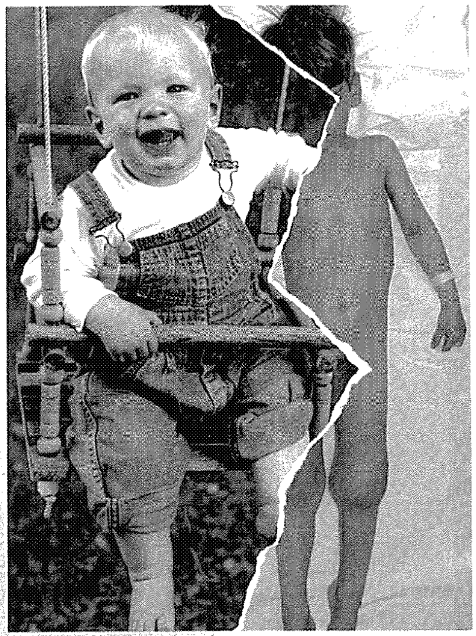
Appendix
N1

The Global Challenge . . .



PJ
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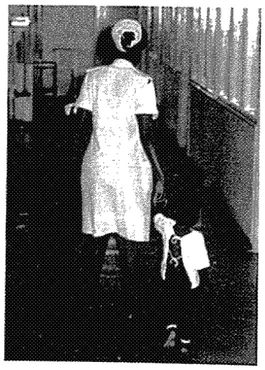
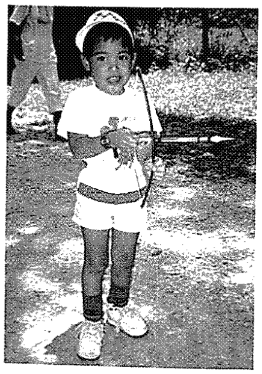
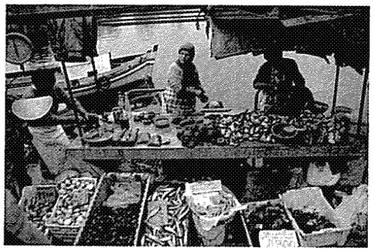
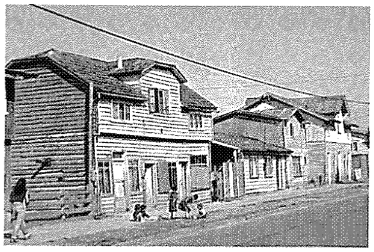
World Federation of Hemophilia Decade Plan





. . . to deliver effective therapy to people with hemophilia throughout the world.





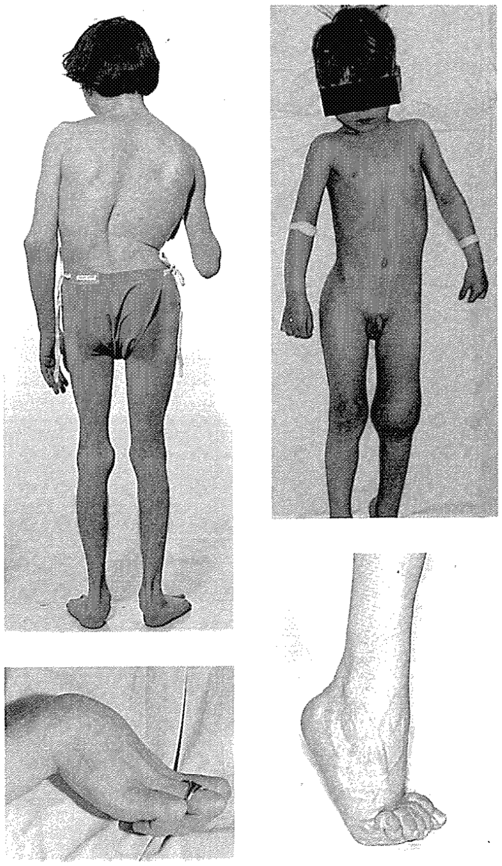
World Federation of Hemophilia Decade Plan

Hemophilia is inherited. It affects males. Bleeding into joints and muscles causes painful arthritis and deformity.

Hemophilic bleeding can only be stopped by injecting active clotting agent into a vein . . . repeatedly.

80% *of people with hemophilia receive no treatment.*

Many die in childhood . . .



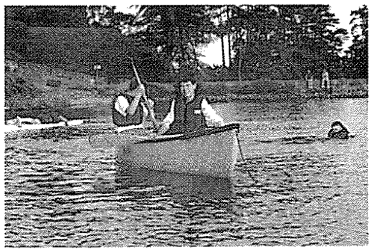
. . . the rest are crippled.

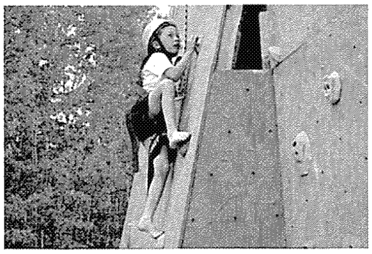
This tragedy *should not exist*

Effective therapy *already exists*

Our task: *to help bring treatment to people with hemophilia throughout the world.*

World Federation of Hemophilia Decade Plan





. . . answering the challenge

Table of Contents

Mission of the World Federation of Hemophilia

Founded in 1963, the World Federation of Hemophilia (WFH) is a federation of national member organizations representing over 70 individual countries.

