The International Haemophilia Training Centres of the World Federation of Hemophilia: A 30-Year Review

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WORLD FEDERATION OF HEMOPHILIA FÉDÉRATION MONDIALE DE L'HÉMOPHILIE FEDERACION MUNDIAL DE HEMOFILIA Published by the World Federation of Hemophilia.

This publication is accessible from the World Federation of Hemophilia's web site at www.wfh.org, Additional copies are also available from the WFH at:

World Federation of Hemophilia 1425 René Lévesque Boulevard West, Suite 1010 Montréal, Québec H3G 1T7 CANADA

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INTRODUCTION

The year 2000 is the thirtieth anniversary of the formation of the World Federation of Hemophilia (WFH) network known as the International Haemophilia Training Centres (IHTCs). It is appropriate, therefore, to retrospectively examine the history of the IHTC program: its aims and objectives, some of its achievements and lessons learned, and possibly some directions for the future.

The Early Years: 1969-1972

Formation of the WFH and IHTC

The World Federation of Hemophilia was founded in June 1963 at the palace in Copenhagen, Denmark, where representatives of haemophilia societies from all over the world met to organise an international society.(1) The aims of this society were to stimulate activity in the problems of haemophilia and, especially, to stimulate interest in the diagnosis, treatment, and rehabilitation of people with haemophilia, as well as to encourage research into all aspects of the condition. The founding Chairman and driving force for the WFH was the late Mr. Frank Schnabel of Canada, with Mr. Henri Chaigneau of France and Mr. John Walsh of the United States as Vice Chairmen. The initial Medical and Scientific Advisory Committee was made up of Professor Kenneth Brinkhous of the United States, Professor J.P. Soulier of France, and Sir Weldon Dalrymple-Champneys of the United Kingdom. Dr. Cecil

Harris of Canada, Dr. E. Neumark of Great Britain, and Dr. K. Sjolin of Denmark were Medical Secretaries.(1) Over the next few years, the WFH focused on establishing its structure, status, and acceptability in the international communities of haemostasis and thrombosis, haematology, and haemophilia as a viable and credible champion for the cause of haemophilia. Progress was immediately apparent and continues at an ever-increasing rate in present times.

The need for special haemophilia centres was first recognised in the United Kingdom in 1954, when the Ministry of Health established a chain of 'haemophilia reference centres'.(1)(2) Rosemary Biggs at Oxford played a key role in the development of early ideas for haemophilia centres in the U.K.(3) Indeed, the Oxford Centre, first under the leadership of Dr. Biggs, then Dr. C. Rizza, and later Dr. P. Giangrande has been most helpful in the development and growth of the IHTC network. The U.K. centres had two common features: first, one or more physicians with a career commitment to haemophilia and, second, a large clientele of haemophilia patients. A parallel system of federally funded regional comprehensive haemophilia programs was introduced in the U.S.A. in 1976. These numbered 25 by 1981.(4)

A.F.H. (Tony) Britten, the founding chairman of the IHTC program, a South African born and New England trained physician, saw a precedent in the United Kingdom's group of nationally recognised treatment centres. Writing in 1981, he mentioned that the U.K. centres demonstrated leadership at the international level and had a profound influence on the advancement of understanding of haemophilia and its clinical management.(4) Dr. Britten suggested that within the jurisdiction of the newly formed World Federation of Hemophilia, there be the recognition, acknowledgement, and development of a similar, but international, group of treatment centres which would benefit people with haemophilia worldwide.(4) Accordingly, the concept of a chain of International Haemophilia Treatment Centres was approved at a WFH meeting in 1967, and in 1970, 18 centres were selected in the following cities: Athens, Beograd, Boston, Buenos Aires, Chapel Hill, Huizen, London, Los Angeles, Malmo, Mexico City, Milan, Oxford, Paris, Sydney, Tehran, Tokyo, Vienna, and Warsaw.(5)

"The selected centres," Dr. Britten announced, "would be assuming a responsibility not receiving an honour. These centres will bring treatment to a few, inspiration to many, and leadership to all of us".(6)

