Current Studies in Hemophilia
Données nouvelles sur l’hémophilie

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Comptes rendus du 3e Congrès de la Fédération Mondiale de l'Hémophilie

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Introduction

The World Federation of Hemophilia was created in Copenhagen on June 25th, 1963.
This first meeting of the national hemophilia organizations took place concurrently with the meetings of the International Society for the Rehabilitation of the disabled.

Hemophiliacs from Argentina, Australia, Austria, Belgium, Canada, Denmark, England, France, Germany, Italy, Japan, Netherlands, Portugal, Sweden, Switzerland and the United States were represented, whether by appointed delegates or by hematologists. At the Copenhagen meeting, it was decided that an international hemophilia organization be formed and that its name is to be World Federation of Hemophilia.

Mr. Frank Schnabel, President and instigator of the Canadian Hemophilia Society, became Chairman of the Federation.

The principal aims of the World Federation of Hemophilia are the followings:

To help hemophiliacs and sufferers of related disorders in every way possible, and to provide fellowship to all concerned with hemophilia throughout the world.

To stimulate interest in the development and improvement of diagnosis, treatment, rehabilitation and research in hemophilia.

To act as a co-ordinating body to develop the collection, distribution and exchange of information on hemophilia and related disorders.

To encourage the creation and development of hemophilia organizations.

The membership of the World Federation of Hemophilia was open to national hemophilia societies and to individual members.


Delegates from 14 countries met under the chairmanship of Professor S. van Creveld, President of the Dutch Hemophilia Society.

The minutes of this meeting were published by: the National Hemophilia Foundation, 23 West 39th street, New York 10018 (USA).

Introduction

In Amsterdam, the structures of the World Federation of Hemophilia were firmly established by the ratification of its constitution and the election of an executive board and a scientific and medical advisory committee.
The 3rd congress of the World Federation of Hemophilia was held in Paris on September 7-9, 1965, and was sponsored by the International Society of Blood Transfusion. 120 delegates from 22 countries met in the building of UNESCO, under the chairmanship of Prof. J. P. Soulier, Honorary President, and Mr. H. Chaigneau, President of the Association française des Hémophiles. The proceedings of this third meeting are the first to be printed with details taking into consideration the importance of the scientific and social contributions presented.

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Introductory Address
Communication and Expectation:
The Hemophilia Revolution

On behalf of hemophiliacs throughout the world, we wish to express our profound appreciation for your participation in this distinguished Congress. We extend to you a most cordial welcome.

Nous désirons exprimer à nos amis français notre plaisir et notre joie de nous retrouver dans leur magnifique capitale. Au nom de la Fédération Mondiale de l'Hémophilie, nous remercions Monsieur Henri Chaigneau, le Professeur Soulier, Madame Barbot et tous les membres de l'Association française des Hémophiles pour le long et intensif travail qu’ils ont consacré aux préparatifs de ce congrès.

La Federación Mundial de la Hemophilia se complace en dar la bienvenida a los delegados latinoamericanos en el Congreso que se lleva a cabo en París. Es un placer para mi informales que durante mi visita a Costa Rica en julio, se hicieron planes para organizar una Sociedad de Hemofilia en Costa Rica. En un futuro cercano, anticipamos la participación de muchos países latinoamericanos como miembros de la Federación.

If I may, for a moment, indulge in reflection, I would like to return to Copenhagen, June, 1963. The World Federation of Hemophilia was born with difficulty, some felt prematurely. Subsequent to Copenhagen, the Federation experienced an accelerated development. National representation increased from 6 at Copenhagen to 14 at Amsterdam. The Amsterdam meeting, August 1964, was a surprising success, beyond our expectations, thanks to Professor Doctor van Creveld.

And now the splendid Paris Congress. Those of us in Denmark 2 years ago could never have visualized such a Congress: sponsored by the International Society of Blood Transfusion, housed in the UNESCO Building, simultaneous translation, philatelic commemoration by France and participation by internationally distinguished doctors and scientists.

Our progress has, indeed, been remarkable and it is symbolized by this Congress. There is a sequence in the development of an organiza-
tion, particularly hemophilia organizations. The cycle of development can be characterized by an alliteration of As; apathy, antagonism, acquiescence, acceptance, acknowledgment and affirmation. Assuming the accuracy of this sequence, we have arrived at affirmation here in Paris.

I would like to share with you a few personal observations. Visiting many of the world’s hemophilia treatment and research centres, as an observer and occasionally as a patient, I have had the opportunity of being exposed to the reality of the hemophilia condition. In retrospect, for decades, pessimism prevailed in the hemophilia world. The prospect, however, is much more promising. The mid-1960s, I believe, will mark a turning point, a landmark, in the long history of hemophilia perdition. Today, the light of optimism, beginning to glow on the horizon, is by no means universal. It is, in fact, confined to too few of the earth’s major cities. Nevertheless, I believe that a hemophilia revolution is underway and that this is a time for great expectations.

