

HEMOPHILIA SOCIETIES: CHALLENGES AND DEVELOPMENT

Revised Edition

Brian O'Mahony
Irish Haemophilia Society
European Haemophilia Consortium

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World Federation of Hemophilia
1425 René Lévesque Boulevard West, Suite 1010
Montréal, Québec H3G 1T7
CANADA
Tel. : (514) 875-7944
Fax : (514) 875-8916
E-mail: wfh@wfh.org
Internet: www.wfh.org

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Hemophilia Societies: Challenges and Development

Brian O'Mahony

Introduction

National hemophilia societies are vital to the work of promoting access to, and to improving or maintaining, hemophilia care in their country. They can be strong and powerful forces representing the interests of people with hemophilia. However, the range and complexity of challenges facing hemophilia societies is growing, and will continue to grow in the future. This monograph is intended to help hemophilia societies identify and develop the skills necessary to meet these challenges. It also includes suggestions for building a stronger organization and profiles the development of several hemophilia societies around the world.

When this monograph first appeared in 2000, I was Chairman of the Irish Haemophilia Society and President of the World Federation of Hemophilia (WFH). My perspective therefore came from some 18 years as a volunteer. At the time of writing this update, I am the Chief Executive of the Irish Haemophilia Society (IHS) and therefore now manage the staff team at the IHS and work with the elected volunteer board. I am also the President of the European Haemophilia Consortium (EHC) which represents 44 organisations in Europe. My perspective has broadened as have the complexity of the world and the issues facing many of the national member organizations (NMOs) of the WFH. The core challenges previously outlined remain the same, but new challenges have arisen in recent years.

Challenges Facing Hemophilia Societies in Developed Countries

In a 1997 survey carried out by the EHC, European hemophilia societies identified their major challenges:

- Financial constraints;
- Lack of office equipment and facilities;
- Lack of qualified volunteers;
- Need to strengthen local chapters;
- Lack of information available in languages other than English;
- Lack of contact with health officials.

In the current environment and with the developments of the past fourteen years, new challenges have emerged, including:

- an unprecedented global financial recession;
- a new wave of communication methodologies;
- formal involvement in policy at a national level.

Economics and fundraising

In many parts of the world, government cutbacks are threatening funding for hemophilia treatment. In Western European countries, where spending on hemophilia care has traditionally been high, governments are becoming concerned about the ever-increasing cost of health care and are starting to methodically examine the treatment modalities for many high-cost conditions. Despite the relatively low prevalence of hemophilia, factor replacement therapy will appear on the list of the most expensive therapies in many countries. As governments try to contain healthcare costs for conditions such as diabetes, high cholesterol, and ulcers, the relative cost of therapy for hemophilia is being examined and questioned.

Evidence-based medicine is a major yardstick used by health funding agencies, and formal reviews using health technology assessments are being initiated. The first such formal review focusing on hemophilia has now taken place in Sweden. The cost effectiveness and comparative effectiveness of relatively expensive therapies, including the use of prophylaxis for children or adults, recombinant concentrates, and treatment for those with inhibitors (including immune tolerance therapy), is being examined. There is a real risk that, unless NMOs

and healthcare providers are proactively engaged in these processes, the progress made in access to optimum therapy may be at least partially reversed.

NMOs and their clinical partners must become familiar with the evidence-based clinical data, which is required to defend optimum hemophilia care. They must be able to collect real data that demonstrates the benefits of therapy and treatment regimes and that can be used in any formal analysis of their level of care. In short, in an environment where the financial commitment required to bring about improvements in care may no longer be feasible, NMOs must become more familiar with the economics of hemophilia care. For more information on this topic, see the WFH monograph, *An Introduction to Key Concepts in Health Economics for Hemophilia Organizations*.

Hemophilia societies are also facing financial constraints. Fundraising is becoming more difficult. Government-provided financial support is decreasing in some countries (see the example from the United Kingdom in Appendix 2). Many societies are finding that specific funding that was available in the past, specifically linked to HIV or hepatitis, has been cut or eliminated.

The fact that HIV and hepatitis have not been transmitted via any of the currently licensed factor concentrates since the early 1990s and the success of highly active anti-retroviral therapy (HAART) for HIV have contributed to these cuts. Financial assistance to people with hemophilia who have HIV has been seen in many countries as less of an imperative. However, the continuing burden of living with HIV and/or hepatitis and the more rapid clinical progression of hepatitis C in those who are co-infected with HIV has led and will, I believe, lead in the future, to a requirement for more support for this group of members. The availability of new and more expensive therapies for hepatitis C may require NMOs to be proactive in setting out the economic rationale for provision of treatment. A hepatitis C database published in Ireland (available at www.hemophilia.ie) that compares the progression of hepatitis C in the hemophilia population compared to other people infected via blood products, demonstrated a higher level of progression in the hemophilia population. This is likely true in many countries and the level of support required to address this will increase as funding decreases.

New methods of communication

Methods of communication are evolving quickly. The internet is the primary means of getting information and connecting with others. The websites of NMOs must be accessible, user-friendly, and frequently updated. They must contain relevant information delivered in relevant language. An informative and frequently updated website can be labour-intensive and costly. If you do not have the staff resources to allow for frequent updates, source volunteers (see the example from China in Appendix 2). In many places, the internet is more effective, timely, and more cost-effective than large mailings on specific issues. The U.K. Haemophilia Society has a membership and mailing list of about 7000 people. Placing an update on a crucial topic such as vCJD on the website is a faster and more effective way to share information with their membership, particularly if there are cost constraints.

Social media

Social media tools are becoming an increasingly vital medium for disseminating information and building community. Communication between young people with hemophilia or between parents or carriers may now be more likely to take place via social networking tools such as Facebook, discussion forums, YouTube, or through personal blogs or Twitter pages. More and more organizations are mobilizing and raising awareness of their cause using social media platforms.

However, the proper use of social media tools requires a clear development and management plan and the investment of resources for frequent updates and monitoring. NMOs must familiarize themselves with these rapid changes in personal and interactive communication styles and utilize them as effectively as possible.

Patient education and dissemination of information

Providing information to patients and families is a key role of the NMO. No single organization has the resources or capacity to produce all the educational materials or web content they would like. Wherever possible, NMOs should share their publications and their list of planned publications with other NMOs where the language of the publication is the same and/or the content is likely to be largely applicable to another country. If you are planning a publication, an ideal first step is to ask other relevant NMOs if they have produced or are planning to

produce a similar publication in the near future. If so, permission can be sought to use or adapt the existing publication.

Availability of materials in languages other than English is another major challenge. There is an abundance of quality information available on all aspects of hemophilia, but it is generally only available in English and/or Spanish. Hemophilia societies need to develop the ability to translate this material into their own language.

The list of WFH publications should be constantly perused by NMOs. The WFH encourages the translation and reprinting of its publications for educational purposes, and new titles are added every year. Under the leadership of Yuri Zhuylov, for example, the Russian Hemophilia Society has translated many WFH publications into Russian and distributed them throughout the country.

Recruiting volunteers and succession planning

Hemophilia societies in developed countries are also trying to develop or maintain the specific skills necessary to run a modern hemophilia society, or find volunteers with the skills required. The boards of many societies consist primarily of parents and people with hemophilia within the same age group. These societies need to attract younger members to ensure that committed volunteers are available for the future.

Developing and maintaining a pool of qualified volunteers is always a challenge. Strategies for succession planning are beyond the scope of this monograph, but NMOs must become proactive in ensuring that qualified, dedicated volunteers are available to take their organizations forward.