A further significant development was detailed in a 1972 memorandum to IHTC Directors from the Chairman of the WFH. In this memorandum, Mr. Schnabel made mention of the difficulties surrounding haemophilia centres offering treatment to international visitors, and further began to realise how important was the concept and principle of training as a key role for these international centres. Accordingly, the suggestion was made that there should be a change of designation from International Haemophilia Treatment Centre to International Haemophilia Training Centre.(7) The 1972 memorandum contains two key messages in regard to the modus operandi of the IHTC program. One is the important role of training of medical and paramedical staff from various countries in the world, and the second is the development of a program based on teaching workshops in different countries. The ideas developed in this memorandum were endorsed by Professor Pier Mannucci, then Chairman of the IHTC program, in October 1973. As of late 1973, it had become apparent that fellowships and workshops were the key activities of the IHTC program.(5) According

to the WFH *Bulletin* of August 1984(8) the IHTC program was the Federation's most visible and effective direct assistance program.

IHTC Fellowships

Throughout the history of the IHTC program, the term fellowship has applied to an opportunity initially for medical but in later years for paramedical people to spend six to eight weeks in an IHTC environment learning as much as possible about haemophilia. For medical people this time was spent being involved in laboratory diagnostic techniques, clinical care, and therapeutic methods, as well as other aspects of treatment. Paramedical people have received upto-date instruction at the IHTC in their area of interest as well as having the opportunity for a broad exposure to haemophilia care.

IHTC Workshops

This term applies to an intensive three- or four-day course of lectures and instruction on various aspects of haemophilia care ranging from diagnosis and clinical skills to therapy and avoidance of complications, as well as various aspects of transfusion medicine and haemophilia matters deemed appropriate to the host country. Workshops have usually been conducted by a visiting faculty of IHTC staff, as well as local speakers. More recently, these instructional workshops have often included an additional day or so for a laboratory course, with "hands on" experience in laboratory diagnosis, methods for coagulation factor assays, and the monitoring of therapy, and for special sessions for the local hemophilia organisation.

The Middle Years: 1972-1986

IHTC 'Starting to Move'

What might be termed the middle years of the IHTC program were largely influenced by the enterprising, imaginative, productive, and forceful leadership of Professor P.M. Mannucci of Milan, Italy.

Much of these years is documented in the August 1984 special issue of the WFH *Bulletin* dedicated to the IHTC program, which is an historical treasure. In an article entitled 'Facts and Fancies',

Professor Mannucci disavows a number of misconceptions about the IHTC network, and again emphasises that for an IHTC 'the burden exceeds honours'.(9) He also mentions the importance of good communication with IHTC trainees or fellows in their own tongue, that their training is more effective when carried out in an environment similar to that of the trainee's homeland, and the need to develop more IHTCs in the developing world.



Workshop – WFH Team Bangkok Thailand 1979

This IHTC *Bulletin* was also of interest since it made a first attempt at what could be called an audit of the IHTC program. All the IHTC fellows until that time were traced and their reports reviewed. In another interesting feature, that issue of the *Bulletin* summarised various policy statements from the Chairman's reports of Professor Mannucci from 1974 to 1983(10). Such matters as training resources, the relationship of IHTCs to WHO, candidate selection, follow-up by visiting teams, fact-finding tours, clinical laboratory fellowships, site visits by IHTC teams, effective regionalisation and relationship with other WFH committees, and a socio-medical role in workshops were all mentioned. Many, if not all, of the above matters are as important now as they were in those middle years.

Several IHTC success stories date back to this period, where centres were sites of IHTC workshops and fellowship programs. These

included San José (Costa Rica), Bangkok (Thailand), and later Kuala Lumpur (Malaysia).

Professor Mannucci's 14-year term as IHTC Chairman concluded at the 18th Congress of the WFH in Rio de Janeiro in 1984. He himself put forward a balance sheet which is a tour de force.(11) Fourteen workshops and seminars had been organised in Mexico, Costa Rica, Brazil, Japan, Nigeria, Algeria, Iran, Thailand, Jamaica, Philippines, Kuwait, India, and Paraguay. During this time the IHTC Committee had awarded and seen the completion of 56 fellowships at a total expenditure of some US\$79,000. Successful applicants came from Australia, Brazil, Bulgaria, Chile, Costa Rica, Cyprus, India, Jamaica, Kenya, Malaysia, Malta, Nicaragua, Nigeria, People's Republic of China, Portugal, the Philippines, Switzerland, Thailand, United Kingdom, Uruguay, and Yugoslavia.

