

Treatment for all

A Vision
for Improvement

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

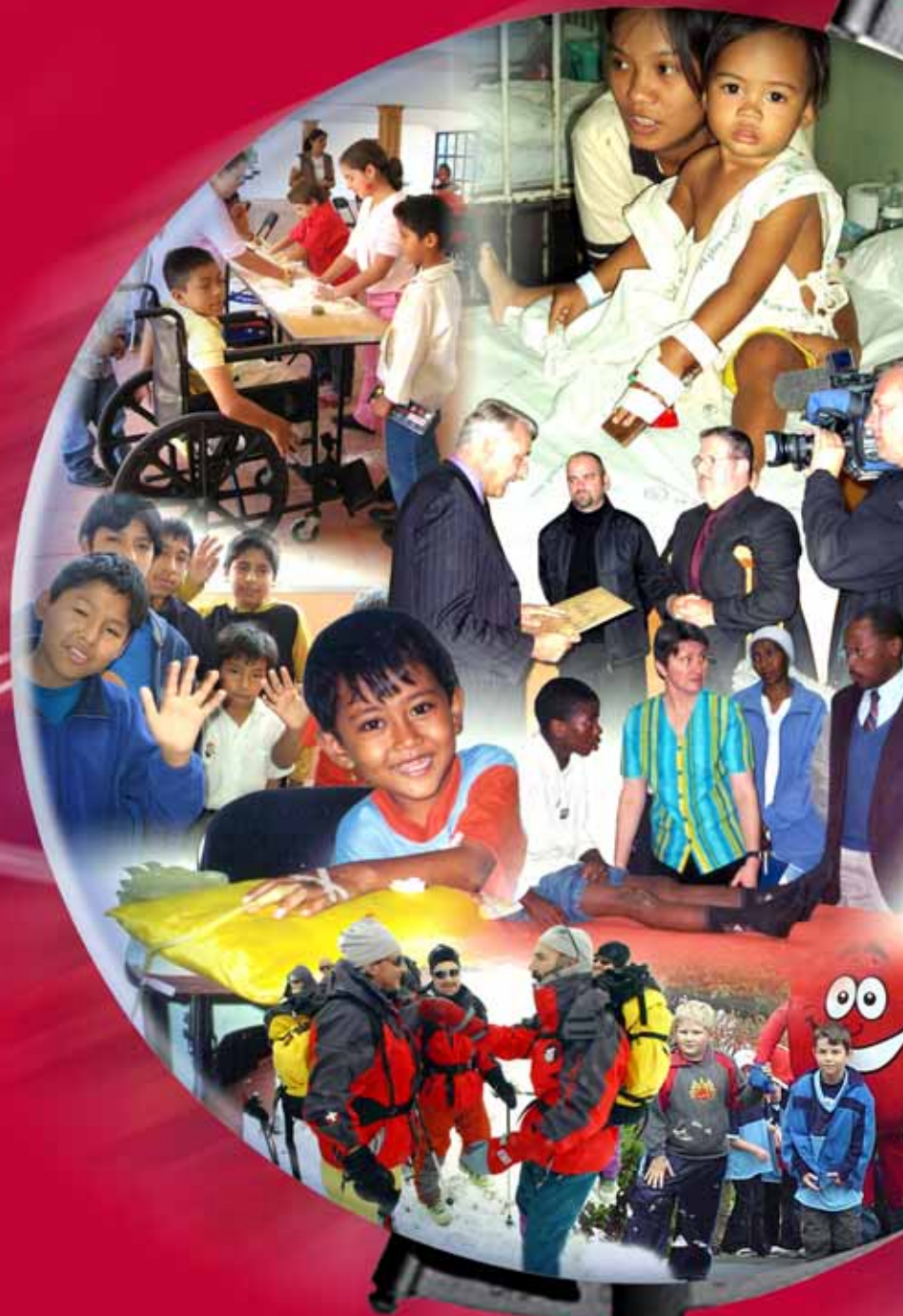




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EXECUTIVE SUMMARY

The World Federation of Hemophilia (WFH) is a not-for-profit organization working on a global scale to improve and sustain treatment of people with hemophilia and other inherited bleeding disorders. It has been a member of the World Health Organization since 1969 and has national member organizations (NMOs) in more than 100 countries.

