

MAKING YOUR CASE EFFECTIVELY

A GUIDE TO GOVERNMENT RELATIONS

David Page

Canadian Hemophilia Society



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

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World Federation of Hemophilia
1425 René Lévesque Boulevard West, Suite 1200
Montréal, Québec H3G 1T7
CANADA
Tel. : (514) 875-7944
Fax : (514) 875-8916
E-mail: wfh@wfh.org
Internet: www.wfh.org
eLearning.wfh.org

The *Hemophilia Organization Development* series aims to help hemophilia society leaders, staff, and volunteers develop the skills necessary to effectively represent the interests of people with hemophilia. The World Federation of Hemophilia does not engage in the practice of medicine and under no circumstances recommends particular treatment for specific individuals.

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Making Your Case Effectively

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Introduction

In many countries of the world, people with hemophilia do not have access to adequate care. They are held back from reaching their potential as human beings. They suffer great pain and run a high risk of crippling. Death at a young age is not uncommon.

In some other countries, where hemophilia care has been well-developed, authorities are cutting back resources in Hemophilia Treatment Centres (HTCs). High-quality care is endangered.

It is the role of National Member Organizations (NMOs) of the World Federation of Hemophilia (WFH) to work with governments and health authorities to raise the level of care so that people with hemophilia can live healthy lives. The purpose of this monograph is to provide hemophilia organizations with some practical guidance to improve the effectiveness of these government relations.

Note: The suggestions in this monograph may be very effective in some countries, but inappropriate, or even damaging, in others. Readers must decide which recommendations are relevant given the political, social, and cultural context in your particular country.

Lessons Learned in Government Relations

Create win-win situations

The hemophilia organization and the government are partners in the work to improve hemophilia care. If you are successful, people with hemophilia will have better lives and the government will have contributed to bettering the health of its citizens. This is a “win-win” situation.

The hemophilia society should see itself as a partner in finding a solution to the government’s healthcare problems.

Always remember your cause

It is essential to focus on your cause, whether it is:

- Outreach to regions and better diagnosis;
- The creation of a national hemophilia treatment centre;
- Access to factor concentrates for all people with hemophilia; or
- Improved comprehensive care.

Your cause is a good one. Hemophilia can be treated. When it is treated, there is a dramatic improvement in the quality of life of that person and his family members.

Avoid being distracted by side issues. If the hemophilia society is distracted, the government will be, too.

Be patient, but be persistent

Major improvements in hemophilia care do not usually happen overnight. In most countries, this is a slow, gradual process over many years. It is important not to be impatient, because then discouragement is easy.

On the other hand, a hemophilia organization must be persistent. When government officials see that the organization has a clear idea of people’s needs, that it never loses sight of its goals, and is prepared to work over the long term, they will take the organization seriously and considered it a useful partner.

Remember you are not alone

It is easy for a small group of volunteers in a hemophilia organization to feel alone, especially if progress to reach their goals is slow. But you are not alone. Your members and their families support you. Many will lend a hand if asked. You also have the support of healthcare professionals – doctors, nurses, physiotherapists, social workers – who work in the field of hemophilia. They have the same goal: to improve the care of their patients. Other social or religious organizations may be willing to help you, as well.

If government officials see that you are not alone, they will give your demands a better hearing.

When good things happen, give credit

Most people react similarly when there is a problem. They get upset and criticize. But when things are going well, they relax and sit back. As a result, they forget to praise achievements. When government officials do good things, it is important to acknowledge these achievements publicly. And your hemophilia society will be seen as an organization that recognizes solutions and doesn't just complain about problems.

Never give up

While achieving your objectives may at times seem impossible, it is important not to give up. Times change, governments change, and what was impossible one year may be realistic the next. People with hemophilia need the hope that comes from knowing their organization will continue to work in their interests.

Preparing Your Case

A hemophilia society will usually get only one opportunity to present its case to government officials. If the society's presentation is not well prepared and convincing, the group may not get another chance for a long time. Therefore, it is extremely important to take the time necessary to prepare your case well.

Taking the time

"Before our hemophilia society met government to request greater access to factor concentrates, we took months to prepare. We looked at how many people with hemophilia were diagnosed in the country and how much it would cost to provide them with adequate care. We listed all the individual and social benefits. When we finally submitted our request, it had to be taken seriously. We never regretted taking the extra time."