The overall mission of the WFH is to advance and stimulate services worldwide for persons with hemophilia and related disorders.

To achieve this mission, the WFH offers medical, psychosocial, scientific and technical support to affected families through its various centres of expertise.

The WFH:

1. defines clear, long-term goals,
2. energizes volunteerism and interested organizations,
3. encourages the provision of resources to achieve the goals,
4. organizes appropriate activities and
5. promotes the reputation and esteem of the organization.

"Ancient prophets have said 'where there is no vision, the people perish'. Our vision for the World Federation of Hemophilia is of a world where all persons and families affected by hemophilia have access to modern comprehensive care. A cure is on the horizon through genetic engineering. The WFH requires a comprehensive plan to achieve its vision. This plan assures that the WFH will not perish. We are excited about the bright future."

Charles J. Carman
President
World Federation of Hemophilia
July 1992

The Decade Plan

In 1989 the World Federation of Hemophilia started a process to develop a strategic plan which would carry it into the 21st century. In April of 1990 fifty-four experts in the medical treatment and research of hemophilia, and national leaders of hemophilia associations, met in Paris to start the planning process. They began with the identification of critical issues and concerns affecting the global comprehensive care of persons with hemophilia and their families. Since Paris, subsequent work sessions in Washington DC in 1990, and in Barbados in 1991, and ongoing activity by strategic planning units as well as ad hoc task forces have produced the WFH Decade Plan.

The Decade Plan will be the foundation from which the World Federation of Hemophilia will turn its vision into reality.

Organization of the Decade Plan

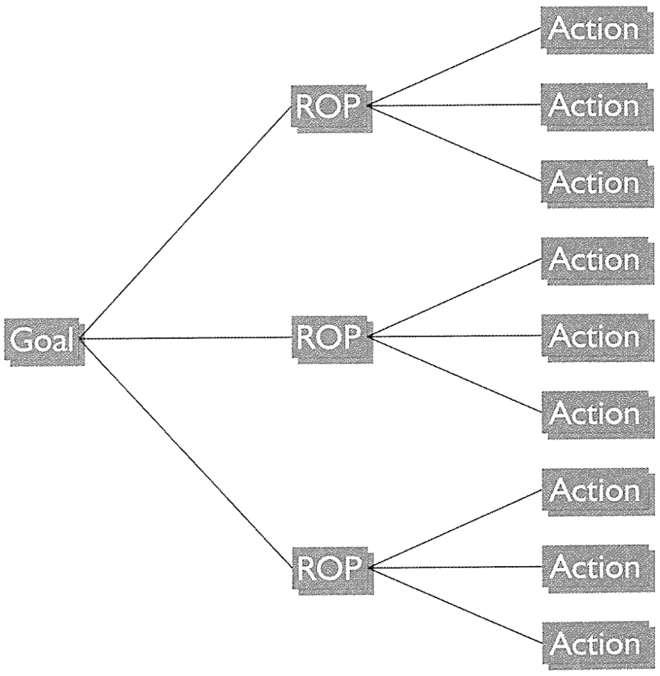
The Decade Plan is organized as follows:

- Five goals have been identified.
- Each goal has Results Oriented Programmes (ROPs).

  There are eighteen ROPs.
- Each ROP has actions to achieve its objective.

  There are seventy-three actions.

The following diagram illustrates the organization:



Within the text, each of the five goals is followed through to its actions in sequence.

WFH Decade Plan

The Goals

1. **The WFH will:** ***encourage and foster*** the highest possible levels of diagnosis, comprehensive care and support for persons with hemophilia and related disorders, for all countries throughout the world.

2. **The WFH will:** ***help initiate and assist*** programmes to address the local factors which restrict access to areas of comprehensive care for persons with hemophilia and their families in the developing world.

3. **The WFH will:** ***encourage*** the education and training of direct care givers as well as persons with hemophilia, their families, concerned organizations and the general public, using the most appropriate means.

4. **The WFH will:** ***promote*** research and development of the medical treatment of hemophilia and related disorders, and encourage the development of the technology base for this support.

5. **The WFH will:** ***accomplish*** its goals through appropriate organizations at global, regional and national levels.

x need funds →

Forum
JW
Mannucci

Goal 1

***The WFH will:* encourage and foster** the highest possible levels of diagnosis, comprehensive care and support for persons with hemophilia and related disorders, for all countries throughout the world.

World Federation of Hemophilia
Decade Plan

Goal 1

ROP 1.1 Provide support to all persons with hemophilia throughout the world, irrespective of the politics of their country.

Actions

1.1.1 After review of relevant United Nations and Helsinki documents, propose a resolution supportive of this ROP for approval by the WFH General Assembly and the World Health Organization demanding of all governments that the health needs of persons with hemophilia be met.

Now

✓

S Taylor

Goal 1

ROP 1.2 Promote the dignity, image and self-esteem of persons with hemophilia.

Actions

Now Simoni T. 1.2.1 Develop a global statement on human rights for persons with hemophilia. ✓

Now B O'Mahony 1.2.2 Encourage and support National Member Organizations to promote advocacy of equal rights before their governments. ✓

Now D. Watters 1.2.3 Promote a philosophy of positive concepts and images in WFH publications. ✓

Now E Seay. 1.2.4 Develop a logo in accordance with this philosophy. (✓)

Goal 1

ROP 1.3 Promote comprehensive state-of-the-art treatment, including accurate diagnosis and clotting factor prophylaxis, where appropriate, for all persons with hemophilia and related disorders and their families.

