in these communities and also introduced HFMD volunteers to the community leaders.*

As with the project team, it is important to ensure that new allies receive basic training on hereditary bleeding disorders and the campaign itself so that they properly understand the importance of the outreach project.

If things work well, these allies may continue to be involved in the bleeding disorders community after the campaign has ended.

### **Tips for overcoming resistance**

In some instances, outreach projects may meet with some resistance, particularly in the case of HIV/AIDS screening. Confidentiality of patient information is also a major issue for both physicians and those who could potentially be identified as having hemophilia or another bleeding disorder. Resistance can be manifested as hostility, deception, delays, divergence, conflict, impatience, etc. Unfortunately, there is no easy way to overcome the stereotypes, fears, distrust, or misperceptions that may surround bleeding disorders in your target population. Therefore, each situation must be carefully analysed and approached. The following are a few ways to reduce resistance:

- Submit the project to those who are interested in order to benefit from their contribution and enable them to use it and adapt it to their situation.
- Highlight the advantages of patient outreach without obscuring the difficulties or shortcomings.
- Reduce the unknown as much as possible.
- Reduce sources of insecurity as much as possible.
- Find credible support.
- Inspire trust in your target population, through both the image of spokesperson and the quality of the project.
- Demonstrate openness to the possibility of review in the case of difficulties.
- Be receptive to avoid falling victim to power games with those who are not part of the project.

Adapted from: Colletette, P.,G. Delisle, and R. Perron. *Le Changement organisationnel : théorie et pratique*. Québec : Presses de l'Université du Québec, 1997.

## Step 6: Determine your strategy

Your strategy is the approach you will take to meet your goal. It is not possible to have a single outreach strategy that will work in all countries. Your strategy will depend on the needs, circumstances, and available resources in your country. The political, social, and cultural context of the country (or target population) must be taken into consideration—strategies that are effective in some countries may be inappropriate or have detrimental effects in others. You will also need to have good knowledge about the population being targeted by the outreach campaign.

To develop a strategy you must look at all these different elements, along with possible approaches and potential problems that will affect your campaign, to determine what path is most likely to succeed. The project team must carefully analyse the situation in order to develop the most effective outreach strategy for a particular population, based on its characteristics and available resources.

Some questions to consider when developing your strategy include:

- What is the goal or purpose of the campaign?
- What resources are available?
- Who is the target population and how will we find them?
- How will people suspected of having a bleeding disorder be tested or diagnosed?
- What data will be collected?
- How will information on newly identified patients be collected, recorded, and managed?
- How will we ensure participation in the campaign or activity?
- What support and services will newly identified patients need and who will provide them?

### **What is the goal or purpose of the campaign?**

Look back to the goal you identified in step 1. Your strategy is founded upon this. Is it to diagnose new patients, to build a national registry, to find an underserved population, or to raise awareness of bleeding disorders among general practitioners and others?

### **What resources are available?**

Look at the human and financial resources available for this campaign. This will help you determine the scope and complexity of your campaign.

Develop a list of the major activities involved in the successful completion of your outreach campaign. Indicate the number of people you will need and the range of expertise of each.

Before starting a campaign, you must make sure you have enough financial support to carry out the outreach activities. Some governments, institutions, and patient or community organizations can help by providing resources such as meeting rooms, expert or technical assistance, volunteers, or grants. For example, you could contact:

- Colleges and universities
- Churches/synagogues/mosques/temples
- Community health organizations
- Public health agencies and organizations

- Hospitals
- Blood collection agencies
- Hemophilia treatment centres
- Pharmaceutical companies
- World Federation of Hemophilia
- Philanthropic foundations

For more information on fundraising, consult the WFH publication *Fundraising*.

### **Who is the target population and how will we find them?**

If you are conducting a campaign to identify patients, consider what sources of information are available. Sources include registries or records kept by treatment centres, physicians, hospital emergency departments, blood banks, or patient organizations.

Contacting known patients to see if they have other family members who may have a bleeding disorder is also an effective strategy. At the time someone is diagnosed, other cases of hemophilia in the family may not be known. Discussion with patients and their families, asking the right questions, may reveal that other family members have or have had bleeding problems that were never diagnosed. The family network is always a good place to start.

*Example: In the Republic of Georgia, one of the challenges was contacting patients living in remote areas. Volunteers from the Georgian Association of Hemophilia and Donorship conducted targeted door-to-door searches to find patients.*

### **How will people suspected of having a bleeding disorder be tested or diagnosed?**

If your outreach campaign involves diagnosis and testing, you need to think about how this will be done. Will individuals presenting with symptoms be directed to visit a treatment centre to be tested? Will diagnosis clinics be organized? Will there be a medical team making home or community visits to perform testing?

It is important to consult the medical team and establish basic medical criteria before performing tests in order to avoid unnecessary testing of people who do not display any symptoms of hemophilia, von Willebrand disease, or other bleeding disorders. The products required to perform tests are costly and resources must not be wasted. Furthermore, it is possible to become discouraged when many tests are performed but only a few patients receive a positive diagnosis. Sometimes financial supporters and other partners also see this as a lot of work and resources for few results. For more information on diagnosis, see the WFH laboratory manual *Diagnosis of Haemophilia and Other Bleeding Disorders*.

Another consideration is how you will motivate physicians and medical personnel to get involved. In some cases a prominent doctor may be able to encourage others to get involved; in other cases you may have to provide an incentive.

*Example: In the Republic of Georgia, general practitioners received US\$10 when a patient they referred was diagnosed with hemophilia.*

### **How will information on newly identified patients be collected, recorded, and managed?**

Consider what data should be collected and how the information will be collected, recorded, and managed. There needs to be a registry in place and a process for updating and continuing to add newly diagnosed patients to the registry. If this is not well maintained, there is no point identifying the patients in the first place.

### **How will you ensure participation in the campaign/activity?**

Consider how you will publicize and promote the campaign, and how you will ensure that people will show up. Think about reasons why someone may have difficulty getting to the activity, and ways to overcome them. For example, should transportation be provided? Are babysitting services needed? Should the activity take place on the weekend when most people are not working?