While the benefits of improved care for people with hemophilia are obvious to those who live with it every day, this is not the case for government officials who may know very little about bleeding disorders.

Moreover, governments face many challenges in improving the health system. Some problems affect a much larger percentage of the population. Therefore, it is your responsibility to make a convincing argument that improved hemophilia care not only benefits those directly affected, but also benefits the country as a whole.

Identify ways in which improved hemophilia care benefits a country

There are many benefits for a country when it improves hemophilia care. These are some of them.

Social benefits

- Much pain and suffering, especially among children, is avoided.
- There is much less disability among people with hemophilia who receive good treatment. This avoids the social costs of caring for them.
- People with hemophilia who receive adequate care grow up healthy, can receive an education, work, and contribute to society.
- Better health and less disability result in less stress on families. Other members of the family can be more productive.

Medical benefits

- Morbidity and mortality is decreased.
- The outreach efforts needed to diagnose people with hemophilia can be copied for use with other conditions.
- With adequate diagnosis and care, there can be less strain on hospitals as people with hemophilia are admitted less frequently. More care is given at home or on an outpatient basis.
- The idea of comprehensive care developed for hemophilia (involving a multi-disciplinary team including the patient and his family, home care, outpatient care, etc.) can be used as a model to treat other diseases.
- The development of medical expertise in the treatment of hemophilia gained through the creation of a national hemophilia treatment centre can be used to treat other hematologic conditions.

- The physicians in a country with a national hemophilia treatment centre and links to international experts through the WFH receive valuable information and training.
- A well-developed hemophilia care system can ensure that valuable resources are wisely used for the best outcomes and not wasted.
- The partnership among health authorities, doctors, and patients is well developed in the field of hemophilia. This is a powerful concept that can be applied to other areas of the health system.

Blood safety benefits

- Efforts to increase the safety of blood and blood products for people with hemophilia through improved blood donor screening and testing measures will have a positive effect on all people who require transfusions.
- Links between the government, the hemophilia organization, hemophilia treaters, and the WFH can lead to better choices when purchasing factor concentrates, and even to cost savings.

Present good data

Government officials need good data in order to make decisions. It is essential that the hemophilia society present the key data it possesses.

However, the data must be accurate; otherwise, your organization will lose credibility. The information provided each year for the WFH Global Survey can be used in preparing your case. Depending on the information available in your country, this could include:

- The number of people with hemophilia A and B, and von Willebrand disease registered in the country;
- Their average survival;
- The expected number of people with hemophilia A and B, and von Willebrand disease;
- The number of people infected with HIV/HCV;
- The number of people who have died in the last 12 months;
- The current level of factor VIII usage (in I.U. of factor VIII/capita/year);
- The desired level of care (in I.U. of factor VIII/capita/year);

- The number of hemophilia treatment centres (HTCs) and the services they provide; and
- Current medical resources.

While HTCs cannot give out confidential patient information to a hemophilia society, they can share collective data on the people they serve. It is important to work with HTCs to ensure that the data you present to government is as complete and accurate as possible.

Present solid arguments

Based on the ways improved hemophilia care will benefit your country and the data you have, you can prepare solid arguments to support your case. Try out these arguments with people you know to find out their reactions and discover any holes in the logic.

When meeting with government officials, it is better to use a few strong arguments that are difficult to contest than a long list of weak ones that are easily dismissed.

Remember! You have the solution to the government's problem. But you may have to begin by proving there really is a problem.

Before Approaching the Government

Know what you want

It is crucial to know what you want. You should build a strong consensus among all your members and the healthcare professionals in the hemophilia field. This will give you confidence in your proposals.

You must avoid sending conflicting messages to government officials. If this happens, it will be very easy for them to dismiss your demands. It is worth taking the extra time to work out differences, especially if they exist between the patients and the physicians.

Verify that your requests are the right ones

Send draft proposals of your requests to key volunteers in your hemophilia society and healthcare professionals. Ask for their feedback and incorporate it when useful. This will make people feel that your proposal is also their own. They will have a sense of ownership and support you more strongly.

Make sure your requests do not leave out any segments of your population. Remember! As a hemophilia society, you represent all people with hemophilia.