Having a small number of key experienced volunteers may be an attractive proposition, but the danger is that these individuals will take on an unsustainable burden. In this situation, volunteers may “burn out” and, if no strategy has been put in place to replace them, the organization may face a major lull in their activities. For more on building a healthy volunteer base, see the WFH monograph *Recruiting and Retaining Volunteers*.

Encouraging participation of new volunteers from demographic groups such as young people and people with von Willebrand disease and other rare bleeding disorders will increase your pool of potential

volunteers. New volunteers must be welcomed, trained, mentored, and recognized. Delegate responsibility to volunteers, but also supervise their activities to make sure that the tasks they are assigned are both manageable and stimulating.

NMO leaders should cultivate and encourage leadership skills in others: look at delegating tasks that other board members or staff can accomplish, and try not to take on too much at the same time. By involving people of different ages and demographics in your planning and goal setting, you will develop programmes and activities that are relevant to your membership as a whole.

Other NGOs or associations may be able to provide help and guidance when it comes to training new staff or volunteers. In some countries, there are networks of professionals who are willing to volunteer their time to non-governmental organizations and give advice and training in areas such as governance, budgeting, leadership, or strategic planning.

As hemophilia organizations develop and grow, the volunteer leadership can sometimes be reluctant to recruit and hire staff because of concern about the amount of time it would take to teach them about the unique issues facing hemophilia organizations. This is short-sighted. While it will certainly take some time to train a new staff member, the right person will soon save enormous amounts of time for the volunteers, allowing them to take on a more strategic and visionary role in the development of the organization.

Advocacy and policy setting

All NMOs should strive to have a formal role in setting national policy on hemophilia, and ideally be involved in the selection of factor replacement therapy for the treatment of hemophilia. Establishing a National Hemophilia Committee (NHC), which includes the key clinicians, the hemophilia organization, the Ministry of Health, and, in many cases, the paying authority, can be a very progressive step in improving hemophilia care. Such a committee gives the NMO a formal role in recommending and guiding policy on the development of hemophilia care on a national scale.

NHCs have been set up on a formal statutory basis in Ireland and in Georgia. In Ireland, the creation of an NHC in 2004 was the culmination of many years of work and was seen as the final step in the

development of a cohesive national strategy for hemophilia care, with the inclusion of the patient organization at all levels of the decision making process. In contrast, the National Hemophilia Council in Georgia was set up at the conclusion of the WFH Global Alliance for Progress (GAP) programme in 2007. Georgia is at an earlier stage of development in relation to national hemophilia care, but the creation of an NHC in that country shows that the formal inclusion of the NMO, the healthcare providers, and the Minister for Health in the decision-making process is the optimum way to organize care, regardless of where the country stands in the development of its hemophilia programme. It increases the influence of the NMO. It increases the opportunity for a coordinated approach to be taken by the NMO and clinicians. It increases the amount of personal contact between the NMO and the key health and government officials who make the policy allocation decisions on health budgets and can result in hemophilia having a higher profile with these key officials. The Statutory Instrument or Law establishing the NHC in Ireland and the legal terms of reference for the NHC in Georgia are included in Appendices 3 and 4.

NHCs have been established on a non statutory basis in countries as diverse as Tunisia, Jordan, Thailand, and Ecuador. The Archer Report published in the United Kingdom recommended the establishment of a formal NHC that includes the hemophilia society, the clinicians, and the Ministry for Health.

Standards and guidelines published by reputable sources can be tremendously helpful in advocacy efforts. The excellent WFH publication *Guidelines for the Management of Hemophilia* sets out practical recommendations for factor use in countries where there is no resource constraint or separately where there are significant resource constraints. It can be used as an advocacy tool when seeking access to a better level of hemophilia care. Principles of hemophilia care set out by the European Association for Haemophilia and Allied Disorders and endorsed by the EHC and the WFH set out core principles for hemophilia care, which can be and have been very useful to many European countries. They can also be used as a tool in advocating for improved treatment or care. NMOs should be intimately familiar with these documents and should use them in their advocacy and lobbying efforts.

Other recommendations were published in 2010 by the European Directorate for the Quality of Medicine (EDQM) on the optimal use of blood and blood components, which include a specific section on hemophilia. These standards and guidelines are indispensable reference materials when seeking improvements in care on a national basis.

Broadening the community

There is strength in numbers. Hemophilia is a rare disease, and governments may look at a hemophilia society and realize that it represents one person in 10,000, or 0.01% of the population. We can increase that percentage by expanding our membership to include people with von Willebrand Disease and other bleeding disorders, carriers of hemophilia, women with bleeding disorders, and others who share many of the same goals. People with severe hemophilia will always consume more of the healthcare budget in the area of bleeding disorders than any of the other groups. However, by including these other groups we strengthen the society, we bring in new members, we have more lobbying power, and we can call for greater resources to be spent in this area.

Many hemophilia societies, including those in the U.S.A., Australia, U.K., and Ireland, have made positive efforts to expand their mandate to include women with bleeding disorders. The Netherlands Hemophilia Society has incorporated people with idiopathic thrombocytopenic purpura (ITP). At first, this may not seem like an automatic link. However, if it succeeds in gaining more resources and improving the chances of better treatment in the Netherlands, then it is worth doing. There is increasing debate on the merits of providing services for persons with thrombophilia (clotting disorders) or bringing these conditions under the mandate of NMOs.

Challenges Facing Hemophilia Organizations in Developing Countries

Hemophilia organizations in developing countries face many of the same issues described above. The global economic downturn and the ensuing threat to healthcare spending are even more severely felt in the developing world. All hemophilia societies struggle to recruit and keep volunteers, particularly

young volunteers who will take the organization into the future. Communicating effectively with members is even more critical in parts of the world where the infrastructure may be inadequate and virtually no support for families exists. However, organizations in developing countries also face a different set of challenges, including:

- Lack of adequate factor replacement therapy;
- Inadequate treatment infrastructure;
- Major economic constraints;
- Communication problems;
- Lack of community among people with hemophilia.

The situation in many developing countries is far more serious than in developed countries. In some cases, there is little or no factor replacement therapy available for people with hemophilia, and many rely solely on humanitarian aid. The per capita usage of factor concentrate is often extremely low and does not conform to any definition of reasonable treatment. In addition, services tend to be located in the capital city, and in many cases there is no comprehensive approach to care.

Hemophilia is a low priority in the healthcare budget. These countries have major economic constraints, and governments have many other health priorities to deal with before they are willing to commit significant resources to improving hemophilia care. Building relationships with health officials takes a significant amount of time and energy, and it can take years to see tangible results.

Hemophilia societies in many developing countries also face many challenges with communication. There is often inadequate social support and little personal contact between people with hemophilia and their families. Availability of treatment is the primary concern. Yet real advances in treatment can only come about as a result of long-term improvements in the national hemophilia treatment system, and this means that hemophilia societies must organize themselves and create a sense of community among their members.

Skills development

Running a successful hemophilia society requires a vast mix of skills, including management, budgeting, fundraising, information technology, lobbying, public relations, counselling, and economics. In addition, leaders of hemophilia societies need to be knowledgeable about blood

products and new technology, and the politics surrounding these issues. It is impossible to employ staff who will have all these skills. Therefore, we need to find volunteers who can fill the gaps.

Management and budgeting

A hemophilia society must set out an annual budget and follow it. As voluntary organizations, hemophilia societies have a responsibility to their members to ensure that the funds raised are used properly. Proper accounting and bookkeeping procedures must be in place to make sure that all money received and spent is accounted for.

Fundraising

Fundraising must be done in an ethical manner. New and innovative techniques in fundraising also have to be explored. Fundraising activities can vary from small events such as a coffee morning to huge national campaigns. Look at how other groups fundraise in your country. Talk to other national hemophilia organizations and the WFH about fundraising ideas and plans (see one example from the United Kingdom in Appendix 2). The WFH monograph, *Fundraising*, also offers many useful tips.