The WFH and the IHTC program had much to be proud of in those middle years, and is most grateful for the leadership of Professor Mannucci as Chairman. In the later years, he did receive considerable assistance from Dr. Louis Aledort as Vice Chairman, from Professor Kevin Rickard as Secretary of the Committee, and from the untiring efforts and efficiency of Mrs. Sheila Brading of the WFH Secretariat in Montreal. Mannucci, in his concluding remarks, mentioned that the IHTC program was a 'weapon of immense value' and acknowledged the assistance of many people including J.P. Allain (France), A. Ahlbereg (Sweden), S. Dietrich (USA), M.J. Larrieu (France), W. Bowie (USA), R. Cordero (Costa Rica), P. Levine (USA), P. Kernoff (UK), K. Rickard (Australia), and, of course, Frank and Marthe Schnabel of Canada. He also paid tribute to all of the Director participants of IHTCs for their contributions to this global program for improved haemophilia care.

Dr. Louis Aledort of New York, U.S.A., succeeded Professor Mannucci as Chairman from 1984 to 1986, and continued to plan and organise vigorous IHTC activity.



IHTC Workshop Kuala Lumpur Malaysia 1988

The Later Years: 1986-2000

"The Jewel in the Crown"

In 1986, Professor Kevin Rickard became IHTC Chairperson, a position he held for 10 years. During this time, there were three IHTC Secretaries: Dr Peter Kernoff of London, Dr Carol Kasper of Los Angeles, and Professor Christine Lee from London.

At the original Kuala Lumpur workshop in 1988, formal written recommendations were presented to government, probably for the first time, and there was also active government participation in the workshop. In 10 years, that initial IHTC workshop, with its recommendations, as well as fellowship trainings, led to markedly improved care for people with haemophilia throughout Malaysia. In 1998, the Kuala Lumpur Blood Services Centre became a WFH-accredited IHTC.

By the late 1980s, the IHTC program had achieved a considerable degree of international recognition and credibility. The IHTC record of training people and societies in haemophilia care had earned it the title of 'Jewel in the Crown' of WFH activities. Certainly, by the later years of this period, IHTC was the first choice for conducting training exercises in developing countries, and the number of applicants for IHTC fellowships was steadily increasing. Accordingly, the competition

among applicants became quite intense. It was often extremely difficult to choose who should be selected for a fellowship.

The network of IHTCs was now well established, and the majority of centres were regularly participating in teaching and workshop activities as well as accepting fellowship trainees. There was a steady stream of centres applying for IHTC status, all of which were carefully considered, and

a small number of them were accepted over the years. Criteria for acceptance depended primarily on the applicant centre's ability to contribute and accept developing world trainees, whilst the centre's location in regard to world geography, language, facilities, and relation to other centres were also important.

It was also realised that several existing centres could better fulfil IHTC goals if they combined their enormous talents. In Paris, the Bicetre, Necker, and Cochin haemophilia centres joined forces to become the Paris IHTC, and in New York, Mt. Sinai Hospital and Cornell Medical Centre formed the New York IHTC.

Since 1996, Professor Christine Lee, who succeeded Dr Peter Kernoff as Director of the Katharine Dormandy Haemophilia Centre at the Royal Free Hospital in London, has been IHTC Chair. She has streamlined and restructured a number of the processes involved with IHTC management. As a result, the quantity and quality of fellowship applications have increased enormously. Applications now undergo a very thorough pre-selection analysis process to ensure that awarded fellows are truly committed to hemophilia care in their country. The IHTC program is still primarily about training activities by virtue of the fellowship program. Workshops

have also taken place in Pakistan, Russia, Indonesia, Iran, South Africa, and Thailand.

As the WFH has evolved and responded during the period of the 1980s and 90s, the IHTC program has continued its role as a major resource for training. It is still most important and vital for teaching about haemophilia in the developing world.

valuable Centre twinning programs, many of which are quite naturally IHTCs twinned with centres in the developing world, the training possibilities of IHTCs have been greatly expanded. Such 'twinning' permits an ongoing interchange of information, often personnel exchange and even a visiting team, actively participating in haemophilia care in the developing world.