Be knowledgeable. Do your homework

In addition to collecting the data about the hemophilia situation in your country, you need to understand the overall health system. Here are some questions you can ask yourselves.

- If your country has a federal system, what level of government – national, state or municipal – is responsible for dealing with your request?
- What are the rules governing payment of medical services, including factor concentrates? Make sure you know about all the different systems, including social security, private insurance, the military sectors, and others. Is there legislation that deals with “catastrophic diseases”?
- What is the current state of the blood system in your country? Are there issues of safety and supply that you need to know about?

Identify the right person to approach

A natural instinct is to want to talk to the person “at the top”, for example, the Minister of Health. The hope is that he/she can settle the problem immediately. You may well have an opportunity to meet him/her at a later date. However, the Minister is extremely busy and has little time to understand the details of your request. In any case, he/she relies on advice from the officials whose job it is to evaluate dossiers such as yours.

Therefore, it is essential to identify this official since your request will eventually end up on this person’s desk. The official could be one of a number of people, for example:

- A physician in charge of the national hemophilia treatment centre (HTC);
- The director of the hospital where the HTC is located;
- An official with the blood transfusion service;
- A government official responsible for blood diseases and the blood system; or
- A government official responsible for the purchasing of blood products.

Your objective is to convince this person to defend your request to his superiors; in other words, create an ally. If you succeed, he/she will be helpful in opening other doors necessary to get action on your request, right up to the Minister of Health’s level.

Preparing for the Meeting

Request a meeting

There are many ways to request a meeting. If you already know the person you want to meet, a simple telephone call is probably the best way. If you don’t know the person, an official letter from your hemophilia society will probably work better. A letter creates a written record of your request. You can follow up the letter with a telephone call several days later.

In any case, you will want to tell the official the reason you want to meet and the two or three specific topics you want to discuss. If your organization is not known to this person, a short introduction is required.

Decide what information to send beforehand

If you have a well-prepared and detailed dossier, you may want to send it to the government officials in advance of your meeting. This will allow them to be familiar with the problem and make their own inquiries. It will also allow you to focus on key issues during your meeting, rather than spend most of your time presenting your dossier.

You may also want to send documents describing your organization: its legal status, history, mission, goals and activities.

Decide who should attend the meeting

In most situations, your organization should not send more than four or five people to the meeting. A larger number can lead to confusion and, in any case, it will be difficult to find a role for these extra people.

Standing room only

“The leaders and volunteers in our hemophilia society were really pleased that we had finally obtained a meeting with government representatives. Everyone was

excited, but little was planned. On the day of the meeting, seven people showed up, including an inexperienced volunteer who wanted to learn from the experience! The situation became awkward when the Minister's assistant had trouble finding an office space large enough to hold both our society representatives and the Minister's staff! We could have avoided this problem if our leaders had decided who should go and why, and confirmed that the number was acceptable."

Who should attend? Having the right people at the meeting can make all the difference. Be very selective about whom you invite to your meeting with the government. Include only people who have been briefed on appropriate behaviour and protocol for the meeting. Avoid inviting guests who may be unable to follow your guidelines on appropriate protocol.

Typically, these are the types of people who can contribute most:

- The leader of your organization;
- A dedicated physician whose medical credibility will add force to your delegation;
- A person with hemophilia or a parent of a child with hemophilia who can describe the reality of living with the disease and make the problem come alive;
- An additional person whose main role is to observe the discussion, take notes and help to keep the meeting focused on the agreed objectives;
- In certain situations, a representative from the WFH.

Definitely do not invite a person who has different goals for the meeting or who cannot be trusted to follow your plan. There is nothing worse than appearing disunited or disorganized.

Decide on your goals, or key messages

Do not have a long shopping list of goals. Focus on one or, at most, two; for example:

- Government cooperation in an outreach project;
- The designation of a national hemophilia treatment centre;
- The purchase of increased amounts of factor concentrates through a national tender process; or

- Reimbursement of the cost of factor concentrates for those without insurance coverage.

It is often unrealistic to expect to find a solution to the problem at the first meeting. However, you do want to achieve some of your objectives, even if they are modest. Here are some examples.