Actions

1.3.1 Establish and regularly update a process to define the elements of state-of-the-art comprehensive care and counselling for persons with hemophilia and related disorders and their families. ✓

Now Doreen Brettler

Inter Shelby Dietrich

1.3.2 Promote the dissemination of information on state-of-the-art, comprehensive care. (✓) ✗

1.3.3 Facilitate the process of monitoring provision of comprehensive care in relation to methodology, resources and performance appraisal. ✓

Now Gordon Bray

Inter Klaus Schimpf

1.3.4 Encourage surveillance programmes for the early detection and elimination of side effects of treatment. ✓ ✗

Now Eric Preston

1.3.5 Define criteria for detection of hepatitis and chronic liver disease and its complications and promote programmes for management. ✓ ✗

Inter Jeanne Lusher

1.3.6 Disseminate information on options for the treatment of clotting factor inhibitors. ✓

Now Mike Heim

1.3.7 Develop and disseminate guidelines for the prevention and treatment of musculoskeletal disorders. ✓

Now Lily Heijnen

1.3.8 Encourage the development of guidelines and facilities for sports and recreation. ✓ ✗

Now Pilar Arranz

1.3.9 Develop and disseminate guidelines for psychosocial care. ✓

Goal 1

ROP 1.4 Encourage the availability of safe, virus free, effective and affordable replacement therapy in sufficient quantity.

Actions

?? Titiko Mondalaki. 1.4.1 Collaborate with the World Health Organization, the International Society of Blood Transfusion and the International Federation of Red Cross and Red Crescent Societies, in promoting the development of blood transfusion services to ensure regular and adequate blood donations and to generate safe and effective methods of collection, processing, distribution and transfusion of blood and blood components. ✓

Now Wolfhart Kreu.. 1.4.2 Recommend guidelines for the safety of both donors and recipients of plasma products and update this annually or as needed. ✓ ✗

?? Augusto Gonzaga 1.4.3 Develop a comprehensive examination of all sources and processes for replacement therapy products with involvement of industry, blood transfusion centres, and other interested parties. ✓

Now Craig Kessler 1.4.4 Establish criteria to help choose type of product for replacement therapy, recognizing problems of affordability in many countries. ✓

[illegible] G. [illegible] 1.4.5 Investigate the feasibility of facilitating the cost-effective provision of safe clotting factor concentrates to developing countries. ✓ ✗

?? C Patrick. 1.4.6 Facilitate implementation of a plan for the contract fractionation of plasma to provide state-of-the-art clotting factors to developing countries. ✓

[illegible]. Craig Kessler 1.4.7 Monitor and disseminate information concerning developing technologies, including recombinant clotting factors and gene therapy, and their potential impact on the worldwide availability of products for replacement therapy.

Goal 1

ROP 1.5 Promote programmes for prevention of human immunodeficiency virus (HIV) infection and optimum care of persons with hemophilia and their families.

Actions

Now Bruce Evatt 1.5.1 Continue to monitor the demography of HIV infection in order to predict future impact on the hemophilia population. ✓

Now Sam Schulman 1.5.2 Encourage provision of medical and psychosocial care for HIV infected patients and their families. ✓

Now Stephanie Seremetis 1.5.3 Emphasize the need for safe blood products. ✓

Now Kees Smit Sibinga 1.5.4 Coordinate joint action with the Global Blood Safety Initiative (GBSI). ✓

Now Kathy Parish 1.5.5 Encourage National Member Organizations and hemophilia centres to provide individual counselling on safer sexual practices. ✓

Now C Brackmann 1.5.6 Educate health care workers and those treating persons with hemophilia about safety precautions. ✓

Sales. S. Dietrich 1.5.7 Facilitate availability of information about HIV infection and AIDS in key languages. (✓)

Now Jenny Ross 1.5.8 Encourage National Member Organizations to support persons in neighbouring countries by sharing experiences and identifying key people to help in the management of HIV infection. ✓

Goal 1

ROP 1.6 Promote the availability of desmopressin for all those who might benefit from it.

Actions

New P.M. ✓

1.6.1 Encourage the identification of potential beneficiaries of desmopressin.

1.6.2 Promote the worldwide distribution of desmopressin.

1.6.3 Encourage the World Health Organization to designate desmopressin on the Model List of Essential Drugs.

Goal 2

The WFH will: **help initiate and assist** programmes to address those local factors that restrict access to areas of comprehensive care for persons with hemophilia and their families in the developing world.

World Federation of Hemophilia
Decade Plan

Goal 2

ROP 2.1 Persuade government and health authorities in developing countries to recognize hemophilia as an important health and social concern and to commit human and financial resources.

Actions

Inter
~~New C'mit~~
E. Bleny

2.1.1 Explore ways of linking hemophilia care to other major health care issues, particularly inherited hematological disorders. ✓

New C'mit

2.1.2 Request members and friends of WFH to identify people who influence health care policy in developing countries. ✓

[illegible]
Lom A.