The Network

The valuable chain of international training centres now represents a vital and interconnecting system of haemophilia centres located in 30 academic institutions in 27 cities around the globe. These institutions are a worldwide network of first-class medical centres. located predominantly in hospitals with academic and university affiliations. The centres provide comprehensive haemophilia care for people from their own



Participants and visiting WFH faculty at the 1993 workshop in Tianjin, China. A 'wet' or practical laboratory workshop was held in conjunction with the by now traditional workshop format.

countries, and strongly support the aims and ideals of WFH. They are all involved at some time or another, in the training of medical and paramedical people from the developing world, and may participate in regional and local workshops in haemophilia care. It is pleasing to see that all of these activities and information flow is often bidirectional. Much can be learnt from the developing world trainees.

A list of current IHTCs and their directors is provided in Table 1, and IHTC chairpersons and secretaries from the program's inception are listed in Table 2.

The major educational thrust for international medical training is via fellowships and workshops. In addition, ad hoc cooperation is often required in WFH activities while regional consultative meetings have been held, e.g. in Hong Kong, Johannesburg, Moscow, and St. Petersburg. More recently, by playing an active role in the WFH's

Fellowships

International fellows submit applications, which are reviewed by the IHTC Sub-Committee. At the annual IHTC Directors meeting, final decisions and choices for fellowships are made and arrangements for a host IHTC and funding are concluded. Another very important step in the fellowship application process is to obtain vital input and priority assessment of candidates from their respective national hemophilia organisations. This ranking is then factored into the final decision-making process.

Workshops and Regional Consultative Meetings

It is fair to say that WFH workshops, over the history of the IHTC program, have proved very productive and successful for the introduction of haemophilia care into a large number of developing countries as well as for raising awareness of all aspects of haemophilia

management to a wide variety of medical, and paramedical people in the developing world.

Workshop Development

Workshops have developed either because there was a request to the WFH for help in a particular country, or location, from the local society or physicians, or because WFH authorities at the time perceived a need for haemophilia support in that particular area. Programs are generally broad based on multiple aspects of haemophilia care, ranging from laboratory diagnosis to clinical management for medical, surgical, and dental care, as well as critical approaches to therapeutic support. The latter aspect quite naturally involves some of the areas of transfusion medicine and its associated safety requirements.(12) It is important to appreciate that the workshop faculty, who are all volunteers, generally need to put considerable effort into preparation of their lectures or presentations, as well as being prepared to travel, often to distant lands on their own time. More often than not, a significant proportion of their travel expenses are met by WFH but are often significantly supplemented by the faculty member.

Workshops have also involved people with haemophilia and their families, local societies, and relevant government representatives. The involvement of the latter is especially important. As the WFH has developed new program tools, such as twinning for centre and hemophilia organizations, workshops have expanded to include a wider audience to establish an integrated approach to develop hemophilia care.

Workshop Recommendations

In the writer's experience, a concluding workshop session in the nature of an open forum or tutorial type arrangement is particularly valuable. In such an open forum, all sorts of ideas, expressions of interest, and methods of contribution were often expressed, and new ideas floated. From this forum, together with the happenings in the previous few days, it was generally possible for the workshop leader, in collaboration with colleagues, to formulate a series of formal workshop recommendations, which could then be presented to the local society and to relevant government agencies. These workshop recommendations have become a key output of recent workshop

programs. The forum and recommendation concept has also proved most valuable at recent regional consultative meetings in China, Indonesia, India, Thailand, and South Africa. The open forums do need a great spirit of co-operation by all relevant parties, a real sense of the local difficulties and problems, and appreciation of the entire concept of 'enculturation', a relatively new word and idea, but a vital concept for WFH. For real enculturation we need to appreciate that if future progress is to be made in a particular geographic area a great deal of good will, interest, and application to haemophilia needs to be developed. Further, any recommendations that evolve from a WFH workshop are really made as a "snapshot in time" with regard to the evolution of care in a particular country. In terms of enculturation, the recommendations are being put forward in a truthful sense of suggestion that may be able to be incorporated into the ways, means and methods of operation of the particular host country.