### **What support and services will newly identified patients need and who will provide them?**

Keep in mind that a diagnosis of hemophilia or another bleeding disorder can have a major impact on the life of an individual and their family. Consider:

- How are the results disclosed to the patient and family members?
- What basic information about treatment and challenges should be given at the time of diagnosis?
- What services and educational resources are available to newly diagnosed patients?
- How is the emotional impact of the diagnosis handled?
- Who can give advice on healthy living, including exercise and emotional support?
- Who can explain the patient's rights (local legislation and available health services) and suggest ways to deal with issues that may arise? The patient and the family may face problems related to confidentiality, stigmas regarding hemophilia, and discrimination.

## **Step 7: Develop an action plan**

Once you have determined a strategy for how you want to approach the campaign, develop a detailed action plan outlining specific objectives or activities you need to do. Having a plan ensures that everyone is working toward the same common goal and ensures that no key steps are forgotten.

Your objectives should be specific and measurable. At the same time, they must be flexible. It is a good idea to regularly review the objectives as the campaign progresses.

Possible objectives or activities include:

- Setting up meetings with key stakeholders to persuade them to participate in the outreach campaign;
- Developing a questionnaire to gather information from patients;
- Organizing educational workshops to inform newly diagnosed patients and their families about bleeding disorders;
- Organizing a telephone campaign to contact already identified patients to see if they may have relatives with a bleeding disorder who have not been diagnosed;
- Holding a testing day in one or several cities where people suspected of having a bleeding disorder can come for diagnosis;
- Conducting a workshop to educate physicians about bleeding disorders;
- Creating a publicity campaign to raise awareness about the outreach project or bleeding disorders in general;
- Developing posters and publications about bleeding disorders.

For each activity on your action plan, identify the task, person responsible, amount budgeted, and a realistic timeframe for completing the activity. Also make sure that you have a way to measure the activity's success. If, for example, you are distributing a questionnaire, your measure of success may be that 80% of patients contacted fill in the questionnaire. For more information on developing an action plan, see the WFH publication *Action Planning*.

### **Human resources**

For a successful outreach campaign, you must have adequate human resources for every step of your action plan, and each member of the project team (as well as all volunteers) should receive the resources they need to be successful. Be careful not to overwhelm them with too much work or unreasonable expectations.

For each activity or task, identify the range of expertise and number of people required. Responsibilities should be assigned according to the skills of each team member and based on the various stages of the campaign. For example, Who will be the spokesperson? Who will bring the publications to distribute? Who will oversee the collection of information on newly identified patients? Who will be on hand to answer questions from patients, their families, or physicians? Who will compile the information obtained? Who will take care of snacks and refreshments?

It is essential to have skilled medical experts draw blood and to have trained and meticulous laboratory personnel analyse the blood samples in properly equipped lab facilities with the required diagnostic materials. If the wrong diagnosis is given to a patient, he or she will not receive the proper treatment and a life will potentially be put in danger.

Depending on the project, you may need to recruit more volunteers. A good place to start is the hemophilia organization, whose volunteers or staff are usually people with hemophilia or family members, healthcare providers, and others who support the cause. Most of them will have some knowledge of bleeding disorders and some commitment to the cause.

It is especially important to assign detailed responsibilities covering all aspects of the day or days when the outreach activities will take place to ensure a smooth and successful campaign.

### **Budget**

Develop a detailed budget listing the project costs of each activity (publicity, educational materials, medical materials, event space, transportation, equipment, meals and/or refreshments, administrative expenses, etc.). In some cases, financial compensation may be needed for travel costs (for team members, volunteers, individuals thought to have a bleeding disorder).

### **Timeline**

It is important to develop a schedule of all the steps and activities in the campaign. The dates and deadlines should be practical and take into account the schedules of team members and other key volunteers, and dates and timeframes suitable to the target population. In some cases, more time will be needed to raise awareness and persuade people about the importance of outreach towards improving care for patients. Building this type of support is rarely achieved quickly. Sufficient time must be invested to educate the population if there is little knowledge about the symptoms and effects of bleeding disorders, and the benefits of treatment. Otherwise, it will be hard to secure the support needed from key partners.

## Communications and publicity

Strong communications and publicity expertise is essential to successfully promote the campaign. A communications plan with a concise message and appropriate communication tools need to be developed. Communications tools may include posters, pamphlets, educational materials, information booths, press releases, newspaper articles, and radio and television interviews.

***Example:** In New Jersey, the Hemophilia Association of New Jersey (HANJ) identified healthcare professionals working in schools and on university campuses, family doctors, obstetricians and gynecologists, and healthcare organizations in target communities and sent them letters introducing the registry project. Information booths were set up at health-related events in order to raise awareness, generate dialogue, and develop contacts.*

*HANJ developed a webpage and publications to increase awareness and access to information on women and bleeding disorders. Information was sent to schools and health organizations. A seminar on bleeding disorders was developed specifically for physicians who see a large number of female patients.*

One of the keys to successful communications is to know your target audience and adapt your communications accordingly.

***Example:** The Venezuelan Association for Hemophilia (AVH) developed and distributed posters describing hemophilia using simple language and adapted it to the regional culture, to raise awareness and reach more people. However, with experience, AVH found that when very general symptoms were described, people often wanted to be tested even though their problem was not related to hemophilia.*

The media (newspapers, radio, and television) are often valuable for helping communicate basic facts to the public and publicizing the patient outreach campaign—media relations should be part of the communications plan. However, before doing any media relations, make sure you have a well-developed message and a strong spokesperson who can present your message well.

On the day of an event, it is important to have posters and signs that clearly indicate where the event is taking place. Sometimes putting arrows on the floor or walls to guide the way is helpful. If volunteers are available, they can welcome people and bring them to the right place.

It is also important to have publications available to inform those in attendance about hemophilia and/or other bleeding disorders. (For example, the WFH booklet *What is hemophilia?* is available in English, Spanish, French, Russian, Arabic, and Chinese.) Medical publications intended for physicians and medical specialists tend to be too complex for the general public but would be useful for a medical audience.

## Planning for the day of the activity

Depending on your event or activity, you may need to arrange for space at a hospital or clinic for testing, or rent a room for a workshop or information session. You will also need to make arrangements to have all the necessary materials available in time for your event.