It can be costly to set up a new hemophilia organization, and fundraising will likely be necessary from the outset. In the early stages you may have to rely on a number of different resources, including monetary donations or donations in kind. For example, if one of your volunteers has an office or business, he or she may let you use their facilities to photocopy, print, etc. Fundraising in itself is a specific skill, and you should try to find volunteers with experience in this area.

Lobbying and public relations

Lobbying and public relations are skills that all hemophilia societies must acquire. Hemophilia is always going to be relatively expensive to treat and in any country there will be conflicting priorities. We have a responsibility to ensure that hemophilia remains high on the government's priority list. Requests to government must be set out correctly with definite objectives over a definite time period, backed up by information from the WFH and the World Health Organization (WHO).

The WFH has organized several regional workshops on advocacy and lobbying for NMOs over the past several years. The skills transmitted to NMO leaders should in turn be passed on to key board

members. The volunteers and staff of NMOs must be familiar with and capable of using advocacy and lobbying skills to help them successfully push for improvements in care (consult the WFH monographs *Government Relations* and *Developing and Sustaining an Effective Lobbying Campaign*).

Societies should look for volunteers among their members who are working in journalism, the media, or public relations. We must be able to get our message across to politicians, health officials, and the general public. For useful tips on working with the media, see the WFH publication *Media Relations*.

Knowledge of blood and blood products and new technology

Hemophilia societies must be very knowledgeable about the collection, screening, viral inactivation, licensing, and regulation of blood products. Due to the catastrophe that befell the hemophilia community in the 1980s with HIV and hepatitis, people with hemophilia have rightly become much more proactive in terms of seeking information from their societies on new developments. People with hemophilia should be informed consumers of blood and blood products, and the hemophilia organization must be able to provide them with this information. This means hemophilia societies need to be well informed and keep up to date with safety and supply issues and new technologies, such as recombinant technology, transgenics, and gene therapy. National, regional, and international societies also need to cope with an enormous amount of information on licensing and regulation. (The WFH's *Registry of Clotting Factor Concentrates* is an invaluable reference guide).

Ideally NMOs should seek to have representatives on the national tender committees in their countries. This is the case in countries as diverse as Ireland, Brazil, Uruguay, the U.K., Canada, and Australia. In this way, hemophilia societies have an assurance that criteria such as safety, efficacy, and quality are also considered when deciding on factor replacement therapy, in addition to the cost. However, inclusion in a tender committee will only be successful if the NMO representatives are able to make a useful and knowledgeable contribution to the discussions and decisions. NMOs should identify key volunteers who have a long-term interest in representing the organization in this area. (Useful materials include the WFH publications *Guide to the Assessment of Clotting Factor Concentrates*

and *Guide to National Tender for the Purchase of Clotting Factor Concentrates*).

It is also very important that societies be knowledgeable about the economics of factor replacement therapy.

Counselling

Some hemophilia societies have funding available to provide full-time, professional counsellors, but this is not the case for most. Hemophilia societies tend to be very good at listening to their members and at helping them deal with their problems in a realistic manner. However, volunteers who provide counselling should be qualified and/or trained to do so.

Establishing and maintaining a patient registry

A patient registry is an invaluable tool for improving the lives of people with hemophilia. It is essential for tracking the identification and diagnosis of people with hemophilia and monitoring of their health, as well as long-term planning for hemophilia organizations and priority setting for health care. Having a national patient registry means being able to answer fundamental questions about the hemophilia population within your country – such information is essential for lobbying government and advocating for improved care.

In a joint meeting of the WHO and WFH on hemophilia care in developing countries held in Geneva, Switzerland in 1997, having a national registry of people with hemophilia was identified as a key priority. According to the joint report published after that meeting, “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. In order to be successful, such a scheme must guarantee confidentiality and respect for human rights.” The WFH *Guide to Developing a National Patient Registry* by Dr. Bruce Evatt is a valuable resource to help hemophilia societies build and maintain a patient registry.

Strategic planning

When we look to the future, it is sometimes disheartening to see the gulf that remains between where we are and what we still need to accomplish. Taking a strategic approach to planning will dramatically improve our ability to reach our goals. To develop a strategic plan, objectives are defined and set as long and short term goals. Priorities should be set for each year, along with a step-by-step plan for achieving them. Progress should be measured at the end of each year and goals should be re-prioritized based on progress.

Examples of five-year goals might be to increase the per capita usage of factor replacement therapy or to obtain a different type of factor replacement therapy. A three-year goal might be for the hemophilia society to acquire the skills required to accomplish this, with specific elements being sought and acquired for each of those three years. Any goal can be achieved if a step-by-step approach is taken. If it becomes apparent that an objective or goal cannot be achieved in the foreseeable future, the objectives should be redefined and new goals and priorities set.

Short and medium-term action planning is a prerequisite for the development of any organization. Objectives should be reasonable, achievable, and practicable. NMOs should examine their current level of treatment and care and the factor replacement therapy they have available in light of the economy of the country and the region. They should set achievable goals for the short and medium term. If these goals are not achievable or practicable, they will be difficult – if not impossible – to achieve, and the organization's volunteers and members will quickly become discouraged or disillusioned (for more on goal setting, see the WFH monograph *Action Planning*). Hemophilia organizations can learn from each other, which is another reason why information sharing among NMOs is so important.

Changing membership

Since the advent of viral inactivation and safe blood products in the mid to late 1980s, we are now seeing a generation of children with hemophilia who have a vastly different set of needs and are unaffected by HIV and hepatitis. As the level of care in a country evolves, more have access to prophylactic therapy, should have a better quality of life, and enjoy full integration into society. They will be more concerned with sports and with leading a normal life.

This new generation of members presents many challenges to hemophilia societies. We must ensure that we cater to the needs of this group and that we do not decrease or diminish their expectations by reference to our own, probably lower, expectations, having lived with severe hemophilia in a time when treatment was either unavailable or unsafe.

In developing countries, we must work to ensure that the next generation of children have the opportunity to benefit from adequate and safe therapy. That will allow them to look beyond the narrow confines of previous generations and cherish the expectation and reality of a more normal quality of life. Recruiting and engaging young people to contribute to the work of the hemophilia society is just as important as it is in the developed world, to support and sustain the work of the organization over the long-term.

Building community and joining forces

One of the keys to a successful organization is to link up with individuals and organizations with related interests so you can work together toward common goals.

Establish one national organization

To make progress in hemophilia care in any country, people with hemophilia must work together in a strong, unified national organization. Several local groups acting independently of each other in different regions, with no national plan or structure, can waste valuable resources and even hinder each other. Different groups operating within a country should come together to form a stronger, national organization, while ensuring good regional representation.

Depending on the geographical distribution of people with hemophilia and the size of the country, it may be sensible to have local groups or chapters. However, they should operate under the umbrella and coordination of a national organization.

Build a partnership with treaters

The traumatic history of hemophilia, including HIV and hepatitis in the last 25 years, led to situations of conflict between doctors and NMOs and between NMOs and governments, and to the absence of a coordinated, cohesive approach to the development of hemophilia care on a national level in many countries. This has now been rectified in most countries, but these issues from the past can

be a salutary lesson. NMOs must recognize the importance of coalition-building between the NMO and the key clinicians who treat hemophilia, and the importance of a coordinated advocacy approach.

Hemophilia societies should work closely with the treaters in their country to lobby government to develop a national plan for improving hemophilia care. If government is faced with conflicting demands and requirements from hemophilia treaters on the one hand and hemophilia societies on the other, they will probably ignore both. If the government is faced with a unified request from the hemophilia society and the treaters, it has a much greater chance of success.