The major recurring themes of these recommendations are summarised in Table 3 and mentioned below.

Improved and expanded training in all aspects of haemophilia has been the universal appeal from all workshops. The idea of linkage has arisen as a crucial notion with regard to improving haemophilia care. Linkage simply means that improved haemophilia care cannot be developed as a stand-alone entity but rather improvements can only occur hand in hand with improvements in other services, such as in blood transfusion medicine, in surgical and obstetric care, and, importantly, in laboratory medical operations. In the latter, the whole notion of alignment with international benchmark standards and quality control is critical. Universally, workshops saw the need for developing countries to have designated haemophilia centres and a local champion – preferably a physician committed to haemophilia care. Here again, we see the need for enculturation. Improvements in haemophilia can really only develop and survive within the context and appreciation of local customs, cultures, and morays. To try to do otherwise is to court disaster. It has been universally accepted in workshops that adequate diagnostic facilities and availability of therapeutic material are a "sine qua non" of

improved haemophilia care. There is always a need for a viable transfusion service, which takes into account the necessity for safe blood component practice in all its aspects.

Finally, none of the above can be achieved without a reasonable budget – indeed a budget is in fact a plan. Budgets generally need to be funded by government support, with perhaps, in some developing countries, supplementation from voluntary sources.

Fellowships

A summary of the fellowship numbers and their monetary value for the period 1987 - 2000 is presented in Table 4. During this time, 169 worldwide fellowships were awarded for a total value of US\$365,500.

External Quality Assurance and IHTC

Discussion at IHTC Directors meetings and in other informal meetings of Directors had long considered the importance of international benchmark standards and external quality control in laboratory medicine. Dr Peter Kernoff, from the Royal Free Hospital in London, had during the Chairmanship of Professor K.A. Rickard, suggested participation of IHTCs in such a continuing multinational study. This idea was vigorously pursued by Professor Eric Preston of Sheffield, the Chairman of the United Kingdom National External Quality Assurance system, and with the willing agreement of the IHTC Directors, the WFH External Quality Assurance System was established in 1993.

This has proven to be of great benefit to IHTC laboratories around the world and using IHTC performances as a benchmark standard, the system has been utilised and applied to haemophilia centres in the developing world.(13)

In two surveys, results obtained by the IHTC were closely aligned to those obtained by participant laboratories in the United Kingdom National External Quality Assessment Scheme (U.K. NEQAS) for blood coagulation on the same samples. A subsequent further eight surveys demonstrated close agreement between IHTC and U.K. NEQAS median results. Looking at the simple prothrombin time tests, the majority of

centres identified abnormal PTs but a high proportion of developing world haemophilia centres failed to detect an abnormality whilst a high proportion of centres failed to detect an abnormal APTT on samples from two donors with haemophilia A.(14) These results may have much to do with APTT reagent sensitivity. It is reassuring to note that for factor VIII:c and IX:c assays, there was reasonable agreement between IHTC and haemophilia centre medians but there was a much wider spread of results amongst the haemophilia centres than amongst the IHTC. Follow up questionnaires indicated that many centres cited reagent cost and lack of equipment and facilities as the main reasons for failing to perform essential tests of haemostatic function in the developing world.

There is a striking resemblance to these sorts of conclusions as demonstrated by scientific studies to the summary recommendations, which have arisen from workshops over the years of IHTC activity. Again, by these studies in external quality assurance for laboratory methodology, the vital role of the IHTC network can be seen to be critical in the establishment of haemophilia care in the developing world. If the correct diagnosis cannot be made in the first instance, then it is impossible to develop and establish haemophilia care in any given country. The IHTCs play a very important role in instructing fellows in laboratory methodology and accuracy of diagnosis, as well as by the utilisation of 'wet workshops' to provide on-site laboratory training.