- Make an effective presentation.
- Impress the government official with your seriousness and credibility as a representative of people with hemophilia.
- Obtain agreement to study your request within a certain time period.
- Obtain a second meeting in the near future to pursue the discussion.
- Obtain a meeting at a higher level.

Decide on the roles for each person

It is essential that one person, usually the leader of the hemophilia society, be the chief spokesperson for your delegation. He/she will orchestrate your presentation, make introductions and request others (e.g. the physician, the person with hemophilia, the WFH representative, etc.) to intervene to present the information for which they are responsible.

Once upon a time...

"Our hematologist was late for a meeting with the government. When he arrived, we, the hemophilia society leaders, had already begun the negotiation process and were handling the situation very well. Instead of joining the process, he started talking about the past, describing how great the hematology institute was before the collapse of the country. This continued for twenty minutes, effectively ending the negotiation process.

He would have made a greater contribution to the meeting if we had briefed him on the objectives of the meeting and proper protocol for negotiations."

Find out beforehand exactly whom you will meet

It is advisable to have some prior information about the people you will meet. Some of this information can be requested directly of them, for example: name, title, and responsibilities.

Other information, for example, their ideas about healthcare delivery and patient organizations, may need to be pursued informally through contacts.

These are some questions you should research:

- How many government representatives will there be?
- What are their names and exact titles?
- What power do they have to make changes?
- Do they have any link to hemophilia?
- What have they said/done about hemophilia in the past?
- What are their general ideas on health care? On patient organizations?

Find out how much time you have to present

This is essential for your preparation. You do not want to run out of time before you have made your key points.

"The day before our meeting with government representatives, there was a fire in our office. Our registry and other documents we wanted to present were destroyed. We had worked really hard to get the meeting, but upon arrival, we talked only of the fire. By the time we got around to talking about the real purpose of the meeting, it was too late: the Minister stated that our time was up."

Think about the difficult questions

Try to anticipate the questions you will be asked during the meeting, especially the difficult ones such as:

- Why should we invest so much money in hemophilia care when our country has so many other challenges in the health field?
- Why should we purchase factor concentrates when we have local cryoprecipitate?
- Why shouldn't we invest in prevention of hemophilia rather than its treatment?

Do your research and make sure you can answer these questions to the best of your abilities.

Determine proper protocol

Often, you will have some control over seating at the meeting. Decide on the approach you want to take to best meet your goals.

- Should you sit together so as to seem united?

- Should you scatter around the table so as to seem non-confrontational?
- Is there one person, for example, the leader of your delegation, who should have a prominent position?

If you have international guests as part of your delegation, they will need extra preparation on the cultural DOs and DON'Ts.

Rehearse

It is worthwhile to take the time to rehearse your presentation in the days before the meeting. Invite all those who will be attending the meeting and several others who can play the roles of the government officials. Provide them with the difficult questions you expect to be asked.

Such a rehearsal will allow you to:

- Be more at ease with your presentation;
- Make changes to your plan;
- Ensure you can make your key points within the allotted time;
- Clarify each person's role; and
- Give you confidence that you are well-prepared.

When you are satisfied with your preparation, make notes for use at the meeting so that you will not forget anything important.

Prepare dossiers for each government official

Whether or not you sent information in advance of the meeting, prepare a dossier with key documents for each of the government officials you expect to meet. Hand out this information before your presentation or, if you prefer they listen to you rather than shuffle through papers, at the end of the meeting.

Do not feel obliged to provide a thick dossier. Supply the documents you really hope will be read and understood.

At the Meeting

If your dossier is well prepared and you are well rehearsed, the meeting is likely to go well. These are some points to remember.

Things to do

- If appropriate in your country, take the lead in the meeting.
- Present your dossier as planned.
- Focus on your goals and key messages.
- Focus on the future rather than dwelling on the past.
- Be constructive. Don't just complain.
- Be clear, but brief, when presenting your arguments.
- Stick to the roles assigned.
- Respect the time allotted to you.
- Take notes of key points discussed.
- Be polite, yet firm.

Things not to do

- Do not get side-tracked on minor issues.
- Do not argue about facts.
- If at all possible, do not let the government official take over the meeting to discuss issues important only to him/her.
- Do not lose track of time.
- Do not make promises you cannot keep.