Improve communication with national and international organizations in related areas

National hemophilia societies can benefit from building stronger links with organizations that share similar goals, such as AIDS organizations, liver disease foundations, various blood and plasma user groups, and societies for other inherited disorders. In both the U.S. and Europe, the hemophilia community has joined with other organizations whose members rely on plasma-derived products. These include conditions such as primary immune deficiencies and alpha-1-antitrypsin deficiency. In some areas of policy, joining forces can lead to more influence on the debate. In Europe, a plasma users coalition (PLUS) consisting of seven organisations (including hemophilia) has succeeded in obtaining regular access and consultation with the European Commission where it would have been very difficult for any of the separate organisations to achieve this. A similar coalition (A-PLUS) exists in the United States.

Better access for people with disabilities or mobility difficulties, improved social welfare allowances, and better treatment for HIV and hepatitis are all areas where improvements will benefit the members of several organizations. Co-operation with these other groups can increase the effectiveness of lobbying on these issues. Legislative change in areas such as patenting on biotechnology or orphan drugs can significantly alter the conditions for the development of gene therapy or new or novel products. These developments hold out much hope for the future, not only for people with hemophilia but also for many others with inherited disorders. Co-operation and a joint approach to lobbying can increase the possibility of appropriate legislation being passed.

Hemophilia organizations can also benefit from building ties with international organizations. The WFH has strong links with the WHO, the International Federation of Red Cross and Red Crescent Societies, and the International Society of Blood Transfusion. The EHC has developed links with organizations such as the International Patient Organization for Primary Immune Deficiencies, the rare diseases coalition EURORDIS, as well as with several of the European genetic support groups, which share concerns on E.U. directives and guidelines.

The Role of the WFH

The WFH has a vital role to play in helping develop strong national hemophilia organizations. Governments and health ministers place great emphasis on official documents and official guidelines from the WHO. The WFH is officially recognized by the WHO as the organization with expertise in the area of hemophilia.

The WFH is willing and able to help improve hemophilia care in any country by assisting the national hemophilia society intervene with their government. The WFH has met with the health ministers in many countries, alongside the national hemophilia society, to support their goals and interests.

The WFH provides training programs for doctors and healthcare workers, and has organized countless workshops all over the world to help patients and NMO leaders acquire the skills necessary to support the goals of their organizations. The Advocacy in Action workshops are specifically designed to provide patient organizations with tailored advocacy training, individualized coaching and support, dedicated advocacy leadership and resources, and advocacy tools. The WFH also produces a number of publications, many of which are listed in this monograph, and other resources to help patient groups build strong and effective organizations.


The WFH's Hemophilia Organization Twinning (HOT) program has greatly assisted the development of many hemophilia associations by creating partnerships with well-developed, knowledgeable, and experienced societies. The HOT

program also helps the more developed society by presenting it with new challenges. A new challenge can be invigorating to an organization and offers the opportunity to increase experience and expertise.

Conclusion

Above all, hemophilia societies must develop national policies and goals, understand the realities of their region, and appreciate the global reality for people with hemophilia.

While national differences are acknowledged, the hemophilia community is one global community, and we should advise and assist each other in reaching our mutual goals.

Developing and sustaining an effective national patient organization requires many skills, much perseverance and an integral approach including volunteers, staff, and key clinicians. Hemophilia societies have to be professional, even if they are operating with 'amateur' resources. They have to be business-like, but compassionate. NMOs are there to serve the interests of their members and the hemophilia community. It is important not to lose the sense of humanity that should underpin the work and ethos of all NMOs. Regardless of the unique challenges each may face, the ultimate aim is to make a difference to the lives of people with hemophilia. 

APPENDIX 1

Suggestions for Creating a Strong Hemophilia Organization

1. Find committed and enthusiastic volunteers

Find volunteers who are keen and enthusiastic. They should be people who will stay and help for some time. Finding people with the right skills is hard work. You don't want to lose them after one or two years. New people need to be brought in alongside experienced ones.

2. Establish a list of members

Keep a list of members with the names of as many people with hemophilia around the country as possible. This is called a registry. Building a registry may be hard at first if you are starting a new group. People with hemophilia often do not know each other. If there is a hospital that treats people with hemophilia, the staff can help you make contact with patients.

Here are some ways to let people know about your group and build your membership list:

- a. Ask the hospital or hospitals that treat people with hemophilia to let patients know about your organization. Ask the hospital to send out a membership form with a letter with your group's address and telephone number on it. Forms can also be handed out to people when they visit the hospital.
- b. Ask hospital staff if volunteers from your organization can be at the hospital during hemophilia clinics to give out information about your organization.
- c. Find low-cost ways to publicize your group, such as writing letters to local and national newspapers or speaking on local radio stations.

If you have a lot of names on your mailing list, you should look into segmenting it. A hemophilia society is not a homogenous entity. Within each society you will find people with hemophilia A, hemophilia B, von Willebrand disease, carriers, and people with other bleeding disorders, as well as those with HIV, hepatitis C, hepatitis B, and inhibitors in various combinations. It is very useful to have a database that can stratify your membership to allow for specific publications and meetings to be planned for specific groups. A database can also be stratified by geographic location and by age.

3. Access information from other hemophilia organizations

Much of the information you need and solutions to many of the problems you face will be available from other hemophilia groups or the WFH.

- a. Use the publications and information available from the WFH.
- b. Use the publications and information available from hemophilia organizations in other countries, particularly if you share the same language.
- c. Use the network of the European Haemophilia Consortium (EHC).
- d. Have your organization added to the mailing list of other strong hemophilia groups, such as those in the U.K., U.S.A., Canada, Australia, Netherlands, India, and Ireland.
- e. Ask the WFH for a "twin." This special one-on-one relationship helps new hemophilia groups develop quickly.
- f. Get your group connected to the Internet, an excellent source of information.

4. Access to translation

Make sure you can translate information into your national language or languages. Also, have members on your executive committee who can speak English or Spanish. These people can communicate with other hemophilia organizations on your behalf as well as attend and benefit from international meetings.

5. Communicate effectively

Make sure that you can communicate nationally and with other societies. Ensure that you have access to phone, fax and e-mail.

6. Establish a permanent address

Make sure that your organization has a permanent address. Many societies start by working from the home of a volunteer. If this is the case, the same address should be used permanently until the society moves to an office location.

Make sure that the address for your group is attended full time or part time by volunteers or paid staff. Information will not get to your organization if it cannot be reached. Having someone in the office even one or two days a week is a major advantage.

7. Obtain official recognition

Get official recognition for the organization using the appropriate structures in your country:

- a. Register as a recognized charity, which may give you tax-exempt status for any fundraising that you carry out. In some countries it is necessary to register with the government as an official organization.
- b. Check with the WFH to find out if another national hemophilia organization already exists in your country. If such an organization does exist you, you should work together. If no other organization exists, register with the WFH as a “forming National Member Organization” and work towards achieving full member status.

8. Organize national meetings

Hold a national meeting at least once a year. Conduct the business of the organization and elect your executive committee at this meeting. Decide what the group will do for people with hemophilia in your country over the next twelve months.

Depending on the size of your country and where most of the people with hemophilia live, it may be possible to hold more meetings each year. You can organize meetings to educate people about particular topics so they learn that the hemophilia society is a reliable place to get information. Meetings allow people to meet and make strong friendships. All of this strengthens the organization and allows you to find new and skilled volunteers.

9. Keep minutes of meetings

Minutes of meetings of the executive committee should be kept in a proper form. Ideally the following should be noted for each item discussed:

- Decision taken
- Action required
- Responsibility (who will carry out this action)
- Timeline.