Our successes over the past decade have produced an increased demand for our services and have led to tremendous expansion in WFH programming. This document presents a strategic vision for the continued success of the WFH over the next three to five years.

Our Vision

Treatment for All: that is, one day, treatment will be available for all those with inherited bleeding disorders, regardless of where they live.

Our Mission

The World Federation of Hemophilia improves and sustains care for people with inherited bleeding disorders around the world.

Strategic Themes

The plan addresses the following strategic areas:

- **Improving treatment in emerging countries**
The WFH has created a highly successful model for building sustainable treatment for people

with bleeding disorders in countries with emerging economies and healthcare systems (“emerging countries”). We act as a catalyst for the creation of coalitions comprising patients, healthcare providers, and governments.

- **Ensuring continued development and sustaining treatment where it is already well established**

There are many countries with established healthcare systems that provide treatment in a very competitive environment. At a time when there is competition for public health funding and when high cost/low volume diseases such as hemophilia could lose out to diseases that affect a higher proportion of the population, we will work to protect hemophilia care against such pressures.

- **Enhancing access to treatment for von Willebrand disease, rare factor deficiencies, and inherited platelet disorders**

Surveys of our stakeholders identified an unmet need for people with other inherited bleeding disorders, such as von Willebrand disease, rare factor deficiencies, and platelet disorders, which often are undiagnosed or misdiagnosed. We will expand the scope of our activities to improve treatment for people with these disorders.

- **Sharing knowledge and building capacity through information exchange and training**

The WFH offers a wide range of skills training, publishes more than 80 titles on hemophilia and other inherited bleeding disorders, and provides the largest international congress dedicated to

hemophilia and other inherited bleeding disorders. We will amplify our work in these areas to support our strategic themes.

- **Promoting access to safe and improved treatment and cure-related research**

For many years, the WFH has served as a watchdog on issues of product safety, efficacy, availability, and supply. We work in close co-operation with government agencies, industry, clinicians, and patient groups to achieve both the quality and desired quantity of treatment products. This will continue to be one of our central activities.

- **Expanding and diversifying our financial base**

Our clear aim is to see a sustained increase in our financial resources to support program development and facilitate long-range planning.

- **Enhancing and adapting the WFH organization**

The WFH has grown greatly since it was established in 1963. Today, the WFH is a much larger organization with a strong professional staff, large volunteer network and member organizations in all corners of the world. As we continue to go forward we must be strategic and strengthen the many gains we have made thus far. In addition, we will adapt the organizational structure where necessary, such as reorganizing our Medical Advisory Board to incorporate comprehensive care, multidisciplinary approaches into action planning for program integration and healthcare development.

STRATEGIC PLAN 2006-2010

Introduction

The World Federation of Hemophilia (WFH) is a not-for-profit organization working to improve and sustain treatment of people with hemophilia and other inherited bleeding disorders. It has been a member of the World Health Organization since 1969 and has national member organizations (NMOs) in more than 100 countries.

Today, more than 75% of the global bleeding disorders community receives either inadequate or no treatment whatsoever.

The WFH has a worldwide reputation earned through the expertise and dedication of a skilled and innovative workforce supported by volunteers who have experienced first-hand the effects of poor or no treatment for those living with a bleeding disorder. Annually, the WFH provides sustainable healthcare development programs in 60 countries across all continents and offers services to the entire bleeding disorders community. We work in partnership with healthcare professionals, people with hemophilia and other inherited bleeding disorders, governments and regulators, pharmaceutical industry, and foundations.

Our successes have produced an increased demand for our services and have led to tremendous expansion in WFH programming in recent years. For us to sustain our many gains thus far and to build on these successes for the future, our growth must be focused, taking into account both the changing nature of our environment and the priorities of our constituents.

Building on past strategic plans, this document presents a vision for the continued success of the WFH over the next three to five years.