2.1.3 Encourage authorities in developed countries to take active roles in initiating comprehensive hemophilia care in developing countries. ✓

Inter
Y. Sultan

2.1.4 Work with indigenous organizations and the World Health Organization, International Society of Blood Transfusion, International Society of Haematology, International Federation of Red Cross and Red Crescent Societies, and the International Society of Thrombosis to promote initiatives for hemophilia care. ✓

Goal 2

ROP 2.2 Promote access to all levels of hemophilia care for persons with hemophilia and their families in the developing world.

Actions

Now, P. Smille (Hoots) 2.2.1 Set up a process to define and review basic standards of comprehensive care for persons with hemophilia and their families. ✓✗

Inter G. Mariani 2.2.2 Establish a process to identify countries and locations in which hemophilia care meets with basic standards and those which do not meet the standards. ✓

? ? G Mariani 2.2.3 Recommend plans for initiating and maintaining programmes in those countries or locations not meeting basic standards of care. ✓✗

Goal 2

ROP 2.3 Establish a process to facilitate the selection of countries or locations which may be targeted for expanded hemophilia care.

Actions

New PI [illegible]

2.3.1 Define criteria to identify target countries or locations. ✓

2.3.2 Recommend programmes and resources and monitor progress ✗ in target countries or locations. ✓ ✗

?? A

Asian summit

Goal 3

***The WFH will:* encourage** the education and training of direct care givers as well as persons with hemophilia, their families, concerned organizations and the general public, using the most appropriate means.

Goal 3

ROP 3.1 Provide a full range of communication modalities about hemophilia in a culturally sensitive and easily understandable manner for medical, paramedical staff, patients and families of patients.

Idea D.M

Idea M.F.

Actions

3.1.1 Publish WFH documents and publications including *Life Paths*, *Hemophilia World*, and others in at least one more language. ✓✗

3.1.2 Develop programmes to design easily understandable materials for the education of persons with hemophilia, their families and their health care providers. ✓ ✗

Goal 3

ROP 3.2 Facilitate the education of medical and paramedical staff about particular needs of persons with hemophilia.

Actions

Inter
C. Ludlam

3.2.1 Encourage the development of programmes to attract and support medical and paramedical professionals to be trained in the management of hemophilia and related disorders. ✓

Inter

3.2.2 Develop and facilitate programmes to foster basic and clinical research in hemophilia and related disorders. ✓

Peake/Aledort

Goal 3

ROP 3.3 Expand the International Hemophilia Training Centres (IHTC) network to further focus WFH educational and training activities in the developing world.

Actions

Now K Richm

Inter

[illegible]

[illegible]

[illegible]

3.3.1 Determine current and potential capabilities of the IHTC network. ✓

3.3.2 Determine the organizational requirements to fulfill an expanded role. ✓

3.3.3 Develop an action programme to implement necessary IHTC network changes. ✓ ✗

Goal 4

The WFH will: **promote** research and development of the medical treatment of hemophilia and related disorders, and **encourage** the development of the technology base for this support.

Goal 4

ROP 4.1 Support and encourage scientific initiatives and research targeted at implementing a cure for hemophilia.

Inter
Glen Pierce

??
Hans
Brackmann

Actions

4.1.1 Gather and disseminate knowledge of scientific initiatives and research, including advances in gene therapy. ✓

4.1.2 Facilitate the speedy delivery of the appropriate technology to persons with hemophilia as soon as a cure becomes available. ✓(x)

Goal 4

ROP 4.2 Encourage the establishment and maintenance of a comprehensive demographic database.

Actions

Inter

E Briet 4.2.1 Encourage national registries for persons with hemophilia. ✓

B. Evatt 4.2.2 Gather basic global demographic information on persons with hemophilia and their families and their treatment centres. ✗

Schinaia 4.2.3 Develop the data systems required. ✓ ✗

Goal 4

ROP 4.3 Encourage the provision of a tiered comprehensive network of laboratories to provide diagnostic, treatment monitoring and genetic analysis services.

Actions

4.3.1 Define coagulation laboratory tests for diagnosis and treatment monitoring. ✓

4.3.2 Promote and use standards and quality control. ✓

4.3.3 Together with collaborating local agencies, develop training programmes for laboratory staff. ✓

4.3.4 Define levels of laboratory services in relation to local hemophilia care. ✓

4.3.5 Promote collaboration and communication between the different levels of laboratory service. ✓

4.3.6 Define and disseminate DNA analysis protocols for carrier detection and prenatal diagnosis in collaboration with the World Health Organization. ✓

4.3.7 Promote education on procedures of genetic analysis and associated counselling. ✓

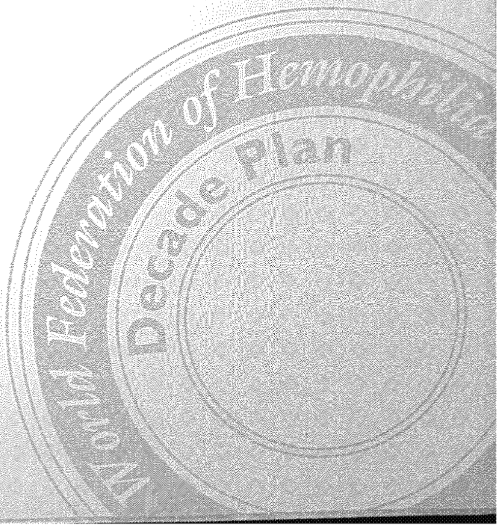
4.3.8 Disseminate DNA storage guidelines to all relevant institutions. ✓

4.3.9 Work with the World Health Organization and other international organizations in this area. ✓

Now
Peake
Seligsohn

Goal 5

The WFH will: **accomplish** its goals through appropriate organizations at global, regional and national levels.