In a national organization, rules and procedures have to be put in place to make sure volunteers can be elected onto the board or executive committee.

Basic procedures for running meetings and for keeping minutes of meetings are very important. If you need further guidance or assistance in this area, then you should talk to well-established organizations in your own country and look at the way they carry out their functions. Internationally you should make contact with the WFH and other national hemophilia societies who can give you assistance with this.

10. Produce a newsletter

Produce a regular newsletter. Newsletters can be produced cheaply with a computer using desktop publishing. It doesn't need to be glossy and expensive. The most important features are the frequency of the publication and the information inside. A simple one- or two-page newsletter produced every month is far better than a glossy newsletter that is produced once a year.

You can find information for your newsletter by looking through the publications put out by the WFH and other national hemophilia societies. The information can be adapted to suit your needs or entire articles can be translated and published in your newsletter. It is very common practice for one hemophilia society to reprint articles from newsletters of other hemophilia societies. Remember to request permission to reprint the article, unless it is stated in the original publication that articles can be reprinted, and acknowledge the source of the article.

11. Provide outreach to regions

It is important to keep in contact with and provide services to people with hemophilia in other regions of the country outside the capital city and to ensure that these people are members of the national organization.

12. Educate the public

Public education in itself is important in many countries. Knowledge of hemophilia among the general public is either non-existent or limited to the story of Alexis Romanov, the Russian czarovich. Many people still assume that people with hemophilia bleed to death from any cut. They must be informed that, with the availability of modern and proper care, people with hemophilia can lead a normal life and can be valued members of society. Children with hemophilia who attend school and men with hemophilia who work will require the assistance of their national hemophilia society to ensure that their teachers and employers are aware, in a realistic way, of their hemophilia.

APPENDIX 2

Profiles of Hemophilia Societies

The following profiles provide brief histories or outline specific development steps or challenges that other hemophilia societies have faced. These serve to highlight the different ways that hemophilia organizations have developed and to highlight some of the major milestones in their development. I am indebted to the following people for their contributions:

- Vijay Kaul, India
- Josef Weiss, Austrian Hemophilia Association
- František Vondryška, Czech Hemophilia Society
- Marius Pigulevicius, Lithuanian Hemophilia Association
- Brian O'Mahony, Irish Hemophilia Society
- D.R. Adhikari, Nepal Hemophilia Society
- Christopher James, UK Hemophilia Society
- Reynaldo R Sarmenta, HAPLOS, Philippines
- Yuguang Chu, China

Starting a Hemophilia Society in a Developing Country

by Vijay Kaul, Hemophilia Federation (India)

The following suggestions for hemophilia organizations in developing countries are based on the realities existing here and on the belief that having a treatment centre and availability of therapeutic material are fundamental needs.

- After a committed group of volunteers has been identified, finding a treatment facility should be the first priority because, in developing countries, treatment comes first, education comes next.
- Convene a meeting of people with hemophilia, their guardians, and treaters to discuss and decide on the fundamental aim of the society. For example, will the society be organizing treatment and therapeutic material or will it stimulate the government system to provide treatment?
- Compile some basic data on the economic status, diagnosis, and physical condition of people with hemophilia in the beginning to help define strategies. It will also help the society organize treatment facilities and factor requirements.
- Treaters should be part of the society's executive committee. They will help the society make the right decisions on certain medical issues.
- In practical terms, the face of the society is the person who looks after the day-to-day affairs of the society and meets and advises people with hemophilia. If a person with hemophilia receives good guidance from the society, half the battle is won. This person will liaise with other people who matter to the society. Therefore, the leader of the society needs to have very good communications and public relations skills, as well as to have some time every day to work for the society. Choosing the right person from the executive committee is advisable.
- When holding a meeting of members, have something very interesting on the agenda to encourage participation.
- Promote the credibility of the society by being transparent with members about the society's workings, finances, and decision making.

Milestones in the Development of the Austrian Hemophilia Association

by Josef Weiss, Austrian Hemophilia Association

1960s

- The Austrian Hemophilia Association was founded in 1966 by Prof. Erwin Deutsch at the First University Medical Hospital of Vienna. It is the oldest medical self-help group in Austria and one of the oldest in the world. Since its establishment, the Association has represented the interests of people with coagulation disorders and their families throughout the country.
- For the first ten years, the Association's executive board was made up of physicians and mothers.
- The Association collected all available information on hemophilia and passed it on to patients whenever possible.
- The number of patients treated and advised at the First University Medical Hospital of Vienna increased from year to year. Over time, a list of members was developed that could also be used for sending out invitations to meetings. However, attending physicians remained the primary means of communication with members.
- The first treatments with plasma products were administered.
- After a few years, more and more of those affected by hemophilia became interested in the Association's work and participated in various areas.

1970s

- In the early 1970s the idea of a summer camp for children was born.
- The Association increased communication with members. First newsletters and then a regularly published journal disseminated all of the available information about hemophilia and the Association's activities.

1980s

- Beginning in the early 1980s, the work of the Association was carried out almost exclusively by people with hemophilia. The physicians increasingly withdrew into advisory capacities.
- Membership files were kept and updated by the Association.
- The supply of coagulants constantly improved.
- Hemophilia centres (out-patient departments) were established in the larger hospitals in the various German states.
- The three-week annual camp was improved from year to year. At the summer camps, patients practiced treating themselves with coagulants.
- Self-treatment enhanced the independence and mobility of patients.
- Members were kept interested and informed through a quarterly newsletter for members, an annual general meeting, countrywide conferences every two years, regional meetings, parents' circles, videos, informational books, etc.
- In the late 1980s, it became clear that many people with hemophilia were infected with HIV. The following years were marked by great disarray among patients and, in some cases, distrust of the pharmaceutical industry and the physicians providing care.

1990s

- Long and difficult negotiations with the pharmaceutical industry, health authorities, and state authorities led to the establishment in the early 1990s of a benefit fund for individuals affected by HIV and their relatives.
- The Association's board of directors now consists of three people with hemophilia as well as the mother and father of a child with hemophilia. Project work can be delegated to the extended board (currently one person with hemophilia). The management of the Association and the benefit fund are in the hands of a physician with hemophilia. The Association is supported by a Scientific Advisory Board that includes prominent experts from all over Austria.

History of the Czech Hemophilia Society

by František Vondryška, Czech Hemophilia Society

The first hemophilia society was set up in the West Bohemian region of the Czech Republic in 1971. The Lay Union of Hemophiliacs came into existence as part of the Union of Invalids. Our aim was to carry out our activities throughout Czechoslovakia. We notified the World Federation of Hemophilia of our organization and received approval. Unfortunately, the government in Czechoslovakia did not favour our activity. Co-operation with the West was out of the question and so after a few years our organization was dissolved.

A fundamental turning point occurred in 1989, when Czechoslovakia became a democratic country. In 1990, independent Czech and Slovak hemophilia organizations were set up but they later united to become one Czechoslovakian society. It became a recognized member of the WFH in 1990. The new society immediately began to work closely with the Austrian Hemophilia Society. Helmut Heissig, the Austrian Society's president at that time, helped enormously with organizing activities for improving the quality of life for people with hemophilia in our country. We also started to work with the Federal Republic of Germany. Our children with hemophilia have taken part in their summer camps twice.

In 1991 our society organized the European Haemophilia Consortium meeting in Prague. It was a very important event as it was the first time the meeting took place in an East European country.

In 1993 Czechoslovakia split into the Czech Republic and Slovakia. Two independent hemophilia organizations were formed, but they continue to work together. The most recent example of this cooperation was a meeting of Central European hemophilia organizations, which was held in Northern Moravia. We are very interested in maintaining good relations between the two societies.