WFH - IHTC - WHO

Collaboration

A most welcome and valuable development in the later years of the IHTC program and in the history of WFH has been an increasingly close liaison with the World Health Organisation in Geneva. Various IHTC Directors have played a key role in this liaison, a key feature of which has been extremely valuable WHO-WFH meetings listed in Table 5. WFH contact persons have been Professor Mannucci from Italy for the first two meetings, and Dr Peter Jones from England for the later two meetings. A large number of IHTC Directors have been vital contributors to all these

meetings. Details of all the meetings have been published as official WHO reports (15, 16, 17, 18) with a very wide distribution, while some have also been published as supplements (19, 20) to the journal Haemophilia, published by Blackwell Science in England. In the developing world, where WHO standards assume much significance, joint publications of WHO and WFH, such as those mentioned above, as well as *Guidelines for the Development of a National Programme for Haemophilia*,(21) can and do play an important role in the re-enforcement of the mission of WFH to reach and improve the standards of care of people with haemophilia, wherever they may be in this world of ours.

Summary

This paper has traced the evolution and development of the International Haemophilia Training Centres of the World Federation of Hemophilia. This important training program has been a continually evolving and vital activity. For a number of years it was the only teaching and training activity offered by WFH for the developing world. The program has relied heavily and almost exclusively on fellowships and workshop methodology for bringing assistance to people with haemophilia in the developing world. The program has also relied heavily on the generous voluntary service of all the Directors and staff of IHTCs throughout the world. Without this generosity and willingness to contribute by the IHTCs, the program would not have succeeded. It is reasonable to offer the value judgement that over the past thirty years of activity, the IHTC program has been a remarkable success. It has justifiably been called 'the Jewel in the Crown' of WFH activities, whose very 'raison d'être' is to improve haemophilia care throughout the world. The success of IHTC activities can to some extent be measured by the award of over 180 fellowships and the conduct of over 40 workshops around the globe in the past 30 years. This represents an enormous amount of work by a considerable number of very generous people involved with WFH, all of whom, it needs to be stressed, work and offer their time and expertise in an entirely voluntary capacity. Further, it is important to stress the notion that the IHTC network continues

to exist and that it is a superb environment for fellowship training and despite some movement in and out of centres over the years, the network has been very stable whilst the contribution from individual Directors and centres has always been and continues to be forthcoming. All of this in itself is salutary, enhancing, and motivating. With the evolution of such a wonderful and worldwide organisation as the WFH, change is to be expected. Certainly, the WFH has changed, evolved, and achieved considerable international and scientific status over the past 35 years, and with these changes to the WFH, the IHTC program is also evolving. Evolution is not only toward a more efficient organisation itself, but also to connect and interlock with such important new WFH initiatives as the very successful twinning program, Operation Access, and country projects. This evolution can only strengthen and broaden the potential of the IHTC network.

Perhaps one criticism that may be levelled at the IHTC program is the relative lack of IHTC centres in the developing world. This matter is well recognised and has been well and truly on the IHTC agenda for a number of years, but there is still a certain reluctance in these developing world areas for newer haemophilia centres to make a somewhat open-ended commitment to a training load when they themselves are still to some extent struggling to survive in their own environment. However, there are now three IHTCs in the developing world, and the WFH hopes to have more in the future. Another area that might be called a need in the IHTC fabric is the sense of some further increase in funding so that fellowships offered in the future are slightly more realistic in the financial sense. Nevertheless, despite these minor criticisms, the very idea of a system of International Haemophilia Training Centres has been most rewarding. The notion of training by way of workshops and fellowships has proved to be most successful for trainees, for trainers, and for people with haemophilia. Further, the IHTC program has often been instrumental in the introduction of the very concept of haemophilia care and therapy, especially by implementing the idea of linkage of haemophilia care to other medical developments or improvement in standards in a whole spectrum of medical care possibilities within a spirit of

enculturation in a large number of countries in the developing world. Finally, it is important to recognise the contribution of all the Directors and staff of participating International Haemophilia Training Centres, and thank them most sincerely for their continuing and precious contributions over the last 30 years. The leadership role of the International Haemophilia Training Centres of the World Federation of Hemophilia has done much to improve standards of care for people with haemophilia throughout the world but this is particularly so in the developing world.