Goal 5

ROP 5.1 Modify the structure and organization of WFH to accomplish the goals.

Actions

Now Tenkel

I.L.

(B. O'M

5.1.1 Review the mission statement and implement any necessary changes in order to reflect the purpose and goals of the WFH in the 1990s. ✓

5.1.2 Review the role, structure and relationships of WFH between the Executive, Council, General Assembly and committees, and implement any necessary changes. ✓

(A. Vargas

5.1.3 Consider the establishment of an international youth council of the WFH. ✓

(A. Tanner

5.1.4 Review the WFH Constitution and implement any necessary changes approved by the General Assembly. ✓

Now Shelley

5.1.5 Develop and implement a fund raising programme suitable for and appropriate to the needs of the organization. ✓✗

(J. Alonso

5.1.6 Create a regional structure in line with the WHO model. ✓

Now PM DM

5.1.7 Determine the appropriate role and possible presence of the WFH in Geneva. (✓)

Goal 5

Jake

ROP 5.2 Establish and support National Member Organizations (NMOs).

Actions

Now J. Ross 5.2.1 Define the criteria for NMOs' accreditation. ✓

PMSC ? 5.2.2 Support NMOs in the pursuit of their national goals. Rosemary Daly ✓

Now Chair 5.2.3 Facilitate communication between NMOs throughout the world. ✗

Goal 5

ROP 5.3 Define, publish and promote policy statements on significant current issues.

Inter

A. Brownlie

Actions

5.3.1 Develop and implement a policy setting process which is efficient, expeditious and responsive to the needs of persons with hemophilia and their families.

Implementation

Strategic planning requires the continued commitment of dedicated individuals if objectives are to be fulfilled. The global challenge is to help provide comprehensive care to all families with hemophilia. In order to fulfill this challenge, each ACTION in the WFH Decade Plan will be assigned to an individual. This man or woman, with proven expertise in the care of hemophilia, will be chosen from the world community. He or she will then be responsible for an Action Task Group which will set targets and timing to achieve progress.

Such is the continuing enthusiasm of the members of the original Strategic Planning Units, which first convened in Paris in 1990, that they will continue to monitor the programme. Ultimate audit and responsibility for the success of the Decade Plan will be with the President, the Executive and the Council. They will act in concert with the National Member Organizations, whose will is expressed through the General Assembly of the World Federation of Hemophilia.

World Federation of Hemophilia
Decade Plan

Financial Support of the Decade Plan

Enthusiasm, dedication and volunteerism alone cannot lead to the success of this Plan. WFH volunteers together with their financial supporters, and in particular the Industry Patron Sustaining Donors and the other companies and organizations which continue to provide financial help and expertise, will do everything they can to fulfill the Goals set out in the Decade Plan.

Individuals and subcommittees working on each of the 73 actions will need continuing logistic support. Implementation of each action will need financial resources. Some problems will have no hope of resolution without substantial, ongoing financial support.

The budget will be held by WFH Headquarters. The Executive will be solely responsible for all fund raising and the funding of Action Task Groups. It will also be responsible for the setting of priorities consistent with monies donated.

On behalf of affected families worldwide, the World Federation of Hemophilia seeks help in order to meet its global challenge.

Your support will make a difference to the quality of human life, creating opportunities for people with hemophilia and their families to enjoy full and productive lives.

GRO-C

Charles J Carman
President
World Federation of Hemophilia

Industry Patron Sustaining Donors

The World Federation of Hemophilia is grateful to all who provide financial support to meet its objectives. Special recognition is due to the industrial group identified as Industry Patron Sustaining Donors. As this designation implies, these donors are committed to sustaining their annual support at a significant financial level. It is their Patronage that helps the Federation towards the fulfillment of its Mission.

As of July 1992 the Industry Patron Sustaining Donors are:

- Aima-Biagini-Sclavo P.J. Mowlem & Sutton Sheila
- Alpha Therapeutic Corporation Shelley.
- Armour Pharmaceutical Company Phenix.
- Baxter International/Hyland Divison SD
- Behringwerke AG KS
- Miles Inc. CC.
- Quantum Health Resources Inc. SD
- Immuno. KS

Participants

The following participants gathered in Paris (France), Washington, D.C. (USA) and Barbados (West Indies) as members of Strategic Planning Units (SPUs), and contributed to the development of the Decade Plan for the World Federation of Hemophilia. In addition, many other colleagues from around the world contributed to the development.