Our society has a seven-member committee, which can be made larger if necessary. We enjoy good cooperation with specialists in different areas who help both children and adults with hemophilia.

Development of the Lithuanian Hemophilia Association

by Marius Pigulevicius, Lithuanian Hemophilia Association

When Lithuania, which is located near the Baltic Sea, got its independence from Russia in March 1990, the situation became critical for the country's 150 people with hemophilia because until that time most of them were treated in the Soviet Union. The Norwegian Hemophilia Society suggested that a hemophilia association be established in Lithuania, and in 1991 Dr. Jurgutis and Dr. Rageliene founded the Lithuanian Hemophilia Association.

There were some serious problems that had to be overcome. First, we did not have a registry of people with hemophilia - we had to make it. Second, we had to establish a hemophilia centre (it was done with Dr. Jurgutis's help). Third, our doctors had only a theoretical knowledge of treatment. With the cooperation of the Norwegian and Swedish hemophilia societies, Lithuanian doctors were trained in these countries. Two physiotherapists were trained there also.

We began publishing a newsletter. We also published two books about hemophilia and distributed them to people with hemophilia, their relatives, and doctors. We began organizing summer camps too. The Association's first summer camp took place in 1993 with the assistance of the Norwegian Hemophilia Society. Since then summer camps have been held annually.

With the help of the World Federation of Hemophilia we became twins with the Norwegian Hemophilia Society and the hemophilia centre was twinned with Malmö Hemophilia Centre. Our twins shared their experience and gave us a lot of useful comments.

We think that it is very important to work together with the associations that are already experienced. Their help is very useful for young and inexperienced organizations.

Major Steps in the Development of the Irish Hemophilia Society

by Brian O'Mahony, Irish Hemophilia Society (IHS)

The Irish Haemophilia Society was founded in 1968. The main initial priorities were:

- a. Establishment of a National Hemophilia Treatment Centre.
- b. Provision of treatment free of charge.
- c. Education of boys with hemophilia.

1970 The National Haemophilia Treatment Centre was established in Dublin, the capital city.

1972 The National Co-ordinating Committee was set up under the auspices of the Department of Health as an informal group to discuss the development of a national strategy for the treatment of hemophilia. The committee consisted of representatives from:

- Department of Health;
- Department of Education;
- National Haemophilia Treatment Centre and two other centres;
- IHS; and
- Blood Transfusion Service Board.

The Co-ordinating Committee was largely ineffective as they had no formal role or mandate and the decision making process was not collegial.

1970 Distribution of newsletter.

1970s Outreach by volunteers around country to encourage persons to join the organization.

An annual budget was established. Very tight accounting procedures were set to keep track of all money received and spent.

Minutes of meetings were kept in a specified minutes book.

Fundraising events – usually on a small scale – were held on a regular basis.

The search continued for new and committed volunteers from among parents and people with hemophilia. After ten years in existence, people with hemophilia were replacing parents on the executive.

1980s When the consequences of HIV became apparent for people with hemophilia, a small group of committed people who had established working relationships with politicians, the Department of Health, and journalists and were able to actively advocate for people with hemophilia. This resulted in:

1987 First permanent office of the Irish Hemophilia Society established and first part-time staff member employed.

1989 Following a protracted lobbying campaign, Financial Recompense acquired for people with hemophilia and HIV.

1989 First full-time staff member employed.

1990 First full-time counsellor employed.

1991 Compensation for persons with hemophilia infected with HIV acquired after a long and protracted publicity and political campaign.

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- 1996 Compensation for people with hemophilia infected with hepatitis C acquired and specific medical services for such persons established.
- IHS hosted the WFH Congress in Ireland.
- 1997 Prophylaxis for all children with severe hemophilia became available.
- 1998 All people with hemophilia A treated exclusively with recombinant products, following representations to health minister by IHS in collaboration with doctors.
- 1999 All people with hemophilia B treated exclusively with recombinant products.
- 1999 Kidlink and Young adult programmes launched to attract more children with hemophilia and young adults and to broaden participation in meetings and activities.
- 2000 Tribunal of Inquiry into Infection of People with Hemophilia with HIV and Hepatitis C established (Lindsay tribunal).
- 2001 Tribunal reports.
- 2002 Establishment of Haemophilia Product Selection Board giving clinicians and the IHS a formal role in the selection of treatment products for the entire country.
- 2004 National Haemophilia Council established as a Statutory Body with responsibility for advising the Minister of Health and health authorities on all aspects of policy and priorities for hemophilia. NHC includes the ministry of health, the health authority, clinicians, and the IHS.
- 2006 First participants who initially participated in Kidlink/teenage group elected to IHS board.
- 2007 Government subsidised Life Insurance and Mortgage insurance made available on a statutory basis for people with hemophilia infected with HIV and /or hepatitis C
- 2007 IHS purchases their headquarters. Official opening by the President of Ireland.
- 2008 Government subsidised travel insurance available for those people with hemophilia with HIV and/or Hepatitis C.
- IHS hosts European Haemophilia Consortium conference.
- 2009 IHS website relaunched.

History of the Nepal Hemophilia Society

by D.R. Adhikari, Nepal Hemophilia Society

Before the setting up of the Nepal Hemophilia Society (NHS), hemophilia patients were treated only with fresh frozen plasma (FFP) from the Nepal Red Cross Blood Transfusion Service Center (NRCS BTS) in Kathmandu, which is the only supplier of FFP in Nepal even now. Fortunately, Dr. Ranjan Singh was the national director of NRCS BTS at the time and he looked after the people with hemophilia as well. But with the increasing number of patients, a separate hemophilia society was needed.

The NHS was formed in 1992 under the chairmanship of Dr. Singh with the coordination of people with hemophilia and their guardians. The NHS appreciates the invaluable contribution of Dr. Singh as the founder chairman of the NHS. The establishment of the NHS was possible because he was the director of a relevant organization where people with hemophilia came regularly for transfusions. Thus, for a successful outcome, having the right person in the right place is very necessary.

The NHS has benefited from visits from other hemophilia societies, such as Mr. Ashok Verma of Hemophilia Federation (India) and Ms. Brigitta Rehnby and Mr. Patrik Östberg of the Swedish Hemophilia Society. The NHS's participation in the 23rd WFH Congress in the Hague, the Netherlands, with the support of the WFH, was a golden opportunity to exchange ideas and experiences with other WFH member organizations. The NHS started a twinning partnership with the Swedish Hemophilia Society and various activities are under way.

WFH training fellowships awarded to Dr. B.L. Bjarachrya, a pediatrician, and Dr. M.P. Srivastava, an orthopedic surgeon, have helped develop skills for treating hemophilia in Nepal.

After continued efforts by the NHS and its current chairman Dr. K.R. Pandey, who is also director general of HMG health services, Bir Hospital (one of the major government hospitals) has provided a room to start a hemophilia care unit. This is one of our major achievements, which was made possible with the cooperation of government.

Although we have a lot to do in the days to come, the NHS is moving step by step towards improving hemophilia services in Nepal.

U.K. Haemophilia Society – Recent Challenges

by Christopher James, U.K. Haemophilia Society

Blood product procurement

There has been no history of involvement of the Haemophilia Society or patients in the procurement and tendering process for blood products. The Haemophilia Society has attempted to change this for a number of years. In 2006, we were approached to have some involvement, but we were unable to follow this up and the process went ahead without us.