Our Vision

Treatment for All

Our vision is that, one day, treatment will be available for all those with inherited bleeding disorders, regardless of where they live. "Treatment for All" means proper diagnosis, management, and care by a multidisciplinary team of trained specialists. It means safe, effective treatment products are available for all people with inherited bleeding disorders. It means expanding services beyond hemophilia, to those with von Willebrand disease, rare factor deficiencies, and inherited platelet disorders.

Our Mission

The World Federation of Hemophilia improves and sustains care for people with inherited bleeding disorders around the world.

A Collaborative Process

This strategic plan says what we will do now and in the future to fulfil our vision and mission. It is the result of an extensive period of discussion and consultation internally and with key stakeholders. Our survey of constituents showed a very high level of satisfaction with our current programs and services. Respondents offered many ideas on how to expand our activities. We are grateful for everyone's contributions. Our challenge in developing this plan was to identify our priorities and focus our efforts to continue toward our ultimate goal of Treatment for All.

In this document, we also outline the values and ethical standards that will govern our actions and influence how we will measure progress and performance. These guiding principles will inform, underpin, and influence the objectives and targets we set.



Guiding Principles

Ethical standards and values are essential for all who work in the not-for-profit field. In delivering our mission, the following values will guide our behaviour and the decisions we make. The aim of these principles is to offer guidance and inspiration to all our constituents and to enable and empower each of us to work within a cooperative framework demonstrating vigilance, innovation, and ingenuity.

We will:

- Ensure the highest quality of service by complying with established standards and continuously auditing our performance;
- Work in collaboration with national member organizations, clinicians, and governments to design and deliver programs and services that support optimal, sustainable treatment and care;
- Promote equality of opportunity for people with inherited bleeding disorders;
- Be open and trustworthy in all our dealings;
- Be courteous in our dealings with people, respecting confidentiality and individual dignity;
- Respect professional standards;

- Accept responsibility and be accountable to the General Assembly or other appropriate bodies for all we do;
- Promote an environment for staff and volunteers that is safe, productive, and characterized by teamwork, open communication, fair treatment, and recognition for their contributions;
- Use all resources responsibly, meeting high standards in business.

We want:

- A healthier and more equitable society for all people with inherited bleeding disorders;
- Excellence and satisfaction in all we do;
- Our members, staff, volunteers, and the community that we serve to be proud of the services we offer and roles we play.

Four Cornerstones

This plan has four cornerstones:

1. Improving Standards of Treatment

The WFH has created a highly successful model for building sustainable treatment and care for people with inherited bleeding disorders in developing countries and those with emerging economies and

healthcare systems (“emerging countries”). The WFH acts as the catalyst for building a “winning coalition” of local champions consisting of patients, healthcare providers, and government officials to develop a locally relevant program to meet a country’s particular needs. Where appropriate, we also work with and alongside our regulatory and industry partners to meet these needs. In our model, there are five target areas for improvement:

- Increasing government support;
- Building a sustainable healthcare delivery system;
- Enhancing medical and laboratory expertise;
- Ensuring the availability of safe, efficacious treatment products;
- Developing a strong patient organization.

We will continue to adapt and apply this model in emerging countries to bring about sustainable improvements. In the future, the WFH must also expand the scope of its activities to improve treatment for those with other inherited bleeding disorders, such as von Willebrand disease, rare factor deficiencies, and platelet disorders, and ensure sustained treatment where it is already well established.

2. Surveillance, Advocacy, and Research to Improve Treatment

In the years since our patient community was infected with HIV and hepatitis C (HCV) in the 1970s and 1980s, the WFH has closely monitored product safety, efficacy, availability, and supply. We work in close co-operation with government agencies, industry, clinicians, and patient groups to achieve both the quality and desired quantity of treatment products. These critical issues will remain a central theme of our work, and we will continue to foster debate and dialogue on them. We will also closely monitor and promote scientific and technological developments that can lead to a cure or more efficacious treatment.