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Spanish Federation of Hemophilia
Spain

Mr Terkel Andersen
Danish Haemophilia Society
Denmark

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International Federation of
Red Cross & Red Crescent Societies
Switzerland

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USA

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Costa Rica

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Karolinska Hospital
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Mr Edmond Secq
Belgian Haemophilia Society
Belgium

Dr Uri Seligsohn
Ichilov Hospital
Israel

Dr Cees Th. Smit Sibinga
Stichting Rode Kruis Bloedbank
Netherlands

Dr Yvette Sultan
Hôpital Cochin
France

Dr Ahmed H. Youssef
Kuwait Hemophilia Committee
Kuwait

(David Watters)

National Member Organizations

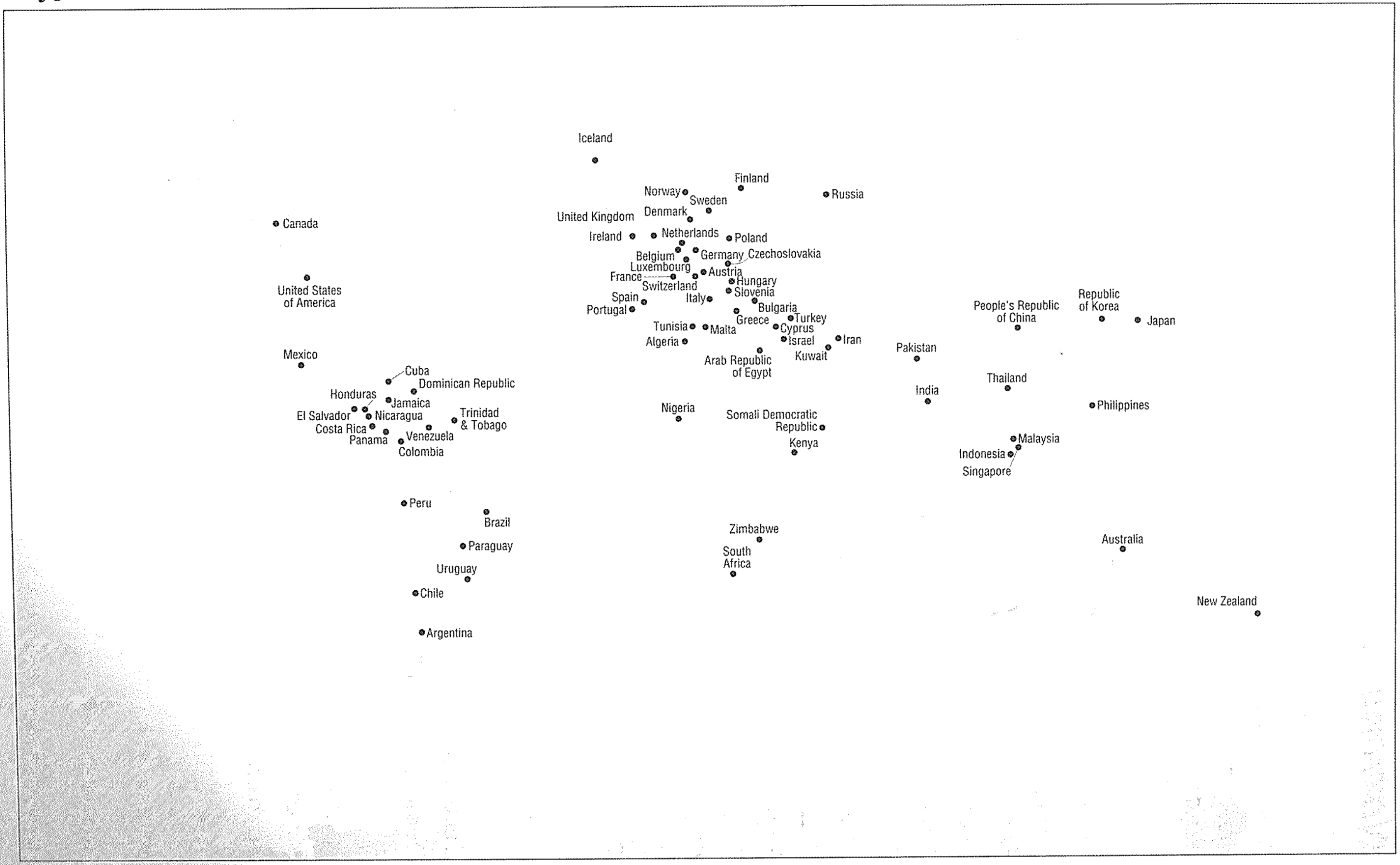
At its founding, the World Federation of Hemophilia consisted of six national member organizations. Today more than 70 nations are striving to improve the quality of life for persons with hemophilia and are active contributing members in the Federation.

National member organizations:

- Algeria
- Arab Republic of Egypt
- Argentina
- Australia
- Austria
- Belgium
- Brazil
- Bulgaria
- Canada
- Chile
- Colombia
- Costa Rica
- Cuba
- Cyprus
- Czechoslovakia
- Denmark
- Dominican Republic
- El Salvador
- Finland
- France
- Germany
- Greece
- Honduras
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Kenya
- Kuwait
- Luxembourg
- Malaysia
- Malta
- Mexico
- Netherlands
- New Zealand
- Nicaragua
- Nigeria
- Norway
- Pakistan
- Panama
- Paraguay
- People's Republic of China
- Peru
- Philippines
- Poland
- Portugal
- Republic of Korea
- Russia
- Singapore
- Slovenia
- Somali Democratic Republic
- South Africa
- Spain
- Sweden
- Switzerland
- Thailand
- Trinidad/Tobago
- Tunisia
- Turkey
- United Kingdom
- United States of America
- Uruguay
- Venezuela
- Zimbabwe