In 2007 the Society, in its submission to Lord Archer's Inquiry into contaminated blood and blood products, recommended that inclusive care could be achieved by the creation of a formal body such as a National Haemophilia Committee on a statutory basis. This body would ensure involvement of patients in policy-making about their treatment. We also asked for formal participation in a tender process in order that we could guard against decisions being made purely on price. In his report, Lord Archer recommended the establishment of such a committee, which would have responsibility for the selection, procurement, and delivery of the best therapies available. Despite the British Government's poor response to Lord Archer's recommendations, due to consistent campaigning by the Society, key stakeholders including the Department of Health over the past two years, we now have a presence in the room in the current tendering round.

In 2008, having been invited to attend the Training Course on Replacement Therapy organized by Brian O'Mahony and Dr. Bruce Evatt, we selected two staff members and a recently-appointed trustee to attend. This training came at exactly the right time for us to help in our efforts to influence and participate in the national tender. We have now attended two training courses now have a team of three people leading our engagement.

Whilst the tendering process is in its early stages, our first impression is that we are making a real difference in establishing the criteria on which products will be judged and ensuring that, this time around, the decisions will not be purely based on price. The training and information and the opportunity to share ideas and experiences with European partners has been key to this success.

Fundraising

All hemophilia societies face one key challenge: they are supporting people with a relatively rare condition and therefore do not have a large supporter base. However, we have a high profile condition. The effect of the contaminated blood disaster and the high-cost of treatment combine to put enormous pressure on the organization as we seek to deliver our services.

The U.K. is fortunate to have a culture of charitable giving, which enables us to develop voluntary donations and take advantage of a well-established network of grant-giving bodies to which we can apply for funding. However, as a small organization we are competing for those funds with larger organizations with greater resources.

For a number of years the Society was sustained by a Government Core Grant of £100,000 per annum, which gave us some security for developing our work. However in 2006 this was reduced to £60,000 and then £30,000 per annum in 2007 and 2008. Combined with a drop in our legacy income, this meant that our activities were no longer sustainable – in late 2008 we were very close to ceasing to exist. We were forced to restructure and reduce our output. Our costs have been reduced by £90,000 in 2008-9 and a further budgeted decrease of £100,000 will be implemented in 2009-10.

We have worked very hard on other income streams including establishing better relationships with the industry – they are now our largest funders – and developing our projects and services in such a way that they appeal more to both statutory and trust funders.

Our greatest challenge for the future is to secure unrestricted funding. We are now making sure that all our funding applications for projects and services include significant elements of core cost, such as salaries and overheads. We are exploring other avenues such as direct marketing, but we see one of the main areas of development as event fundraising and are currently focusing on this.

The future for the Society is going to be tough, but it is essential that we achieve the financial stability we seek so that we can continue as the only national and independent organization for people with bleeding disorders in the U.K.

Development of the Hemophilia Association of the Philippines for Love and Service (HAPLOS) Foundation, Inc.

by Reynaldo R. Sarmenta

History and Structure

- Established in 1993 by 17 hemophilia families together with some haematologists. Registered later as a Non-Profit Organization. Its original office was at the National Hemophilia Center in UST Hospital. At present it shares office space with the Philippine Hemophilia Foundation (PHF) at another hospital.
- The Board of Trustees is headed by the Chairman. The other officers are the President, Vice-President, Treasurer, and Secretary. Working committees handle the different programs and activities.
- During the first ten years, the governance of HAPLOS has been a joint undertaking of parents and doctors. Today the doctors are no longer directly involved, but they continue to give their support through the PHF.

Community and Organizational Programs (developing a strong patient organization)

- Long-term strategic planning is done jointly with PHF. We conduct yearly reviews of operations and planning for the ensuing year.
- Fundraising activities include movie premieres, musical concerts, bingo socials, contributions from business, civic groups, other NGOs, corporate friends and even personal friends, relatives, etc.
- Advocacy is done through a multi-media approach e.g., interviews on TV and radio, audio visual presentations to media, civic groups like Rotary Clubs, student groups, etc, news articles, press releases in print media.
- Participated in the WFH GAP program and was paired with the Hemophilia Foundation of Victoria through the Twinning Program. Senior leaders were trained through participation in WFH Congress, WFH NMO Training Workshops, WFH Youth Leadership Training Seminar, and other WFH conferences.
- Reaching out to other hemophilia groups in the country with the support of WFH. Continuing cooperation with groups in the cities of Cebu, Davao, and other provincial hemophilia groups are done in conjunction with PHF's registry program.

Membership Capability Building (developing a committed and empowered membership)

- Membership meetings are held on a bi-monthly basis. Activities include education on home care therapy, first aid, physiotherapy talks, emotional health topics and livelihood programs. It is also a venue for mutual support.
- Member's development is carried out via national conferences, psychosocial workshops, sessions on hemophilia care (including topics such as inhibitor development, fibrin glue) and participation in research conducted by doctors.
- Psychosocial and emotional health programs include summer camps and physiotherapy activities.
- Newsletter – Hemophilink – has resumed publication recently. Our website is being reactivated. Communication with members is mostly through texting. Email is also available to many.
- Hemophilia care programs like care delivery, laboratory diagnosis, medical treatment, and education on treatment products are mostly done by the PHF. HAPLOS is a partner, participant and beneficiary of these programs.

Government Support

- In April, 2008, President Gloria Macapagal Arroyo Proclaimed April National Hemophilia Month and April 17 as Hemophilia Day.
- Government relations are usually done jointly with PHF. Hemophilia has gained support in the implementation of the National Voluntary Blood Services Program (NVBSP) of the Department of Health by being identified as one of the major beneficiaries of the program.
- HAPLOS was the lead convenor in the first summit on "Hemophilia Care vis-à-vis the National Voluntary Blood Program". Participants included the Department of Health, Philippine National Red Cross, Philippine Blood Coordinating Council, PSHBT, PHF and HAPLOS.
- A Memorandum of Understanding for the Advancement of Hemophilia Care is ready for signing. We hope for more government support for HAPLOS and the other stakeholders of hemophilia from this relationship.

Challenges

- Need for more aggressive fundraising programs to continue programs mentioned.
- Limited availability of volunteers among parents or persons with hemophilia due to financial and health constraints
- Availability of factor concentrates at affordable cost.

Introduction of Hemophilia Home of China Website

by Yuguang Chu, Hemophilia Home of China

Hemophilia Home of China (HHC) originated from the establishment of a website, which was created by some people with hemophilia. It has become the largest Chinese hemophilia patient group with more than 4,000 registered members.

China has a large population and vast territory so it also has the largest number of people with hemophilia in the world. However, before the establishment of HHC, many patients with no access to proper treatment also had no access to information about hemophilia treatment and care. They live in isolation with a sense of loneliness and helplessness. In May 2000, a website named Hemophilia Home of China (www.xueyou.org) was created and run by some patients. In October of 2000, based on the website, the hemophilia patient organization Hemophilia Home of China was established.

In 2003, with the support and help of the WFH, the HHC website was updated. The updated website includes Basic Knowledge, Chinese Traditional Medicine, Treatment Guides, Media Reports, Doctors Online Services, Registration of Patients, Hemophilia News, Knowledge of Hemophilia, Hemophilia Experience, Hemophilia Life, Online Surveys, E-magazines, Chat Room, Guestbook, Forums and other items.

Now the HHC site has become the most well-known, authoritative website in the Chinese hemophilia community and even many doctors and nurses visit the site often. There are more than 4,000 patients from 30 provinces and cities registered through the site. Six experts including a pediatrician, emergency physician, nurse, dentist, psychologist and physiotherapist contribute their time and energy to answer patients' questions on hemophilia through the website. In addition, prominent national hemophilia experts are invited to deliver hemophilia-related lectures via a video chat-room and answer patients' questions. This gives many patients living in remote areas the opportunity to consult with these experts face-to-face. It would be impossible for patients to do so without the Internet. Through the "Treatment Guides", many patients find the proper hospitals or treatment centres where they can go to get diagnosis and/or timely treatment. HHC also organizes network activities such as essay writing and photography competitions through the website in order to help patients develop courage and confidence.