Plan in advance to make sure you have everything you will need on the day of the activity. Compile a list beforehand of everything that is required (for example, posters, signs, publications on hemophilia and other bleeding disorders, pamphlets on the national hemophilia organization, questionnaires, pens, etc. Be sure that healthcare professionals bring the necessary materials, such as disinfectant, syringes, laboratory manuals, etc.)

## Step 8: Implement the plan

Once the plan is developed, the next step is to carry it out. This involves making all the arrangements to carry out the plan: finding and training volunteers or staff to do the work, finding a place to hold the event, making sure all the materials needed are available, and publicizing the event.

### Monitor progress

As you implement the plan, the project team should meet frequently to make sure it is being carried out as planned and to make adjustments where needed. For example, a key speaker or medical specialist may unexpectedly be unable to attend a workshop, someone attending an activity may have special needs, or you may need to recruit more volunteers. Continual monitoring is a way for the team to take stock and make adjustments to ensure a successful campaign.

Common errors include:

- Lack of organization
- Insufficient/inadequate partnerships
- Poor planning
- Unrealistic timeline and goals
- Inadequate training
- Unreliable testing and diagnosis
- Inappropriate communications materials

### Keep staff and volunteers motivated

It can sometimes be difficult to maintain volunteer commitment and motivation throughout the project. It is important to ensure that they get satisfaction from their volunteer work and understand the importance of their support of the campaign.

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“People volunteer for a variety of reasons. Some volunteer because they believe in the cause or want to help people. Others volunteer for social reasons or to learn new skills... Once volunteers have been recruited, the key is to keep them. The best way to ensure that volunteers maintain motivation is to make sure that they get satisfaction from their volunteer work and do not feel taken for granted.”

—Mohamed Aris Hashim, *Recruiting and Retaining Volunteers* (WFH, 2003)

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**Example:** *The main challenge faced by the Hemophilia Federation of the Mexican Republic (FHRM) team was loss of motivation among volunteers. In order to make up for this lack of human resources, the FHRM asked 20 newly identified patients to help by having each one find and refer one new patient. Since the patients often had a parent or distant relative with hemophilia, or a friend with hemophilia met during a hospital stay, the FHRM was able to achieve its target number.*

There needs to be good communication among the project team, staff, and volunteers. People are much more motivated if they know what is expected of them and are kept informed of what is going on. Each person’s responsibilities should be clearly stated and everyone should have a clear understanding of the project and their role in it.

*Example: The Hemophilia Foundation of Minnesota/Dakotas in the U.S.A. organized outreach training sessions for volunteers, so that they would be proficient at explaining the project, its objectives, and the overall action plan.*

Receiving praise and recognition is an excellent way to keep people motivated. When an objective or activity is successfully achieved, be sure to congratulate those responsible.

### **Ensure high turnout for the activity**

Good publicity is critical to ensure a good turnout and successful campaign. People often dislike having their blood taken or do not want to be told that they are sick; some situations may require intensified efforts or incentives. Patients and individuals who may have hemophilia may need to be persuaded to participate in outreach activities by describing the importance and benefits of the campaign.

*Example: In Mexico, the Hemophilia Federation of the Mexican Republic (FHRM) distributed 250 posters on the outreach and patient registry initiative to public hospitals in the larger cities in the Jalisco region. Several patients who were not registered contacted the FHRM after having seen these posters and completed the questionnaire.*

Also take into account and plan for factors that may prevent people from showing up. These include:

**Time off work:** Sometimes, individuals may not be able to afford or get time away from work. A grant or small remuneration may enable such individuals to participate. Holding events in the evening or on weekends, or even information tables over the lunch hour during the workday, can enhance a campaign's effectiveness.

**Transportation:** In some areas, distance or travel costs may be obstacles to participation. There are a number of ways to overcome this. Depending on resources, rent a van to pick up the people who live the farthest away, coordinate a ride-sharing system, or offer to reimburse transportation costs (train or bus ticket).

**Childcare:** Some people cannot come on a given day because they cannot leave their children home alone and there is nobody available to care for them. A childcare service will help ensure the full attention of parents during presentations on hemophilia, von Willebrand disease and/or other hereditary bleeding disorders. Information sessions are more effective without restless or crying children. If testing will be provided onsite, this would also encourage parents to bring along their children for testing too.

**Language:** When a different language or dialect is spoken in the target region or community, it is best to hire an interpreter to avoid any communication issues or harmful miscommunication and misunderstanding.

### **Have a contingency plan**

When developing and implementing the plan, the project team should anticipate possible challenges and obstacles in advance and plan solutions for how to deal with them as they arise. It is important to compile a list of everything that could represent an obstacle to the smooth conduct of outreach activities and develop a contingency plan. Think of how you will communicate problems and changes to the campaign plan, the roles and responsibilities of team members, and instructions for volunteers.

## Document progress

It is important to document the progress and challenges encountered throughout the outreach campaign to be able to track where resources were spent and to learn which activities were successful and which fell short. Documentation should be kept for future reference or outreach initiatives. These records can be useful to other organizations wanting to develop a similar campaign in another region or country, thereby sharing the best practices and lessons learned.

## Step 9: Follow up

Once new individuals have been identified through the patient outreach campaign, ensure that they have access to treatment and go to the hemophilia treatment centre for regular check-ups. It is also important for them to be connected to the hemophilia organization and benefit from its support and services.

***Example:** To ensure that newly diagnosed patients received adequate treatment, the hemophilia treatment centre in Tbilisi, Georgia, followed up by calling them if they did not visit the centre within three months of their diagnosis.*

Another key area for follow-up is to make sure that the patient data collected is entered into a registry and that the registry is maintained. For more information on developing a national patient registry, please see the *WFH Guide to Developing a National Patient Registry*.

Also remember to thank all those who helped make the campaign a success. Send thank-you letters to volunteers and those who helped fund the campaign.

## Step 10: Evaluation

At the end of the patient outreach campaign, the project team needs to do a thorough evaluation to measure its success and shortcomings. A proper evaluation will help determine which activities produced results, which were less effective, and which would improve subsequent patient outreach campaigns (for example, on other bleeding disorders or other public health matters). If the strategy has been well planned, evaluation will reinforce the organization's integrity and the importance of the outreach project and the data collected. This is very valuable for maintaining key partners and attracting new supporters to help advocate and lobby for comprehensive care for hemophilia, von Willebrand disease, and other bleeding disorders.