National Member Organizations

as of June 1992



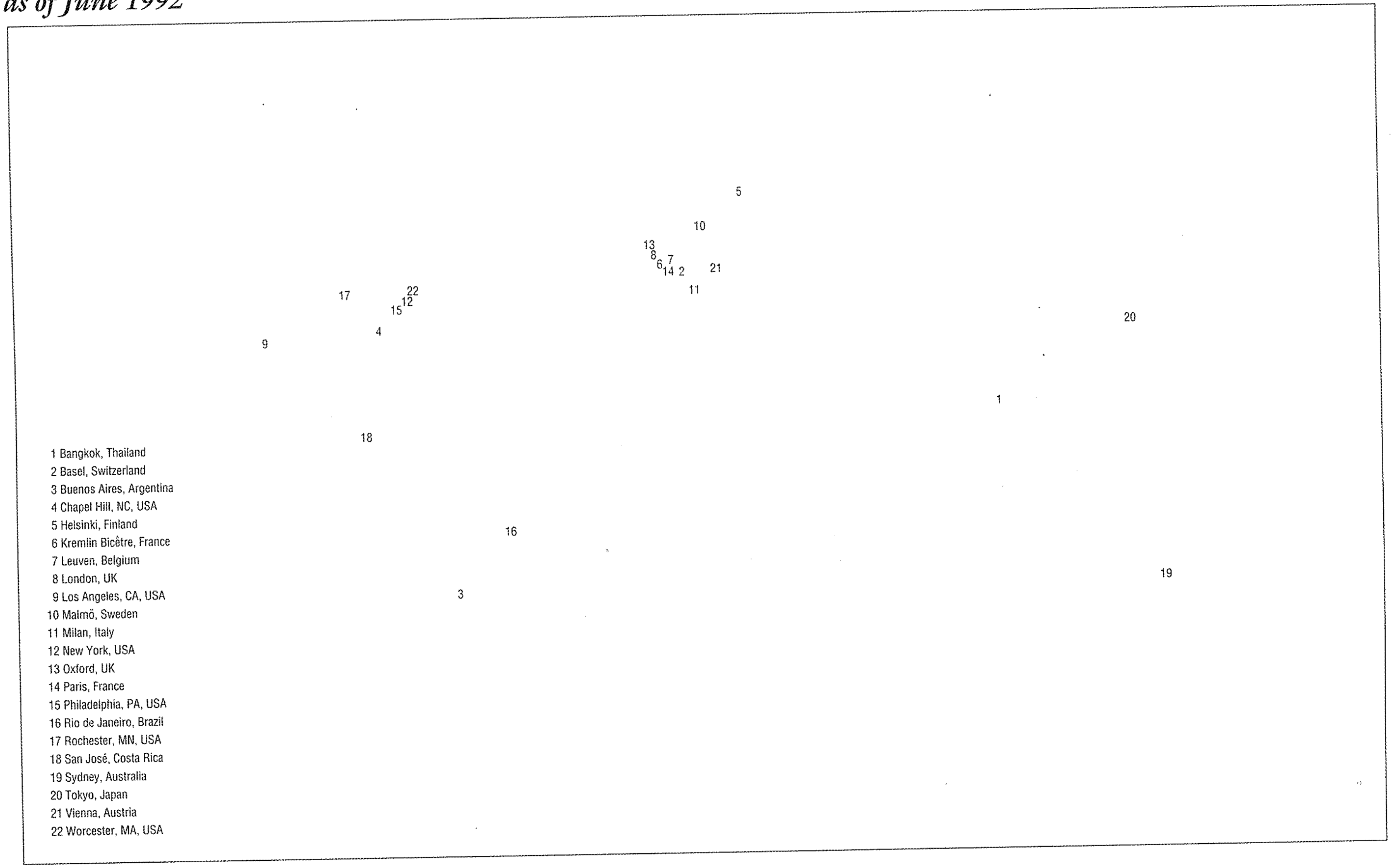
International Hemophilia Training Centres

The WFH has formed International Hemophilia Training Centres in many major cities. The centres educate persons with hemophilia and physicians in the treatment of the disorder.

1 Bangkok, Thailand
2 Basel, Switzerland
3 Buenos Aires, Argentina
4 Chapel Hill, NC, USA
5 Helsinki, Finland
6 Kremlin Bicêtre, France
7 Leuven, Belgium
8 London, UK
9 Los Angeles, CA, USA
10 Malmö, Sweden
11 Milan, Italy
12 New York, NY, USA
13 Oxford, UK
14 Paris, France
15 Philadelphia, PA, USA
16 Rio de Janeiro, Brazil
17 Rochester, MN, USA
18 San José, Costa Rica
19 Sydney, Australia
20 Tokyo, Japan
21 Vienna, Austria
22 Worcester, MA, USA

International Hemophilia Training Centres (IHTC)

as of June 1992



1 Bangkok, Thailand
2 Basel, Switzerland
3 Buenos Aires, Argentina
4 Chapel Hill, NC, USA
5 Helsinki, Finland
6 Kremlin Bicêtre, France
7 Leuven, Belgium
8 London, UK
9 Los Angeles, CA, USA
10 Malmö, Sweden
11 Milan, Italy
12 New York, USA
13 Oxford, UK
14 Paris, France
15 Philadelphia, PA, USA
16 Rio de Janeiro, Brazil
17 Rochester, MN, USA
18 San José, Costa Rica
19 Sydney, Australia
20 Tokyo, Japan
21 Vienna, Austria
22 Worcester, MA, USA