Many patients with frequent bleeding and disabilities cannot leave their houses. The HHC website not only gives them knowledge and information but also provides a platform for them to communicate with the outside world. HHC is a common home for hemophilia patients!

APPENDIX 3

Law Establishing National Haemophilia Council in Ireland

SI No. 451 of 2004

NATIONAL HAEMOPHILIA COUNCIL (ESTABLISHMENT) ORDER 2004

I, Micheál Martin, Minister for Health and Children, (herein referred to as “the Minister”) in exercise of the powers conferred on me by Section 3 of the Health (Corporate Bodies) Act, 1961 (No. 27 of 1961) as amended by Section 22 of the Health (Amendment) (No. 3) Act, 1996 (No. 32 of 1996) and adapted by the Health (Alteration of Name of Department and Title of Minister) Order 1997 (S.I. No. 308 of 1997) hereby order as follows:

1. This Order may be cited as the National Haemophilia Council (Establishment) Order 2004.

2. In this Order:

“Chairperson” means the Chairperson for the time being of the Council;

“Council” means the National Haemophilia Council established by this Order;

“Eastern Regional Health Authority” means the authority established under section 7 of the Health (Eastern Regional Health Authority), Act, 1999;

“haemophilia” means the following disorders: inhibitors to factors VIII and IX, inherited deficiencies of factors I, II, V, VII, VIII, IX, X, XI, XIII and Von Willebrands Disease;

“health board” means-

- a. A board established under section 4 of the Health Act, 1970, or
- b. An Area Health Board established by section 14 of the Health (Eastern Regional Health Authority) Act, 1999;

“Minister” means the Minister for Health and Children;

“officer” means an employee of the Council, unless the context otherwise requires.

THE COUNCIL

3. (1) A body to be known as the National Haemophilia Council is hereby established to perform the functions conferred upon it by this Order.

(2) The Council shall be a body corporate with perpetual succession and a seal and with power to sue and be sued in its corporate name and to hold land.

4. (1) The principal function of the Council shall be to advise the Minister, the Eastern Regional Health Authority, health boards, hospitals and other persons on any matter relating to haemophilia, on its own initiative or at the request of the Minister, the Eastern Regional Health Authority, health boards or hospitals.

(2) Without prejudice to (1) the Council may provide advice relating to:

- i. the care and treatment of persons with haemophilia;
- ii. protocols for treatment of haemophilia;
- iii. health services (including counselling services) for persons with haemophilia;
- iv. education and training of staff who provide services for persons with haemophilia;
- v. education and health promotion for persons with haemophilia and their families;
- vi. the changing needs of persons with haemophilia, in order to help ensure that health services respond effectively to such changing needs;
- vii. developments arising from research into haemophilia;
- viii. appropriate support services for the families of persons with haemophilia.

- (3) The Council may promote its functions through the publication of documents, organisation of conferences and recommending measures to promote the health of persons with haemophilia.
- (4) The Council may request advice from any person in relation to the performance of its functions.
5. (1) The Council shall, not later than 30th June of each year, present an annual report to the Minister in relation to the performance of its functions during the preceding year and for the purposes of this provision the period commencing on the date of this Order and ending on 31st December, 2004, shall be deemed to be a calendar year.
- (2) The Council shall submit to the Minister such information regarding the performance of its functions as the Minister may from time to time request.

MEMBERSHIP OF THE COUNCIL

6. The Council shall consist of not more than 11 members appointed by the Minister, of whom-
- a. 2 shall be appointed on the nomination of the Irish Haemophilia Society;
 - b. one shall be the National Haemophilia Director;
 - c. one shall be a consultant haematologist with an interest in paediatric haemophilia;
 - d. one shall be a consultant haematologist working outside the functional area of the Eastern Regional Health Authority, who treats persons with haemophilia;
 - e. one shall be a registered nurse with an interest in haemophilia;
 - f. one shall be a member of a registered profession with an interest in haemophilia;
 - g. one shall be nominated by the Chief Executive Officers of health boards;
7. The Minister shall appoint one of the members of the Council to be the Chairperson of the Council.

TERM OF OFFICE

8. The term of office of the Chairperson and of each ordinary member of the Council shall be 3 years from the date of appointment. Members may be appointed for more than one term of office. The Chairperson shall hold office until he or she ceases to be a member of the Council or until the Minister appoints another person to be Chairperson.

APPENDIX 4**Law Establishing National Haemophilia Council in Georgia****MINISTRY OF LABOR, HEALTH AND SOCIAL AFFAIRS OF GEORGIA
ORDER**

05.04.2007

Tbilisi

125/0

On Establishment of the Consultative Body - "Hemophilia Council"

Pursuant to sub-clause "p", clause 2, article 5 and article 19 of the Decree No 249 as of December 31, 2005 issued by the Government of Georgia on Approval of Regulations of the Ministry of Labor, Health and Social Affairs of Georgia.

I order

1. The Consultative Body - "Hemophilia Council" be established with the following composition:
 - a. Irakli Giorgobiani - First Deputy Minister of the Ministry of Labor, Health and Social Affairs of Georgia (Chairman of the Council);
 - b. Levan Jugheli - Deputy Minister of the Ministry of Labor, Health and Social Affairs of Georgia (Deputy Chairman);
 - c. Zaza Bokhua - Advisor of the Office of the Minister of the Ministry of Labor, Health and Social Affairs of Georgia;
 - d. Ramaz Laghidze - Chief Specialist of the Department for Healthcare and Emergency Management of the Ministry of Labor, Health and Social Affairs of Georgia;
 - e. Vakhtang Surguladze - Deputy Director of the United State Fund for Social Insurance of Georgia;
 - f. Maka Chachanidze - Specialist of the Management Department of the United State Fund for Social Insurance of Georgia;
 - g. Genadi Iosava - Chairman of the Supervisory Board of the Scientific-Research Institute for Hematology and Transfusiology;
 - h. Marina Abashidze - Deputy Chairman of the Supervisory Board of the Scientific Research Institute for Hematology and Transfusiology;
 - i. Romanoz Khomasuridze - President of Hemophilia and Donor Association of Georgia (Secretary of the Council);
 - j. Mirian Odisharia - Chairman of Administration Board of Hemophilia and Donor Association of Georgia.

2. The Council shall be assigned:
 - a. To submit proposals on creation of medical centers for people with hemophilia and improvement of treatment of patients;
 - b. To submit proposals on the course of various components of the national program for inpatient assistance of population, in particular those intended for treatment of children and adults with hemophilia and provision of medicines;
 - c. To prepare draft normative acts on matters related to hemophilia, if required;
 - d. To make and submit a register of persons diseased with hemophilia;
3. The Council shall quarterly present to the Minister of Labor, Health and Social Affairs of Georgia information on the course of performance of assigned duties.
4. With regard to performing the assigned functions, the Council may obtain proposals and recommendations from respective specialists through their consent.
5. The Council shall be authorized, if the Meeting of the Council is attended by more than a half of its members. Resolution shall be deemed adopted if supported by more than a half of members present, though not less than three members.
6. The present Order shall enter into legal force upon signing.

Lado Chipashvili /signed and sealed/

This is a true and correct translation





1425 René Lévesque Blvd. W., Suite 1010 Montréal, Québec H3G 1T7 CANADA
Tel.: +1 (514) 875-7944 Fax: +1 (514) 875-8916
www.wfh.org