What is hemophilia?

About one in every 5,000 males is born with hemophilia, a lifelong bleeding disorder that is usually inherited and prevents blood from clotting properly. The main danger is uncontrolled internal bleeding that starts spontaneously or results from injury. Bleeding into joints and muscles can cause debilitating pain, severe joint damage and disability. Bleeding into the brain can cause death.

A person with hemophilia does not bleed faster than anyone else, but bleeding usually lasts longer.

How is hemophilia treated?

Effective treatment for hemophilia is available, but as yet there is no cure. The most effective treatment for bleeds is an injection of clotting factor that is made from blood or biotechnology ingredients called recombinants. Bleeding stops when enough clotting factor reaches the affected area.

Other bleeding disorders

The WFH also works to improve the care and treatment of people with other bleeding disorders such as von Willebrand disease (vWD), which affects about one per cent of both men and women. Like hemophilia, vWD is usually inherited, but its symptoms are milder.

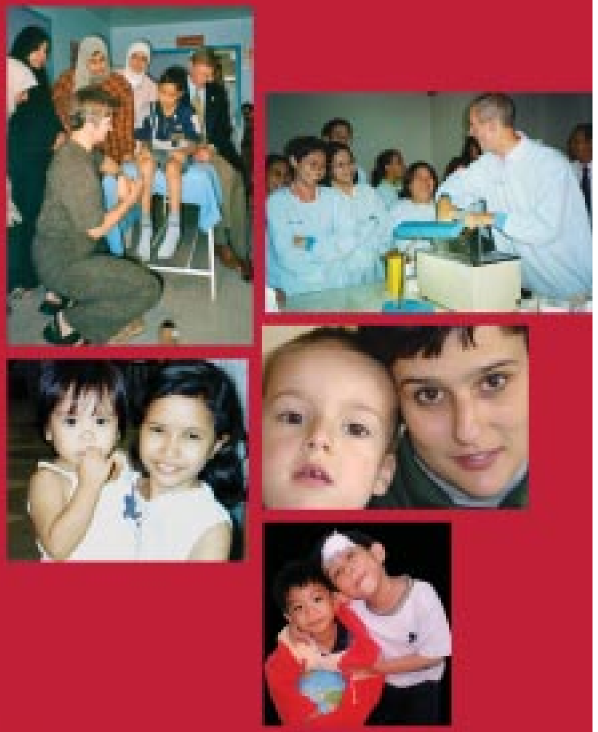
With proper treatment, people with hemophilia can live relatively normal lives. Without treatment, most children with severe hemophilia will die young. An estimated 400,000 people worldwide are living with hemophilia. Only 25% receive adequate treatment.

The World Federation of Hemophilia is striving to close this gap.

World Federation of Hemophilia
1425 René Lévesque Boulevard West #1010
Montréal, Québec H3G 1T7
Canada
Tel: +1 (514) 875-7944
Fax: +1 (514) 875-8916
Email: wfh@wfh.org
Web site: www.wfh.org

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

Improving
global hemophilia care



www.wfh.org

What is the World Federation of Hemophilia?

The World Federation of Hemophilia (WFH) is an international, not-for-profit organization committed to improving treatment and care for people with hemophilia and related bleeding disorders. The Montreal-based organization was founded in 1963 by the charismatic Frank Schnabel, who was born with hemophilia. He dedicated his life to helping others with the disorder and inspired many to rise above their adversity.

The WFH carries on Schnabel's work through an extensive network of volunteers, national hemophilia organizations and healthcare providers in more than 100 countries. Many organizations and individuals also support this work with donations of money, treatment products, and other essential items.

The United Nations World Health Organization (WHO) officially recognizes the WFH and the two bodies collaborate on various hemophilia care, treatment and information projects.

WFH ACTIVITIES

The WFH is committed to building long-term, sustainable hemophilia care based on the cooperation and commitment of governments, hemophilia associations, key medical personnel, and relevant industry sectors.

The WFH provides training, education, and other support for people with hemophilia and their families. The organization is also a global campaigner for the increased safety and availability of hemophilia treatment products.

