

CLOSING THE GAP

THE CONTRIBUTION OF NURSING SPECIALISTS
TO THE WORLD FEDERATION OF HEMOPHILIA



LET'S WORK TOGETHER TO IMPROVE HEMOPHILIA CARE WORLDWIDE

OVERVIEW

The World Federation of Hemophilia (WFH) is pleased to provide the Canadian Nurses Association with this introduction to our global work to improve hemophilia care and treatment.

For more than forty years, WFH has served as the international hub of capacity building and information sharing for people with bleeding disorders and healthcare professionals around the world. We have a long-term commitment to building bridges. Whether it is educating anxious parents in the Philippines on how to care for their children, training nurses in Pretoria, twinning a medical centre in Jordan to one in Toronto, or working with Argentine Ministry of Health, the Federation focuses on increasing the capacity of the hemophilia community to care for itself.

**More than 75% of people with hemophilia worldwide do not receive adequate care.
Most die before reaching adulthood.**

**One third have HCV.
One tenth are infected with HIV.**

**WFH works to change this situation.
Our goal is for everyone with hemophilia to receive quality care.**

AT A GLANCE: WORLD FEDERATION OF HEMOPHILIA

- International non-governmental organization established in 1963
- Work in collaboration with national patient organizations in 107 countries
- 400 volunteers worldwide, including nurses, physicians and other healthcare professionals, scientists, and people with hemophilia
- Operate international healthcare development programs in 68 developing nations
- Affiliated with leading internationally renowned teaching hospitals and universities
- Official accreditation with the World Health Organization
- Headquarters in Montreal, Canada with 27 staff

NURSE SPECIALISTS AT FOREFRONT OF GLOBAL HEMOPHILIA CARE

Nurse specialists in hemophilia care play a vital role in carrying out our mission to **introduce, improve, and maintain care for people with hemophilia and related bleeding disorders around the world.**

In Canada and most countries in the West nurses have taken an increasing central role in delivering hemophilia care and treatment. Often the leader and main coordinator of a multidisciplinary team of specialists, the hemophilia nurse serves as an important bridge ensuring that patient's needs, whether they be psychosocial counselling, dental care, physical therapy or surgery are met.

The role of nurses in hemophilia care in the emerging and developing world varies depending on local customs and healthcare infrastructure. Sometimes the only reachable healthcare provider in a region is a nurse with limited access to specialists in hemophilia care. WFH's programs to **introduce** proper care and treatment for patients with hemophilia in developing countries include:

- In-country training programs for nurses in countries where hemophilia care is at a basic level or is non-existent. Training is geared to the specific needs of a country's nursing population. Topics such as the detection of hemophilia, symptoms, types of bleeds, complications, treatments, and psychosocial aspects are covered. The WFH has successfully upgrading the skills of nurses in countries such as Kenya, Egypt, China and South Africa through on-going training initiatives, creation of support networks and provision of language-appropriate educational materials.
- The WFH Nurses Committee has been instrumental in creating education tools such as the well known and much used Hemophilia in Pictures. This illustrated multi-media tool provides basic concepts, and care and treatment information for people with hemophilia and their families. Available in many formats from three-ring binder to CD-ROM, the guide is portable enough to be used in rural clinics and detailed enough that it provides all necessary information. Hemophilia in Pictures is available in English, Chinese and Russian.

For countries with an existing hemophilia care delivery system, WFH works to **improve** collaboration and coordination among healthcare stakeholders to improve the care that patients receive. To achieve this, WFH introduces the model of comprehensive hemophilia care. The essential element to comprehensive care is a central coordinator, most often a nurse or social worker. Considerable time is taken to assess the healthcare structure and local customs so that territoriality amongst healthcare professionals is reduced and cooperation increased.

At this stage in hemophilia care program improvements, WFH relies on two development program tools: International Hemophilia Training Centre fellowships and Twinning.

Established in 1970, the International Hemophilia Training Centre fellowship program provides training to healthcare professionals from developing countries in the diagnosis and management of hemophilia and related bleeding disorders for six to eight weeks at a leading teaching hospital. Trainees are nurses, hematologists, pediatricians, orthopedists, lab scientists, and physiotherapists, amongst other medical professionals. In total, 31 medical centres worldwide are accredited as training centres in 20 countries, including the UK, France, USA, Australia, and Brazil. These centres are chosen for their training facilities, excellence and appropriateness as role models within their region.

Seventeen (17) nurses from the developing world have been awarded fellowships since 1989. After training is completed, these nurses serve as experts in their own countries, sharing their knowledge with others. The WFH Nurses Committee has developed a standardized course content module for Nursing Management of Hemophilia, providing clear learning objectives for fellowship training in different aspects of care. This module will include both pre- and post-training evaluations to assess the impact of the program.

Nurses have increasingly taken a leadership role in WFH's medical twinning program. Twinning is a formal collaboration or partnership between two medical centres focusing on the diagnosis and treatment of hemophilia patients. The goal is to improve hemophilia care in the emerging hemophilia treatment centre through the transfer of skills, sharing best practices, experience, resources and information. There have been more than ## medical twins since the program began.

Other contributions by nurses to improve hemophilia care include:

- Creation and maintenance of a database of experienced hemophilia nurses worldwide who are willing to be called upon for their expertise.
- Conducting regional and international nursing symposiums. In conjunction with our biennial World Congress, the WFH Nurses Committee organizes a one-day symposium geared to nurses from both the developed and developing world. On average XX participants attend the symposium and more than 200 nurses participate in the Congress itself. As they do in our volunteer multi-disciplinary teams visiting several developing countries each year, nurses are playing a pivotal role on the main organizing team for WFH's 2006 World Congress of Hemophilia, May 17 –21, Vancouver, BC. The event will draw 4,000 participants from more than 80 countries.
- Production of scientific monographs related to nursing issues.

It's important for developed countries to be vigilant and **maintain** a high-level of hemophilia care. WFH's blood safety and supply programs and activities serve to educate and inform nurses and other hemophilia caregivers on pressing issues facing the worldwide hemophilia community and the state of the art in hemophilia care. The registry of hemophilia nurses, nursing and blood safety newsletters, and Internet site serve as tools to improve information sharing amongst nurses.

2004 GLOBAL PROGRAM HIGHLIGHTS

With the volunteer help of nurses, physicians, and other medical professionals along with patient leaders, WFH In conducted healthcare activities in 68 developing countries in 2004. Our global program highlights include:

Country development programs: 30 countries

Twinning projects: 45 in total, with 30 medical centre twins and 15 patient organization twins.

International medical training fellowships: grants awarded to send 23 physicians and paramedical staff from 17 developing countries for four to six weeks of overseas training at leading teaching hospitals

Conferences and/or multidisciplinary workshops: 22 workshops

Laboratory quality control scheme: 59 laboratories centres participating from 35 countries

Humanitarian treatment product donations: 55,000,000 IU/valued at \$US 51 million delivered to 56 countries improving lives of 17,000 people

Capacity building of third-sector patient organizations: 120 participants, including 17 youth delegates, from 80 countries participated non-profit management training.

FOR MORE INFORMATION

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