TABLE 1

List of Current International Hemophilia Training Centres (28)

Madrid/Valencia Bangkok Rochester Basel (x2) Malmo Sheffield Buenos Aires Svdnev Milan Tel Hashomer Chapel Hill Munich Groningen Texas Nara Kuala Lumpur New York (x2) Utrecht Leuven Oxford Vellore London/Cambridge Paris (x3) Vienna

Los Angeles Philadelphia Worcester

IHTC Countries

Argentina Germany The Netherlands (x2)

Australia India Spain (x2) Austria Israel Sweden

Belgium Italy Switzerland (x2) France (x3) Japan United Kingdom (x3) Thailand Malaysia United States (x8)

List of Current IHTC Directors

P. Isarangkura / Vichai Atichartakarn Bangkok

Basel G. Marbet / T. Kühne **Buenos Aires** M. De Tezanos Pinto

Chapel Hill G. White C. Smit Sibinga Y. Ayob Groningen Kuala Lumpur J. Vermylen Leuven London/Cambridge C. Lee / J.P. Allain

Los Angeles L. Logan

Madrid/Valencia Dr. Aznar (Valencia)

Malmo E. Berntorp Milan P. Mannucci Munich W Schramm Nara A. Yoshioka

S. Seremetis / M. Gilbert New York (x2)

P. Giangrande Oxford

P. Molho / C. Rothschild / T. Lambert Paris (x3)

B. Konkle / G. Zohar Philadelphia

Rochester W. Nichols Sheffield M. Makris Sydney K. Rickard Tel Hashomer U. Martinowitz Texas K. Hoots

M. Van den Berg Utrecht

A. Srivastava / M. Chandy Vellore

Vienna I. Pabinger Worcester D. Brettler

TABLE 2

IHTC Chairpersons and Secretaries

Chairperson	<u>Country</u>	<u>Years</u>
A.H.F. Britten P.M. Mannucci L.M. Aledort K.A. Rickard C. Lee	USA Italy USA Australia England	1969 - 1971 1971 - 1984 1984 - 1986 1986 - 1996 1996 - Present
<u>Secretary</u>	<u>Country</u>	<u>Years</u>
K.A. Rickard P.B.A. Kernoff C. Kasper	Australia England USA	1982 - 1986 1986 - 1993 1993 - 1994
C. Lee	England	1994 - 1996

Current IHTC Sub-Committee

Christine Lee, IHTC Chair
Brian O'Mahony, WFH President
Paul Giangrande, Vice President Medical
Bruce Evatt, Vice President Developing World
Carlos Rodriguez Merchan, Chair Musculoskeletal Committee
Angus McCraw, Chair Lab Sciences Committee

TABLE 3

Major Workshop Recommendations

- 1. Need for Medical Training and Education
- 2. Linkage
- 3. Need for Specialized Haemophilia Centre Patient Registry
- 4. Comprehensive Haemophilia Care Enculturation
- 5. Laboratory Diagnostic Facilities
- 6. Availability of Factor Replacement Therapeutic Materials
- 7. Good Blood Transfusion Service
- 8. Budgets
- 9. Strong Haemophilia Patient Societies
- 10. Government Commitment and Support

TABLE 4 **IHTC DIRECTORS' MEETINGS / FELLOWSHIPS AWARDED**

IHTC MEETING	YEAR	F'SHIPS TOTAL	EXPENDITURE TOTAL / \$1000's US
Montreal	2000	22	58.9
Washington	1999	20	52.2
Hague	1998	16	34.8
Florence	1997	18	34.6
Dublin (WFH)	1996	11	17
Jerusalem (ISTH)	1995	11	27.5
Mexico (WFH)	1994	14	38.5
New York (ISTH)	1993	13	25.5
Athens (WFH)	1992	13	24
Amsterdam (ISTH)	1991	7	10
Washington DC (WFH)	1990	12	16
Los Angeles	1989	4	11
Madrid (WFH)	1988	5	10
Brussels (ISTH)	1987	3	5
TOTAL	14 Years	169	365.5

WFH - World Federation of Haemophilia Meeting ISTH - International Society of Thrombosis & Haemostasis Meeting

TABLE 5 **WHO - WFH Meetings**

1990	Possibilities for the prevention & control of haemophilia
1992	Control of haemophilia - Carrier detection & Prenatal diagnosis
1994	Modern treatment of haemophilia
1997	Haemophilia care in developing countries

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