3. Teaching, Training, Education, and Information

We offer a wide range of skills training to medical, allied health professional, and patient groups through various programs, such as twinning and International Hemophilia Training Centre (IHTC) fellowships, or directly through multidisciplinary workshops and NMO skills training. We publish more than 80 titles on hemophilia and other inherited bleeding disorders for healthcare professionals, patients, and NMOs, and our comprehensive website attracts about 40,000 visits per month. We organize the largest international congress dedicated to hemophilia and other inherited bleeding disorders. With around 3,800 attendees, our con-

gress is the only meeting that integrates all constituents including patients, healthcare professionals, and others, and thus provides an international forum for information sharing and collaboration. We will continue to expand our work in these areas in the future.

4. Resource Management

Over the past decade, we have increased our financial resources and strategically widened our international programs. Because of our demonstrated successes, the demand for our services continues to grow. In addition, war, poverty, natural disasters and other socio-political realities add pressure for increased support. Our clear aim is to see a further and sustained increase in our financial resources to support our programs and facilitate long-range planning. However, as we go forward we must ensure that any program growth is both sustainable and feasible in light of economic, volunteer, and staff resources.

Facing the Challenges

The most important challenge facing our community and our organization is that today most people with inherited bleeding disorders do not receive adequate, or any, diagnosis or treatment. More positively, there is a growing global awareness of the health inequalities around the world.

Addressing this inequality will require action in all areas of government policy.

Other challenges include the growing threat of reduced spending for hemophilia care and the lack of new doctors specializing in inherited bleeding disorders. In addition, over the last few years, the pharmaceutical industry serving the bleeding disorders community has faced significant market pressures and consolidation. Other potential funders, notably foundations and international aid agencies, tend to focus their energies on issues that affect larger numbers of people; for example, prevention of HIV/AIDS and other pandemics, women's health, etc. The WFH must identify some of its unique strengths and how these strengths can be shown to benefit a wider group of people that includes those with bleeding disorders.

The WFH will respond actively and vigorously to meet the challenges and seize the opportunities. To do so, we must remain focused and flexible, find innovative solutions, and redouble our efforts as we continue forward toward our ultimate goal of Treatment for All. We will work in partnership to serve all those affected by inherited bleeding disorders by responding to change and helping to secure our respective future roles at the regional, national, and global levels.



Strategic Themes

The WFH has surveyed its members and other stakeholders to ensure we address the right strategic issues in the next three to five years. Below are the main strategic themes that have arisen and our plan for addressing them.

In the life of this strategy (2006-2010), we will:

1. Improve Treatment in Emerging Countries

An estimated 70% of people with hemophilia in the world remain undiagnosed. Seventy-five percent of people with a hemophilia diagnosis receive inadequate or no care. The need for diagnosis and care is even greater for those with other inherited bleeding disorders. A range of environmental issues affects availability of treatment from socio-political, cultural, and economic resources to geographic remoteness.

The WFH has continuously worked to address these humanitarian shortfalls and will continue this vital element of our work in the future. These activities will occur through targeted country development programs to meet specific needs, as well as through comprehensive multi-year development programs such as the Global Alliance for Progress (GAP). To meet this need **we will:**

- Build a *winning coalition*, consisting of patients, healthcare providers, and government officials to implement multi-year country development plans designed to achieve sustainable comprehensive care;

- Conduct individualized needs assessments and implement targeted country development action plans;
- Advocate for an adequate supply of clotting factor concentrates to be available nationally;
- Expand the capacity of countries to achieve accurate laboratory diagnosis.

2. Ensure Continued Development and Sustain Treatment Where It Is Already Well Established

There are many countries with established health-care systems that provide treatment and care in a very competitive environment. Over the years, comprehensive care has improved dramatically and the quality of life has normalized for most people with bleeding disorders and their families. However, at a time where there is tremendous competition for public health funding there is a continued need for advocacy and improvements. In these countries, health indicators guide government funding and there is a danger that high cost/low volume diseases such as hemophilia will lose out to diseases that affect a higher proportion of the population. To protect care against such pressures, **we will:**

- Advocate for comprehensive care models for inherited bleeding disorders including strategies to maintain comprehensive care and treatment networks;
- Optimize/expand WFH activities to meet the needs of established NMOs;

- Identify ways for established NMOs to be more involved in WFH activities.