***Example:** At the end of its outreach project, the Hemophilia Federation of the Mexican Republic had identified 614 people with hemophilia living in the Jalisco region, 72% of the estimated total, and had up-to-date information on 74% of all known patients in the region.*

***Example:** In the Minnesota/Dakotas region of the U.S.A., because newly identified patients were not distinguished as such in the registry, it was difficult to assess the actual results of the project, and this led to the project's termination.*

The evaluation should assess the original goal of the patient outreach campaign and each activity, including resources invested and outcomes. For example:

- Was the expected number of new patients identified? (This is an important measure of success.)
- Was information gathered on newly identified individuals?
- What knowledge was gained by participants as well as organizers?
- Did members of the organization, project team, and volunteers work effectively together?
- What unexpected challenges arose and how were they dealt with?
- Were individuals referred to organizations, treatment centres, and available services and resources?
- Were outreach activities effective? (Review all aspects including telephone or mailing campaigns, distribution of publicity materials such as posters and pamphlets, requests for information from newly identified patients or their physicians, etc.)
- Were the actual costs of the campaign within the projected budget?
- What follow-up has taken place?
- What aspects could be improved for future outreach activities?
- Are there potential new partners in patient outreach and improving hemophilia care?

Evaluation provides valuable quantitative data as well as qualitative information, such as how patient outreach with subsequent care substantially improves health, quality of life, and productivity for people with hemophilia and other bleeding disorders.



## Section 3

# Case studies on patient outreach

Case studies are a useful way to present successful models of patient outreach and registry campaigns, with best practices for both quantitative results (number of patients identified) and/or qualitative outcomes (integration of new patients in the national hemophilia organization or improved care). The collection of qualitative information is important because it provides descriptions and explanations of local contexts—this knowledge is essential in strategy development.

The following cases present different outreach strategies and experiences, and some of the lessons that have been learned.

## Venezuela: Partnership between patient and medical groups

At the beginning of the 1990s, the Venezuelan Association for Hemophilia (*Asociación Venezolana para la Hemofilia*, AVH) wanted to know how many people with hemophilia were living in the country and where they were located. Until that time, the only data compiled were noted in a small notebook by physicians at the National Hemophilia Centre (*Centro Nacional de Hemofilia*, CNH) in Caracas, which listed 495 patients. However, the information was limited and in most cases had not been updated since the patient's first, and sometimes only, visit to the hemophilia centre.

The AVH began seeking ways to track down and confirm the patients listed. Collaboration with the medical community was key in this endeavour. Physicians searched their medical archives for the names of patients. Using this information, AVH volunteers searched for each individual with the goal of gathering basic patient information and developing a national patient registry for hemophilia. The process was very slow, however, and very little information was found.

The AVH and physicians at the CNH decided to develop an outreach campaign to identify patients more effectively, add them to the patient registry, and educate them about treatment and care. The outreach campaign was initially called Operation Progress and became Operation Consolidation in later phases. The primary goal of the campaign was to determine the precise number of people with hemophilia in Venezuela in order for the AVH to properly represent patients to health authorities when advocating for better treatment and care. In all discussions to date with government representatives, the AVH was asked how many people in the country had hemophilia—having an accurate figure is important for effective advocacy because it is the starting point for figuring out the resources that will be needed to provide care for the hemophilia population. Another goal of the outreach campaign was to consolidate the country's hemophilia community.

They started by determining the information that would be useful to the AVH and developing a questionnaire. The patient information section of the questionnaire was completed by patients who came to the medical clinics or meetings with AVH members, and physicians then completed the medical information section. Since some patients did not know how to write, volunteers were always present to help them answer questions. The AVH then forwarded the information to

CNH physicians to verify and ensure a proper, accurate diagnosis (several recently diagnosed individuals did not know if they had hemophilia A or B and sometimes patients reported the wrong blood type). Mutual trust was key in this collaboration between the AVH and CNH.

At the same time, regional chapters of the AVH began to form throughout the country and began forwarding information about new patients to the national hemophilia organization. In each region, one person was designated to ensure that all known patients completed the questionnaire and sent the information to the AVH.

However, there remained a number of people living with hemophilia who were not yet diagnosed and therefore had no access to treatment. Visits to the regions were organized to test people suspected of having hemophilia and make an accurate diagnosis. These regional visits were also a way to educate patients and families in outlying areas about hemophilia and the importance of belonging to an organization such as the AVH.

AVH leaders accompanied by CNH physicians involved in the project made preliminary visits to regional hospitals to establish contact with local physicians who knew individuals presenting with symptoms or with a family history of hemophilia. They also met with healthcare professionals who could play a key role in persuading patients to attend an outreach and diagnosis workshop sometime in the future and eventually treat newly diagnosed patients. Contact was also made with the laboratory personnel to ask them to participate in outreach activities (for example, by taking the blood samples, storing them under appropriate conditions, and sending them for tests in instances where testing could not be performed onsite). The CNH was responsible for coordinating the medical and laboratory aspects of the campaign.

The local organizing committee (project team), composed of patients and physicians involved in regional AVH chapters, was responsible for inviting patients and their families, as well as individuals suspected of having hemophilia, to the testing day. The AVH developed and distributed posters describing hemophilia using simple language adapted to the regional culture, to raise awareness and reach more people who may unknowingly be affected.

With experience, the AVH found that when very general symptoms were described, such as nose bleeds or bleeding gums, there were often several people who wanted to take the tests even though their problem was not related to hemophilia. Also, in order to target people who were more likely to suffer from hemophilia, an age limit was sometimes imposed (few people with untreated hemophilia live to age 50, for instance). For this campaign, the target population was therefore young males with symptoms of hemophilia, their mothers, and adult family members without a confirmed diagnosis.

Other publicity tools included advertisements on popular regional radio stations and local television stations and in local newspapers; posters on hospital bulletin boards and in pharmacies; and information distributed through churches or community organizations. In Venezuela, radio seemed to have the greatest reach and was most effective in drawing people to participate in the campaign.