And just one last thing...

"The allotted time for our meeting had come to an end. When the Minister stood up and said that he had to leave for another meeting, the HEMOPHILIA SOCIETY leader kept saying, "Just one last thing that I didn't get a chance to tell you about." The meeting had gone well until that point, but it ended badly because the Minister's time constraints were not respected."

After the Meeting**Follow up immediately**

What you do after the meeting can be as important as what you do during it. These are some of the actions you can take in the days following your meeting.

- Write a letter in the following days to:
 - express your appreciation for the meeting;
 - summarize the main points of agreement;
 - confirm the actions to be done by your organization; and
 - state your organization's expectations of government.

- Supply all information that you agreed to provide to the government officials in writing.

Follow up over the next weeks

If there has been positive action in response to your request:

- Phone the person responsible to thank him/her.
- If appropriate in your country, phone the person's superior to express your appreciation.
- Write an official letter of thanks.
- Attempt to publicly recognize the contribution of the government officials through:
 - awards at your organization's functions;
 - public recognition in the media.

If there has been no action:

- Make inquiries by phone.
- Write a letter to the official reminding him of commitments made at the meeting.
- If appropriate in your country, write a letter to the official's superior stating that the commitments made have not been respected.

Other Ways to Influence Government

Direct communication with the government officials responsible for your dossier is the most effective way to make progress. Unfortunately, sometimes your requests are refused, ignored or delayed. It may then be necessary to take additional action. This should be done in a series of steps, each of which increases pressure on the government to act.

There is no standard way to influence government. Each hemophilia organization will have to evaluate the actions that are appropriate within its own particular context. These are some examples of strategies that have been used in different parts of the world and found effective:

- Send an invitation to officials to attend patient organization activities.
- Send a letter from the hemophilia society to all elected officials.
- Launch a letter-writing campaign by members and their families to elected officials.

- Organize meetings among members and their families and local elected officials.
- Write a press release which answers the questions: Who? What? When? Where? Why? and How?
- Increase public awareness through coverage in print and electronic media.
- Increase public support for your request from other health organizations, social support networks or religious institutions.
- Encourage the intervention of an influential person at high levels of government.
- If appropriate in your country, organize a high-level delegation from the WFH to meet government officials and give credibility to your request.
- Create negative publicity about the government in the media, especially in the months before an election.
- Send negative publicity about the government to the media.
- Threaten to make appeals to opposition parties.
- Make appeals to opposition parties.
- Threaten legal action to enforce existing legislation.
- Take legal action.
- Stage public demonstrations.
- Organize public demonstrations.

Public attention through some of the strategies listed above is a two-edged sword. In some situations, in some countries, it may cause public officials to cut off discussions with the hemophilia society. Going to the media can even be dangerous for the individual. Be sure to carefully assess your particular situation.

Support your members

In any form of public campaign to influence government, your members will need considerable support from the organization.

If the issue of hemophilia becomes a public one, your members will need to know:

- What you are requesting;
- The actions you are undertaking;
- The fact that their names are confidential; and
- The results you hope to achieve.

If you want members to help with your campaign, they will need even more support, for example:

- A communication from the hemophilia society with the two or three key messages to transmit to family members, friends, other groups and elected officials they meet.
- A sample letter which they can adapt and send to elected officials.
- Training and support if they do interviews with the media.
- Frequent communication with the hemophilia organization so they are aware of new developments.

Remember

- Create win-win situations.
- Always remember your cause.
- Be patient, but be persistent.
- Remember you are not alone.
- When good things happen, praise achievements.
- Never give up.