Acknowledgements

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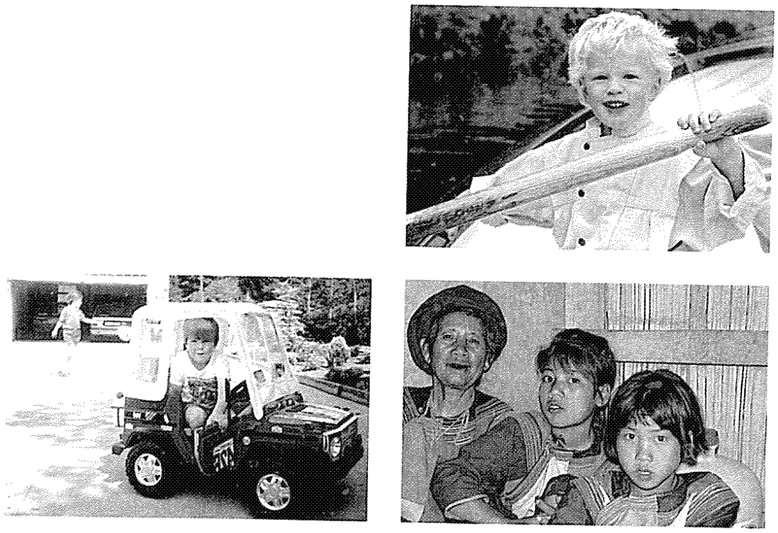
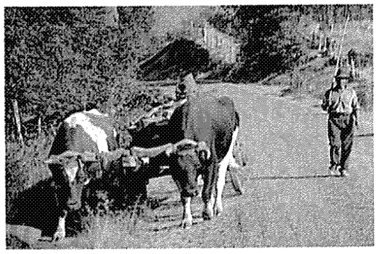
World Federation of Hemophilia Decade Plan

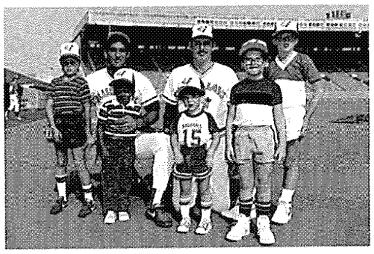
Hemophilia itself is not a handicap . . .



. . . without adequate treatment it can become one.

With treatment: *crippling can be prevented*
children can go to school
men can work, support and
raise their families.
Life can be normal.





World Federation of Hemophilia Decade Plan . . .

. . . answering the challenge.

World Federation of Hemophilia

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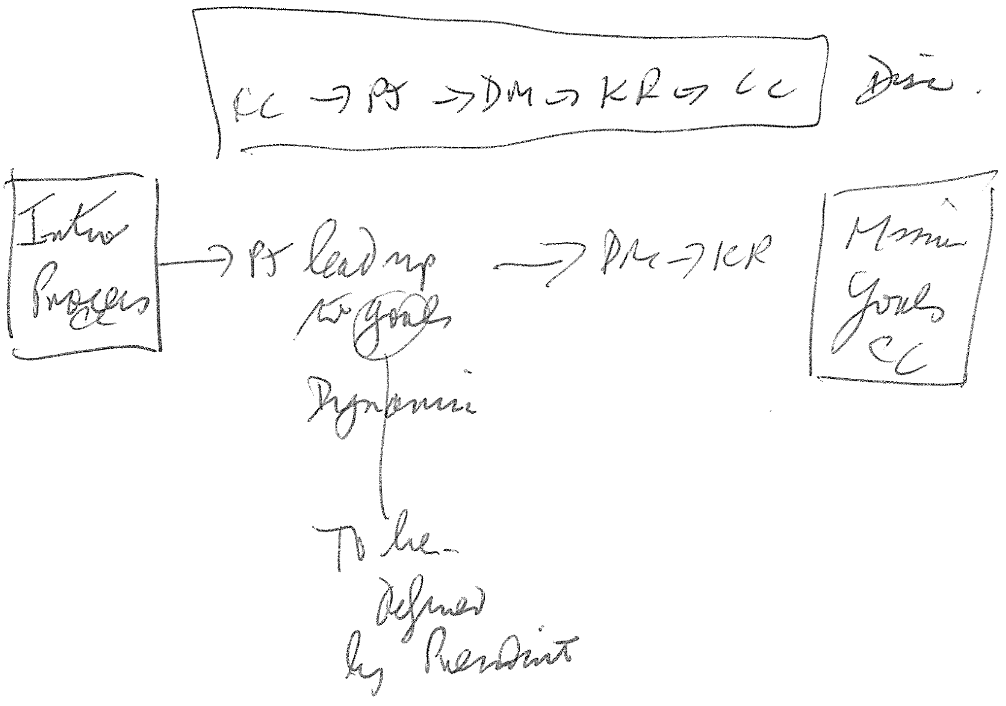

Strategy Generalship Management of army in a campaign

Art of disposing forces in actual contact with the enemy

Tactics / Skillful device Procedure to gain an end with enemy