On the diagnosis day, basic information on hemophilia (including educational publications from the WFH) was distributed. The AVH showed a video on hemophilia followed by a discussion period during which participants could ask questions as well as express their doubts and fears to physicians and AVH leaders. Once the tests were conducted and diagnosis completed, patients were contacted by their physician, who was in charge of conveying the diagnosis. The local chapters of

the AVH then contacted the patients to invite them to future activities and explain the importance of having their updated data in the AVH registry.

The AVH took the opportunity during visits to the regions to hold workshops to help patients and families understand that its leaders, who are all volunteers, work to defend their right to treatment and represent them before health authorities. New members were told about the importance of their support of the AVH and physician involvement in order to achieve the best treatment for all. Individuals with bleeding disorders and their family members learned about how they could play a part in their organization and help achieve common goals.

The AVH outreach campaigns led not only to the identification of the vast majority of people with hemophilia in Venezuela, but also to unifying and strengthening Venezuela's hemophilia community, which is now one of the strongest and best organized in the world. The amount of information collected demonstrates the AVH's strength and caliber. Today, more than 2,700 individuals with hemophilia, von Willebrand disease, and other bleeding disorders are registered in Venezuela, and about 60 new patients are identified every year.

Furthermore, associations representing other diseases (HIV, cancer) in Venezuela are now following the AVH's patient outreach model for data collection towards improving care for patients.

## **Mexico: Pilot project towards a national registry**

In 2001, when the patient outreach and registry project to identify new patients was launched in Jalisco, Mexico, only 231 patients (41%) were known to the Hemophilia Federation of the Mexican Republic (*Federación de hemofilia de la República Mexicana*, FHRM), though there were an estimated 614 people with hemophilia living in the region. At the end of the project four years later, 444 were identified, that is 72% of the estimated total, with up-to-date information on 74% of all known patients in the region.

The FHRM first chose to conduct its pilot project in the Jalisco area because it had a well-structured patient association with 20 volunteers ready to work on the project and physicians available to act as project consultants. The region also had a large urban population and its geography did not present any major hindrances to communication.

Since most patients in Mexico already knew their diagnosis, few tests had to be done compared to other countries where many individuals had not yet been diagnosed. The challenge in Mexico was to incorporate all individuals with hemophilia into a national patient registry; until this effort, such data had never been consolidated or centralized. Unfortunately, although most patients with hemophilia were known by physicians, few were referred to the FHRM because healthcare staff did not see the importance of grouping patients under a national association. The FHRM therefore had to seek out all individuals with hemophilia individually. This is why the project was titled “1,2,3 *por ti*,” the Spanish equivalent of the game “Hide and Seek.”

In order to find these new patients, FHRM volunteers met with physicians at the three major hemophilia treatment centres in the region and asked for a list of their patients being treated for hemophilia. Physicians were not always willing to share this data, so a renowned physician in the region and a FHRM supporter helped promote the project; he wrote to physicians in treatment centres to explain the importance

of the registry project and ask them to share their data with the FHRM. With this introduction, it was easier for FHRM volunteers working on the project to follow up with physicians and obtain patient lists. Since medical information is confidential, physicians only shared patient names, types of hemophilia, and telephone numbers. FHRM volunteers then contacted the patients to complete the FHRM questionnaire, and the data collected were compiled in the national registry. The data collection process sometimes took more time than expected, however, because some physicians were still hesitant to share information, or because some hemophilia treatment centres did not have an up-to-date patient registry and needed time to look up patient names in the hospital archives. The FHRM also signed agreements with hemophilia treatment centre administrators to ensure that hemophilia treatment centres would transmit information on new patients in the future.

In addition, 250 posters on the outreach and patient registry initiative were distributed and displayed in public hospitals in the region's larger cities. Several patients who were not registered contacted the FHRM after having seen these posters and completed the questionnaire.

When a newly identified individual completed the questionnaire, a lot of emphasis was placed on determining whether other members, living or deceased, might have or have had hemophilia. This was a good way to find other family members—immediate or distant—with hemophilia who could then be followed up by telephone.

The main challenge faced by the FHRM team was loss of motivation among volunteers, particularly because some members had to leave the project along the way. In order to make up for this lack of human resources, the FHRM decided to ask 20 newly identified patients for help by having each find and refer one new patient. Since these patients often had a parent or distant relative with hemophilia, or a friend with hemophilia met during a hospital stay, the FHRM was able to achieve its target number of newly identified patients. Each volunteer was asked to refer only one patient, so that the task would be achievable.

Now in the second phase, the FHRM is continuing its outreach project in the national capital region, which has a high population density. It will be much easier to identify new patients there, especially since the capital has the five largest national medical centres in the country for the treatment of hemophilia. With the lessons learned from the pilot project in Jalisco, the FHRM is considering recruiting university students in social work, medicine, sociology or nursing who must complete an internship or volunteer work, to compensate for the lack of volunteers. The FHRM may also include data on female hemophilia carriers in the patient registry, as is already done in Ecuador and the Dominican Republic.

The FHRM learned a number of lessons from the pilot project in Jalisco, Mexico. Travelling to patients' homes to have them fill out the questionnaires required a great deal of time and money—better results were obtained by going through hematologists, treatment centre administrators, and hematology clinic managers. It was also more efficient and economical to have new patients complete questionnaires by telephone. Generally, it was easier for patients and families to complete the questionnaire themselves. It is useful to ask individuals if they have any questions about the organization and its activities as well as hemophilia, and its treatment and care.

The national patient outreach and registry project in Mexico was very important to discussions between the FHRM and Mexican health authorities aimed at providing the country's population with hemophilia with better access to treatment. The FHRM succeeded in updating the data on people with hemophilia in its registry and has seen a 100% increase in member participation at its annual general meeting.

## Republic of Georgia: Door-to-door outreach

In this small, mountainous country in the Caucasus with 4.5 million residents, the estimated number of individuals with hemophilia was 350 in 2001, but only 120 of these were known. That year, the Georgian Association of Hemophilia and Donorship (GAHD) decided to embark on a project to create a registry of patients in order to verify the diagnosis of those who were known and to identify new patients in the country's remote areas.