3. Enhance Access to Treatment for von Willebrand Disease, Rare Factor Deficiencies, and Inherited Platelet Disorders

Our surveys also identified that there continues to be an unmet need for those with von Willebrand disease, rare factor deficiencies, and inherited platelet disorders. The WFH is well positioned to address this need and thus **we will:**

- Improve diagnosis and enhance data collection on their prevalence by country;
- Collaborate with regulators and industry to enhance access to safe treatment;
- Expand training, educational materials, and web-based resources;
- Seek out and establish links with other health-care professionals;
- Actively integrate women with bleeding disorders within our volunteer structure/committees since many of these disorders disproportionately impact women;
- Create visibility for WFH initiatives on other inherited bleeding disorders.

4. Share Knowledge and Build Capacity through Information Exchange and Training

The WFH was originally founded so that national organizations could learn from each other. This remains a key aspect of our work today. We want to continue to share information in three major ways:

- Our biennial congress is an ideal venue for both healthcare providers and patients to learn about the latest developments in treatment and care. We want to increase both participation and the satisfaction rating of those who attend.
- The WFH wants to conduct effective training sessions for member organizations and health professionals on regional, national, and global levels, to help them produce concrete improvements.
- We want to communicate through the Internet (www.wfh.org) and our publications the knowledge of our leading experts on inherited bleeding disorders, and build awareness and understanding of WFH's activities, programs, and achievements.

To support the strategic themes in this plan, our work in these areas must be amplified. Over the next three to five years, **we will:**

- Solidify the WFH Congress' position as the foremost meeting place for all stakeholders to share and exchange information and receive state-of-the-art training;
- Expand the WFH training for health professionals;

- Develop educational and resource materials to meet the information needs of treaters, NMOs, and people with bleeding disorders;
- Build upon WFH data and demographics capabilities to further support public policy initiatives and quantify outcomes of WFH programs;
- Institute an integrated NMO leadership skills training program regionally, nationally, and globally;
- Seek to establish new and build upon existing linkages with international governmental organizations such as the WHO and related non-government organizations;
- Raise awareness about the WFH and bleeding disorders;
- Consolidate the WFH's position as the recognized world leader in standards setting for treatment and care of bleeding disorders.

5. Promote Access to Safe and Improved Treatment and Cure-related Research

In the years since our members were infected with HIV and hepatitis C (HCV) in the 1970s and 1980s, new threats have emerged such as vCJD and West Nile Virus. The WFH has served as a watchdog on issues of product safety, efficacy, availability, and supply. We work in close co-operation with government agencies, industry, clinicians, and patient groups to achieve both the quality and desired quantity of treatment products. This will continue to be one of our central themes and in the period ahead, **we will:**

- Monitor safety and supply developments and take proactive action as required to inform and protect the patient community;
- Pursue innovations to enhance the global supply of affordable clotting factor concentrates;
- Monitor scientific and technological developments that can achieve successful cures or more efficacious treatment of inherited bleeding disorders and foster debate and dialogue on critical issues;
- Monitor research and treatment advances related to adverse events (inhibitors, HIV, HCV) and provide timely information on their prevention, treatment, and management;
- Educate regulators and public health authorities on the selection of safe clotting factor concentrates;
- Contribute to the development of knowledge and expertise in blood product safety, supply, and affordability issues among NMOs;
- Advocate patients' involvement in the national tender process and/or public health oversight committees.

6. Expand and Diversify Our Financial Base

Crucial to our future success and that of our member organizations is the overall level of funding. We must demonstrate our capability to generate increased income opportunities, sufficient to enable us to fulfil our role. To meet this challenge **we will:**



- Develop new and diverse funding sources;
- Expand and develop affiliated organizations to support WFH fundraising efforts;
- Develop global fundraising activities;
- Increase targeted corporate sponsorship opportunities;
- Develop programs to attract and expand non-pharmaceutical corporate revenue;
- Ensure our revenues and staffing are sufficient to meet planned expenditures.