The Global Alliance for Progress (GAP) in hemophilia

GAP is a 10-year healthcare development project, launched in 2003, to greatly increase the diagnosis and treatment of people with hemophilia in up to 40 developing countries. The project aims to close the gap between the number of people born with hemophilia and those who reach adulthood, the gap between the estimated and actual number of people diagnosed with hemophilia, the gap between the amount of treatment product needed versus what is available.

To achieve these goals, the WFH is working with the WHO and other key organizations, foundations and companies committed to improving healthcare worldwide.

GAP country programs are designed to improve four main areas: the care delivery system, medical expertise and diagnosis, quality and quantity of treatment products, and the national hemophilia organization.

Humanitarian Aid

The WFH is a major international distributor of donated clotting factor concentrates to countries with limited access to hemophilia treatment. Distribution focuses on those with the greatest need and donated products are often used for lifesaving treatment of children and newborns.

WFH humanitarian aid has saved many people with hemophilia from death or permanent disability.

The WFH World Congress

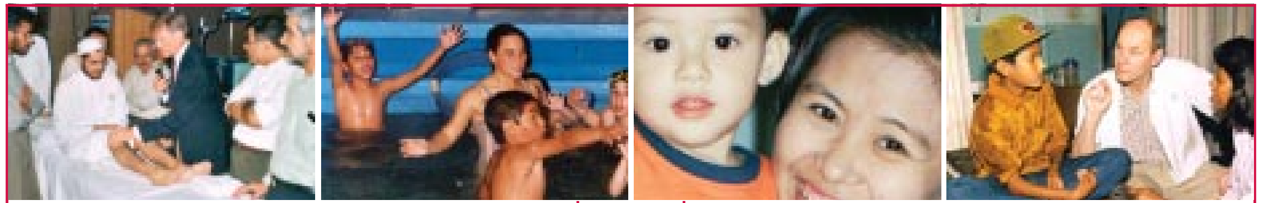
The WFH World Congress is the largest international meeting dedicated to hemophilia and other bleeding disorders. Some 4,000 medical, government, industry, and patient representatives gather every two years to exchange ideas and learn about the latest developments in hemophilia research, treatment, and care.

Safety and supply of treatment products

The threat of diseases such as HIV/AIDS and hepatitis to blood supplies and blood-based treatment products is a worldwide concern. The WFH monitors any potential risks and promotes the safety, availability, and regulation of treatment products through lobbying, research, and information programs.

International meetings of doctors, patient groups, regulators, and product manufacturers are organized by the WFH to highlight the global impact of regional decisions on product safety and availability.

A regular newsletter, the WFH Safety and Supply News, contains the latest information on emerging threats, product recalls, regulatory procedures, research, and industry updates.



The WFH twinning program

By linking hemophilia organizations and treatment centres in developing and developed countries, twinning has improved diagnosis and medical attention for people with hemophilia in many countries. The WFH helps more than 40 twinning partnerships arrange training programs, exchanges, workshops, and other activities.

Twinning partners benefit from sharing their experience in hemophilia treatment, patient education, outreach, organization, lobbying, fundraising, and the optimal use of resources.

Workshops & training

The WFH trains healthcare workers, volunteers, laboratory technologists, members of local hemophilia organizations, patients and their families. The training provides the skills to improve hemophilia treatment and care in their countries.

The WFH also awards annual fellowships to medical professionals for overseas training in the management of bleeding disorders.

Data collection

The WFH annually surveys its member organizations to determine the state of hemophilia care around the world. The survey shows the number of people identified with bleeding disorders, their health status and access to care.

The WFH survey is an excellent tool for comparing levels of care and evaluating the health outcomes of various treatment programs.

Publications and Information

The WFH produces and distributes a wide range of print and electronic publications in several languages for the global hemophilia community. Publications include educational materials for patients, parents, and medical personnel, skills development resources for hemophilia organizations, bulletins, and other material on safety and supply issues, directories, statistics, and newsletters.

Publications are available on the WFH website (www.wfh.org), a leading source of information on hemophilia and related issues. The website attracts tens of thousands of visitors including people with hemophilia and their families, healthcare workers, government officials, scientists, teachers, and students.