Before launching the project, the laboratory technician at the Hematology and Transfusion Institute treatment centre in Tbilisi who performed the diagnostic tests for hemophilia was trained abroad to ensure that proper lab practices and principles were observed. All patients in the country would be tested at the Tbilisi centre, given the short distance between the capital and rural areas. Some of those with hemophilia had already been diagnosed, but the accuracy of their diagnosis was debatable. All patients were to be re-tested to ensure they were accurately diagnosed and thus optimize their treatment. One person was also hired to manage and centralize the data collected.

The first step of the project was to contact by telephone or mail the individuals suspected of having a bleeding disorder that were already known to the GAHD and/or the Hematology and Transfusion Institute, and to refer them to the hemophilia treatment centre for diagnosis and assessment. From the start, collaboration between the GAHD and the hemophilia treatment centre was an important element of the project. In this case, their work was facilitated by the fact that they were located in the same building.

GAHD volunteers then contacted physicians at several hospitals to request the names of individuals suspected of having a bleeding disorder. These patients were contacted and referred to the hemophilia treatment centre in Tbilisi for diagnosis. In addition, the laboratory technician and a hematologist participated in radio and television programs to discuss the patient registry project and the effort to reach unidentified patients.

The GAHD also sought support at the government level, and the Health Department collaborated by asking medical institutions in various regions to refer patients suspected of having a bleeding disorder to the hemophilia treatment centre in Tbilisi for testing.

An effective method proved to be remuneration of US\$10 to general practitioners when a patient that they referred was diagnosed with hemophilia.

Each new positively diagnosed patient was entered in the patient registry, with care being taken to note the name and information of family members who may also have hemophilia in order to follow up and test them as well.

One of the challenges faced by the GAHD was contacting patients living in remote areas, with whom communication was very difficult. In small villages or rural centres, GAHD volunteers conducted targeted door-to-door searches to find patients, staying overnight with families in order to continue their outreach work in villages. Subsequent analysis of the data collected indicated that, contrary to general population trends (52% urban, 48% rural), people with hemophilia in the Republic of Georgia are more concentrated in urban areas (72%) than rural areas, likely due to better access to emergency care in an urban setting.

Most of Georgia's roads are not paved, which was often a problem for transporting people to the capital for testing at the hemophilia treatment centre. Furthermore, it was at times a significant challenge to convince them to go all the way to Tbilisi to undergo diagnosis, especially for those whose hemophilia was not severe and caused few problems. Therefore, regional volunteers were designated to look for unidentified patients and were paid a small allowance for each new patient that was diagnosed due to their efforts. This remuneration was a way to encourage volunteers, often patients themselves, to be more active in remote areas. In certain cases, the GAHD also covered transportation fees to the capital for individuals suspected of having hemophilia so that they could all be properly diagnosed.

To ensure that the newly diagnosed patients received adequate treatment, the hemophilia treatment centre in Tbilisi followed up by calling them if they did not visit the centre within three months of their diagnosis.

During their outreach work, GAHD volunteers also experienced very sad situations where discrimination regarding hemophilia further complicated efforts. For example, during a visit to a rural area, a volunteer met a family where the father did not know that his son had hemophilia, although the mother and son were aware of the bleeding problem. Ashamed that she was a carrier of hemophilia, the mother and her family preferred to keep the son's condition a secret and hide it from the father. The role of the GAHD is also to dispel prejudices and misconceptions by educating patients and families.

Along the way, the GAHD adjusted its objectives because, due to political change, the provinces of Abkhazia and South Ossetia separated from Georgia, and the people with hemophilia living in those areas could no longer be reached.

The active search phase for new patients is now over, and the majority of patients with severe or mild hemophilia have been identified and diagnosed. Since information on hemophilia was widely distributed throughout the country, GAHD now expects that new patients will automatically be referred to the hemophilia treatment centre in Tbilisi for intensive treatment, and to other referral centres for minor treatment.

## **United States: Strategies for identifying underserved patients**

Hemophilia knows no borders and affects people from every culture and ethnic background. However, in 1998, a study conducted by the Centers for Disease Control and Prevention (CDC) found that certain ethnic and cultural groups living in the United States were not as well served as others. Recognition, diagnosis, and treatment of the condition and complications for these groups were delayed and/or inadequate.

There are multiple reasons for inadequate organization of care for hemophilia. Sometimes the cost of treatment, geographical distance from a hemophilia treatment centre, or even illiteracy can be the cause. Transportation costs, language barriers, and concerns over childcare and the healthcare system in general also seem to be deterrents. The attitude of healthcare professionals toward people from a certain ethnic or cultural minority and toward their beliefs and language also affect the willingness of these individuals to consult a doctor. In certain cases, particularly for women with a bleeding disorder, healthcare professionals may not know how to recognize bleeding disorders.

To ensure better access to treatment for the entire population suffering from bleeding disorders, the U.S. National Hemophilia Foundation (NHF) decided to launch the Multicultural Task Force (MCTF). The mission of the MCTF is to ensure that the needs and perspectives of culturally diverse populations are addressed. The MCTF provides technical assistance to NHF chapters and treatment centres in their efforts to identify and reach people with bleeding disorders who do not receive the health care they are entitled to, whether they are women, rural residents, or teens. The MCTF seeks to foster relationships between these individuals and the treatment centres, NHF chapters, and other associations in order to prevent or reduce complications resulting from undertreated bleeding disorders and consequently improve the quality of life of these people.

NHF chapters created a registry of people with hemophilia in Native American communities, then of women with bleeding disorders in the general population.

### **Patient registry of people with hemophilia in Native American communities**

In Minnesota, elders were key to the development of the hemophilia patient registry of the Native American population.

The first task that volunteers of the Hemophilia Foundation of Minnesota/Dakotas (HFMD) took on was to convince authorities of the need to identify underserved patients and create a registry of these vulnerable patient populations. They started by determining the potential number of patients in the area and in Native American communities, key data to better direct their research. A questionnaire was sent to 36 primary care providers to determine how many Native Americans with bleeding problems were treated there. Some 57 Native American patients received care from primary care providers, rather than in a specialized hemophilia treatment centre. The HFMD's goal was to find Native Americans with hemophilia who had not yet been diagnosed. The organization also attempted to identify individuals with von Willebrand disease in these communities.