7. Enhance and Adapt the WFH Organizational Structure

The WFH has grown greatly since it was established in 1963. This growth is the result of a clear need. Our work has gathered momentum over the past decade. However, today, we must recognize the responsibilities of being a larger organization in terms of our duties to volunteers and staff and we must ensure that, in the achievement of our common goals, we do not put undue stress or unrealistic strain on the organization. Therefore, to consolidate our gains thus far, **we will:**

- Adapt the structure of the Medical Advisory Board of the WFH to incorporate multidisciplinary comprehensive care approaches into action planning for program integration and healthcare development;
- Comprehensively review the WFH Constitution and Rules of Procedure to align them with this new strategic plan;
- Review and update all WFH board and human resources policies and procedures;
- Develop and implement a new internal communication plan to strengthen the capacity of the WFH to respond to the new strategic goals;
- Incorporate succession planning into all aspects of the organization;
- Recruit and retain a high quality workforce and volunteers;
- Continue to invest in our staff and our volunteers (lay and medical), through training and development, recognizing that learning and personal growth helps fulfil both the individual's potential and the organization's capacity.

Conclusion

The WFH is well positioned to meet the challenges ahead. We have achieved tremendous program success and are daily making a difference in the lives of individuals with hemophilia around the world. There are certainly vast unmet needs and difficult challenges ahead. However, there is reason for hope and optimism. As a global family, we share a common bond. Whether hemophilia affects us personally or we are a healthcare provider or public health official, we each are dedicated to the same goal.

The prospects are exciting, the challenges are many, but the vision is clear. We are united to achieve Treatment for All.

Adopted by the WFH Executive Committee
26 January 2006.

WHAT WE HAVE ACCOMPLISHED

Over the last decade, the WFH has undergone tremendous growth, and has made great strides in improving treatment for people with hemophilia and other inherited bleeding disorders, especially in emerging countries. Here are some of our achievements.

- 125 million units of life-saving clotting factor concentrates distributed to 30,000 patients through our humanitarian aid program, launched in 1996.
- 120,812 people with hemophilia, 43,334 people with von Willebrand disease, and 11,384 people with other bleeding disorders included in our annual global survey. Since the first survey was conducted in 1998, the number of people with hemophilia included has increased by 50%.
- 40,000 visits per month, on average, to the WFH website, launched in 1996, which has grown to become one of the most comprehensive online resources for information about hemophilia and other inherited bleeding disorders.
- Over 5,000 new patients in nine countries identified or diagnosed through the Global Alliance for Progress (GAP) program, launched in 2003. The program's aim is to dramatically increase the diagnosis and treatment of people with hemophilia and other inherited bleeding disorders in target countries.
- 800 lab specialists and technicians trained through our laboratory training workshops to teach the proper techniques and methodology to accurately diagnosis bleeding disorders.
- 274 fellows trained in the last 10 years through the International Hemophilia Training Centre (IHTC) fellowship program, the WFH's oldest program.
- 80 publications in multiple languages produced on hemophilia and other inherited bleeding disorders.
- 75 regulators and government officials from developing countries educated on the selection of safe products for the treatment of hemophilia and other inherited bleeding disorders.
- 65 treatment centres in 40 countries participated in the International External Quality Assessment Scheme (IEQAS), launched in 2003, to monitor the performance of laboratories.
- 60 treatment centres and 40 patient organizations in developing countries coached and trained through our twinning program.
- 27 international congresses, the largest meeting of the global bleeding disorders community, held since 1963, now attracting about 3,800 participants from more than 100 countries.
- 21 country programs carried out around the world since the first healthcare development project was launched in Chile in 1996.
- Five global skills training workshops for hemophilia organization leaders organized since the program was launched in 1999.
- Four global fora on the safety and supply of treatment products, which bring together regulators, people with bleeding disorders, physicians, and industry, organized to foster discussion and debate on key issues.





Strategic Plan Committee

Chair

Gordon Clarke, WFH Vice President NMOs

Committee Members

Mark Skinner, WFH President

Dr Paul Giangrande, WFH Vice President Medical

Dr. Bruce Evatt, WFH Vice President Programs

Miklos Fulop, WFH Executive Director/CEO

Many people have contributed to this plan: Executive Committee members, NMOs, volunteers, healthcare professionals, industry partners, and staff. We are grateful for their input, for their commitment to the WFH, and for their dedication to improving care for people with inherited bleeding disorders worldwide.



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