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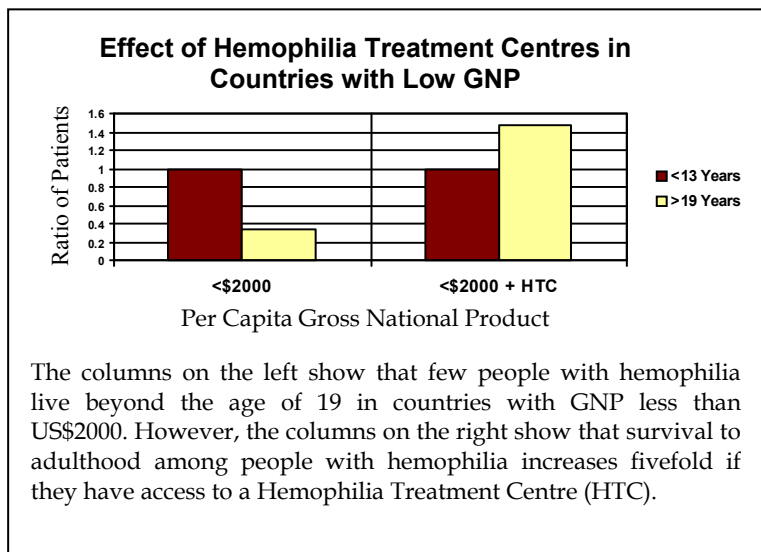
Appendices

Three WFH fact sheets were developed to help hemophilia organizations present governments with clear, factual arguments on the economic benefits of: 1) basic hemophilia treatment and care, 2) treatment with factor concentrate, and 3) comprehensive hemophilia care. The statistics and examples on these fact sheets will be updated and expanded periodically. Please check the WFH web site for the latest version.

Economic benefits of basic hemophilia treatment & care

About 75% of people with hemophilia live in developing countries. Many do not survive childhood, yet specific **low-cost measures** taken by government can significantly improve life expectancy. Government and society benefit from an investment in children's health when, as adults, they are able to work, contribute to the community, pay taxes, and raise a healthy family.

It is within the economic grasp of most countries with limited resources to provide an organized system of adequate hemophilia care.



Benefit to government and society

In the long term, it is less costly to provide basic care than to provide none at all. Data collected by the WFH through an annual global survey¹ clearly demonstrate that treatment in a specific hemophilia treatment centre (HTC) with appropriate replacement therapy, even at a minimal level, in countries with GNP less than US\$2000 resulted in the following:

- Survival to adulthood increased fivefold (500%) for children with hemophilia. [See graph]
- More rapid and complete recovery from bleeding episodes occurred when factor replacement therapy was provided, resulting in a quicker return to work, school, and preservation of functional independence for the person with hemophilia.

The cost of NOT providing patients with basic care and safe treatment products

- **Increased absenteeism and reduced productivity in the workplace for patients and caregivers;**
- **Long-term financial support needed due to** a much higher rate of morbidity with crippling joint deformity and death from major internal bleeding;
- **Increased probability of contracting HIV/AIDS and/or hepatitis C through unsafe blood-based factor replacement therapy, resulting in** increased hospitalization and medication, and further loss of productivity.

Elements of basic hemophilia treatment and care

To achieve the maximum impact for the minimum input, the government needs to provide:

- Hemophilia treatment centres (HTCs);
- On-demand treatment with plasma-derived products for major bleeding and before surgery; and
- Education about hemophilia for healthcare workers, patients, and their families.

For more information, consult the following resources.

1. World Federation of Hemophilia. 2004. *Report on the Annual Global Survey 2003*. Montreal: World Federation of Hemophilia.
2. Evatt, BL, and L Robillard. 2000. Establishing haemophilia care in developing countries: using data to overcome the barrier of pessimism. *Haemophilia* 6: 131-134.

Benefits of treating hemophilia with factor concentrate

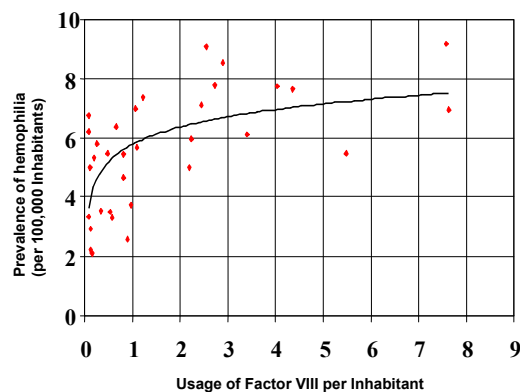
Treating people with hemophilia with safe, regulated plasma-derived factor concentrate is an investment that directly reduces the social and economic impact of this bleeding disorder on the patient. It also reduces the amount of long-term support required from family, community, and government.

It is within the economic reach of most countries, even those with limited resources, to provide safe treatment products before essential surgical procedures and during life- or limb-threatening emergencies.