The second step was to build alliances and partnerships with Native American communities. To this end, the HFMD created a Native American advisory committee to help them obtain the consent and support of Native American elders—respected leaders in their local communities. The advisory committee made recommendations to the HFMD on the best outreach methods to adopt in the communities. The advisory committee also introduced HFMD volunteers to the Native American community, which facilitated acceptance of the outreach volunteers and contributed to building a strong partnership. The HFMD worked with Native American leaders to develop brochures and educational materials on hemophilia adapted specifically to Native Americans. Native American leaders visited the local hemophilia treatment centres and were also invited to participate in annual meetings of the HFMD. Articles about the project and the developing relationships with native American communities were published in the HFMD member newsletter.

Next, a network was established comprising healthcare professionals working in Native American communities in Minnesota and employees of the federal Indian Health Service. Since they would be the ones in contact with patients and providing information, it was necessary to provide basic education about bleeding disorders and the importance of multidisciplinary care for people with hemophilia. Participants were dispersed over a vast geographic territory; organizers determined that the best way to use resources was to bring everyone together at a central location for training at the same time. It was more affordable to hold a workshop and cover participant transportation and accommodations than to train each individual one by one.

A curriculum was developed and participants were given a badge depicting Native American symbols and the HFMD logo to demonstrate their participation. While a small symbol of participation, the badge, intended for uniforms, was coveted by healthcare professionals and motivated them to take the training. Each workshop began with a traditional Native American ceremony.

The HFMD team also worked with the Native American advisory committee to build ties between tribal government leaders and federal health officials.

The HFMD also organized outreach training sessions for volunteers, so that they would be proficient at explaining the project, its objectives and the overall action plan. This plan could then be modified to meet the particular needs and context of each community. Finally, information was provided to staff at hemophilia treatment centres in the region to ensure that those providing care would have sufficient knowledge about the Native American culture.

As Native Americans suspected of having bleeding problems were identified, they were referred to the nearest hemophilia treatment centre for an accurate diagnosis and medical follow-up.

Unfortunately, it was difficult to assess the actual results of the project, because newly identified patients were not distinguished as such in the HFMD registry. This shortcoming resulted in the project's termination, since the financial supporters were not able to see the results of the project. Furthermore, HFMD chose not to identify the ethnicity of its members, so it is impossible to know how many individuals with hemophilia in Minnesota are Native American and whether their numbers are proportional to the number of people with hemophilia in the overall population of Minnesota.

### **Patient registry of women with bleeding disorders in New Jersey**

When the Hemophilia Association of New Jersey (HANJ) started its registry project in the 1990s, in partnership with three hemophilia treatment centres, only 203 women with bleeding disorders had been identified. However, according to the national census at the time, there were 4 million women in New Jersey—the prevalence of bleeding disorders among women was estimated to be approximately 2%, or at least 40,000 women. Should 10% of these women have a severe bleeding disorder, there would be an estimated 4,000 women with serious bleeding problems who remained unidentified and undiagnosed. The 203 women identified to have a bleeding disorder were evidently a small fraction of the actual number of women in New Jersey likely to be living with a bleeding disorder.

Bleeding disorders in women are frequently not recognized or diagnosed properly; unfortunately, about 600,000 hysterectomies are performed each year in the United States, a number of which are unnecessary because the problem is not actually gynecological, but rather an undiagnosed bleeding disorder.

After identifying its target population of 4,000 women, the HANJ, with four hemophilia treatment centres, decided to launch an outreach project with the objective of identifying 4,000 women with bleeding disorders who had not yet been diagnosed. A committee of women was formed to coordinate and work on creating a registry of women with bleeding disorders. The women's committee was officially recognized by the HANJ Board of Directors. A member of the Board also co-chairs the committee. The committee also relies on the expertise of a physician specializing in bleeding disorders and a representative from each of the four treatment centres involved in the project. Moreover, women with bleeding disorders serve on the committee, sharing their experiences and speaking about their bleeding disorder

with other women who may be affected. The committee meets regularly (every two months) and all of its activities are reported to the Board of Directors.

The committee identified healthcare professionals working in schools and on university campuses, family doctors, obstetricians and gynecologists, and healthcare organizations in target communities (including organizations providing health services to cultural or ethnic groups) in order to garner support in the local communities. Letters introducing the registry project were sent to these key partners and information booths were set up at health-related events in order to raise awareness, generate dialogue, and develop contacts.

Next, the strategy was intensified by inviting medical and public health professionals to address committee members during their meetings. One invitation often led to another, which strengthened relationships and enabled the committee to convey its message and build support.

The project's implementation involved the development of a webpage and publications to increase awareness and access to information on women and bleeding disorders. The information was also sent to schools and health organizations, including those providing services to cultural minorities. Other communications tools, including a seminar on bleeding disorders, were developed specifically for physicians who see a large number of female patients.

New Jersey's Department of Health and Senior Services was kept informed of the program's progress. It supported the HANJ patient registry campaign, and subsequently analysed the findings and observed specific trends.

To ensure ongoing outreach and care, the HANJ regularly monitors the number of women identified as having a bleeding disorder, as well as the number who have access to the services of a hemophilia treatment centre and HANJ. Today, more than 1,000 women receive care at the four hemophilia treatment centres that participated in the program.

HANJ is now lobbying to change New Jersey legislation so that women referred to obstetricians or gynecologists are required to be tested for bleeding disorders before undergoing a hysterectomy. The proposition has not yet been passed but the association continues to put pressure on elected officials.

## **Lebanon: Outreach campaign of coagulation disorders**

Lebanon is a small country on the Mediterranean coast, with a population of 3,500,000 residents. After several years of war and uncertainty, economic problems are significant. Approximately 35% of the population lives below the poverty line and the average salary is estimated at \$350 per month. The healthcare system is characterized by a predominance of the private sector over the public, which is almost non-existent. The state budget allocated to health care is less than 2.5%. It is estimated that healthcare costs are covered by social security for 40% of the population, by private insurance for 10% and by government-run funds for 20%; 30% have no coverage.