Economic benefits to government & society

- A person with hemophilia will recover from a bleed within a few days if treated with factor concentrate. If untreated, recovery may take weeks, and may be incomplete. Joints may be permanently damaged. Other treatment products are less expensive but not as effective, and contribute to longer absences from work or school, and decreased ability to contribute to the family and community.
- Treatment with cryoprecipitate (a blood-based product) instead of factor concentrate carries safety risks, because there is no effective system for viral inactivation. A WFH study shows that a person treated with cryoprecipitate over a 20-year period in Venezuela has a 13 to 18 per cent risk of HIV infection. The risk of infection with hepatitis C is almost more than 80 per cent. In contrast, plasma-derived factor concentrate made today has an excellent safety record.
- If a person with hemophilia contracts HIV/AIDS or hepatitis through unsafe treatment products, there is a risk that the infection will be communicated, increasing the number of citizens eventually requiring treatment and financial support.
- Stigmatization and poor health from untreated hemophilia, HIV/AIDS or hepatitis weakens economic activity by reducing productivity through absenteeism, organizational disruption, and loss of skilled workers. Expenses increase when new staff must be recruited and trained even as temporary replacements. For example, by 2005, Botswana will have lost 17% of its workforce to AIDS, and by 2015, its economy will grow 2.5 % **less** than it would have without the impact of AIDS. Safe, regulated plasma-derived factor concentrate can reduce the chance of increasing the viral infection rate among people with hemophilia.

Effect of factor VIII concentrate on patient survival in relation to amount used



◆ = 1 of 34 countries in study

The curve represents the prevalence (survival) of people with hemophilia in relation to increased use of factor VIII concentrate. The sharp incline on the left illustrates the life-saving benefit of even a small quantity of factor concentrate (1 to 2 I.U.) per inhabitant.

For more information, consult the following resources.

1. World Federation of Hemophilia. 2004. Report on the Annual Global Survey 2003. Montreal: World Federation of Hemophilia.
2. Evatt, BL, and L Robillard. 2000. Establishing haemophilia care in developing countries: using data to overcome the barrier of pessimism. Haemophilia 6: 131-134.

Economic benefits of comprehensive hemophilia care

Comprehensive care carried out in a specialized Hemophilia Treatment Centre (HTC) is the optimum treatment for patients with hemophilia and other bleeding disorders.

Hemophilia *cannot* be adequately treated in a general hematology department due to its complexity. This reality is recognized by the World Health Organization (WHO), the World Federation of Hemophilia (WFH), and all developed countries.

An HTC's **basic care team** consists of a hematologist and qualified laboratory personnel equipped to diagnose bleeding disorders.

A **core comprehensive care team**

includes not only a hematologist and lab personnel, but also a hemophilia nurse, a physiotherapist, and an orthopedist. Additional members could include a social worker, a dentist, a psychologist, a genetic counsellor, and an infectious disease specialist.

Benefits of Comprehensive Care

- Studies in the United States have shown that the mortality rate of hemophilia patients receiving care outside the multidisciplinary team environment of an HTC with comprehensive care increases by 70% and there is a 40% higher hospitalization rate even while in the care of a hematologist. [See graph.]
- In some countries, hemophilia management is complicated by HIV and hepatitis C infections as a direct result of contaminated blood products used to treat hemophilia before the 1990s. However, the complications can be safely managed by a multidisciplinary team through a Hemophilia Treatment Centre (HTC).

The cost of NOT providing patients with comprehensive care

- When bleeding episodes are not treated early and appropriately by a specialized clinical team, it is often necessary to give a higher dose of factor replacement therapy, and to provide repeated treatments. Since more than 90% of the cost of hemophilia treatment is actually the cost of factor replacement, proper clinical supervision in an HTC can lead to optimal use of expensive replacement therapy and actually decrease the cost of treating specific bleeding episodes.
- Uncoordinated, non-specialized care costs more than comprehensive care through inappropriate use of expensive blood products leading to increased use of these products, as well as hospital and emergency services.

For more information, consult the following resources.

1. Sohail, Muhammad Tariq and Lily Heijnen, eds. 2001. Comprehensive Haemophilia Care in Developing Countries. Montreal: World Federation of Hemophilia.