Caring for coagulation disorders in this context is a challenge. Only the Department of Health ensures people with hemophilia who do not have a social safety net will receive a maximum of 0.2–0.3 units (U) per capita in substitution factor concentrate. Private insurance does not cover congenital coagulation disorders, and government-run funds and social security only reimburses hemophilia patients at

70% after several months of waiting. It is easy to imagine that few people suffering from a coagulation disorder take care of themselves properly when a unit of factor VIII costs \$1–\$1.2. Furthermore, hemophilia and other coagulation disorders are not well understood. Few people are involved in their care. There is no dedicated hemophilia care centre. Treatment is based on cryoprecipitate, plasma, and available plasma-derived factor concentrates. Health care and test costs are primarily paid by the patient.

In 2005, as part of the creation of a national committee aimed at involving the state in hemophilia treatment, the Lebanese Hemophilia Association (*Association Libanaise de l'Hémophilie*, ALH) launched an identification and assessment project for individuals suffering from a coagulation disorder in the country. The goals of this project are to manage the activities of the national committee and intervene in decisions related to the budget allocated to coagulation disorders. In order to improve treatment, it was imperative to establish the exact number of people living with hemophilia in the country so that the association would know how many it was representing in discussions with healthcare authorities. Each time the ALH went to meet with government representatives, they were asked for the recorded number of individuals involved and their actual problem. It was important to have the answer.

The only data compiled up to that time were noted in a small registry of the association and in the registry of the government's central pharmacy that dispenses drugs. About 100 patients were listed. The lists of the central pharmacy did not include any additional information compared to those of the association. These data did not contain the social and medical information that the association needed, and most did not have an accurate diagnosis or differentiate between hemophilia A and von Willebrand disease.

Co-operation with the medical sector was the first initiative. Few hematologists responded, using the excuse that they don't treat anyone with hemophilia. It was then suggested that a free service be provided to patients, offering them a blood work-up specifying their disorder, inhibitor screen and serology test (HIV, HCV, HBV).

A pharmaceutical company agreed to fund tests for 200 people, to get an idea of the incidence of inhibitors. A simple online registry was created, consolidating patients' social, demographic, and medical data.

All patients known to the association and all hematologists were contacted by telephone and the ALH service was offered. Recruitment was conducted by word of mouth, with each patient promoting the service to their friends and family.

After being questioned by a volunteer ALH physician and being listed in the online registry, a blood work-up was performed at the capital's central university hospital to determine the need in coagulation factor, presence of inhibitors, and serological profile.

The file of patients already known was completed, the diagnosis was corrected in certain cases, and more than 100 new patients were identified. Patient recruitment only stopped due to insufficient funds to pay for blood tests. Several families who contacted the ALH for a blood work-up could not be properly diagnosed or identified due to lack of funds. In six months, 92 individuals with hemophilia A were identified, 26 with hemophilia B, 59 with acute von Willebrand disease, 17 with afibrinogenemia, and 9 with rare coagulation disorders.

A national program held over three years is currently underway in various regions of the country. This program consists of education on coagulation disorders for patients, community nurses, and primary care physicians. The ALH believes that this program will enable the creation of regional coagulation disorder care networks, which will be used to identify new cases. A fundraiser is being planned to finance blood work-ups.



## Conclusion

Patient outreach requires commitment, leadership, and a clear goal. Its aim is to identify more of the people in a given population who have a bleeding disorder but may not know it, or who have inadequate access to the treatment and services available.

An outreach campaign requires collaboration among various partners—hemophilia organizations, medical professionals, healthcare authorities and governments—and a strong project team to manage it. The support of the bleeding disorders community is key to success.

Planning is the most important element of patient outreach—the success of the whole campaign depends on the strength of planning. Important steps are establishing the goal, forming a strong project team, identifying the target population, determining a strategy, and developing a full action plan. Keep in mind that objectives and strategy need to be assessed regularly and adjusted in response to different circumstances and unexpected challenges.

A good turnout is important to having a successful campaign. Effective communications and publicity are critical to attract potential individuals with bleeding disorders to activities. They are also essential for raising awareness among partners, volunteers, and the general public.

Data collection on the number of people living with hemophilia and other bleeding disorders, the type of treatment they receive, and their access to services is essential in order to convince health authorities to invest the proper resources into the treatment of hemophilia and other bleeding disorders. Measurable results also persuade other financial donors to continue to support the organization's work.

Follow-up on newly identified patients is vital. It is important to confirm that the patients have been diagnosed are benefiting from the outreach campaign, for example, through treatment and access to services.

Finally, evaluation of the patient outreach initiative after it has ended will show whether the project was planned and implemented successfully. It will also track the important outcomes that are essential to sustain the interest and support of funders and project partners.



# Resources

The following publications are accessible from the WFH website at [www.wfh.org](http://www.wfh.org).

*Action Planning*. Gordon Clarke. World Federation of Hemophilia: Montreal, Canada. 2001.

*Developing and Sustaining an Effective Lobbying Campaign*. Brian O'Mahony. World Federation of Hemophilia: Montreal, Canada. 2006.

*Diagnosis of Haemophilia and Other Bleeding Disorders: A Laboratory Manual*. Steve Kitchen and Angus McCraw. World Federation of Hemophilia: Montreal, Canada. 2000.

*Fundraising*. Rosalind Franklin. World Federation of Hemophilia: Montreal, Canada. 2006.

*Guide to Developing a National Patient Registry*. Bruce Evat. World Federation of Hemophilia: Montreal, Canada. 2005.

*Hemophilia in Pictures*. Spanish, French, Arabic, Chinese, and Russian versions are available on CD-ROM. World Federation of Hemophilia: Montreal, Canada. 2005.

*Making Your Case Effectively: A Guide to Government Relations*. David Page. World Federation of Hemophilia: Montreal, Canada. 2004.

*Recruiting and Retaining Volunteers*. Mohamed Aris Hashim. World Federation of Hemophilia: Montreal, Canada. 2003.

*What is Hemophilia?* World Federation of Hemophilia: Montreal, Canada. 2003.

*What is von Willebrand disease?* World Federation of Hemophilia: Montreal, Canada. 2008.









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