We are living in a era of accelerated change, people cannot accept the status quo when they become aware that their condition of misery is no longer inevitable. Because of contemporary communications, hematologists and hemophiliacs increasingly realize that yesterday’s practises are unacceptable.

Only three months ago I received a series of transfusions at a centre on the West Coast of North America. In this city facing the Pacific Ocean, I found myself in a hemophilia treatment room in the emergency department, invariably joined by three or four other hemophiliacs. How delightful it was to be with such knowledgeable, positive, optimistic, functional and, of course, relatively healthy hemophiliacs, participating in an efficient totality control program, a program liberated for the most part from hospitalization.

Two months ago, I visited a Latin American country and there I encountered the very antithesis experienced the previous month. Treatment consists of an occasional whole blood transfusion, usually resorted to at the end of a crisis and therefore the hemophilia condition was one of withdrawal, fatalism, hostility and despair.

In making a heaven and hell hemophilia comparison, the explanation should not be ascribed to the differences between developed and under-developed countries. On the contrary, we certainly find

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inadequate treatment programs in all too many areas of the most
advanced countries.

A Canadian scholar, Harold A. Innis, has said that every crucial change in the structure of society has been the consequence of a major change in our methods of communication. Where the hemophiliac’s world is confined or isolated, where management is obsolete, resignation and supplication describe existence. In 1959 I received a letter from the parent of a hemophiliac in New Delhi, India, I quote: ‘... please help a father whose son is undergoing excruciating pain before his own eyes and who is unable to do anything to alleviate the suffering.’

Revolution does not arise from despair, the genesis of revolution is hope. When, through communication, the father in India realizes that his son’s hemophilia hell is no longer inevitable, that advanced medical knowledge and control products are being utilized in certain superb treatment clinics, then the struggle will commence in New Delhi.

Dr. Howard A. Rusk, writing recently in the New York Times on the subject of health communication, cited the medical knowledge explosion resulting from increased research, the rate of which is unprecedented and will inevitably increase. In all fields of science one of the major problems is the time lag that exists between the discovery of new knowledge and its practical application. This is particularly true of the health sciences. In this field life itself is at stake. It is understandable Dr. Rusk continued, that a time lag should exist for extensive clinical testing of new scientific achievements. Unfortunately this time lag often continues when conservative, thorough and adequate testing has been completed. Knowledge lies in the warehouse due to delayed publication. Or often, even when published, material lies buried in the hundreds of thousands of medical articles published each year throughout the world. How long does it take for this information to get from individual articles into standard reference works. This is a serious problem when the producer-consumer lag means pain or comfort, ability or disability, life or death.

We are, then, confronted with the proliferation of hemophilia knowledge. We decry the long time lag in its application and its uneven geographical distribution. It is, of course, obvious that an international lay organization should never endorse one system of medical treatment over another. Formerly, however, there has been precious little exposure. A system exposed or challenged, may improve.

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Where we encounter indifference, cynicism or pessimism, let us participate in encouraging change. Hemophilia and its pessimism can victimize us. In my address at Copenhagen I said:

‘Hemophilia is at war with each of us. We are here to join as allies in a declaration of war against hemophilia. Hemophilia is an ancient enemy, known throughout recorded history. It is a history of defeat and death. In our times, science and social organization have combined to reverse the sequence of defeat. Still ultimate victory is not ours, battles are being won and lost and the greatest battles remain for us to win.’

This is hardly a statement of hope.

Those of us who have survived for three or four decades, if we had kept a file of all the mistaken newspaper articles announcing a cure for hemophilia, such a file would explain our skepticism. Currently, however, the articles covering hemophilia developments are more objective and the contents offer considerable hope.

There has been a tremendous upsurge of interest, medical and public, in hemophilia. I can think of no better way to illustrate this than to recall something said by the Chairman at the Washington International Symposium on Hemophilia. Paraphrasing perhaps, the Chairman confessed that hemophilia used to be a subsection of hematology whereas now hematology is a subsection of hemophilia. A.H.G. fractions, increasingly potent, are the best weapons in the present arsenal. Research laboratories are constantly improving the quality of the fractions, and concurrently, larger quantities are available. One laboratory I visited recently is exploring the possibility of injecting the A.H.G. intramuscularly within a solution which would absorb over one to two weeks thereby raising the A.H.G. level sufficiently to minimize severity.

Last month a magazine medical writer speculated that researchers may some day learn how to help hemophiliacs make their own A.H.G., perhaps through transplants of A.H.G.-producing tissue. The deterrent from a more liberal use of plasma and fractions has been, in many cases, the concern of hepatitis and the circulating anti-coagulant. Apparently scientists are close to a vaccine for hepatitis and if we can dominate the circulating anti-coagulant, then, do we not arrive at a situation somewhat analogous to insulin and the diabetic?
The ultimate answer is not control, but a cure. Because of the hereditary nature of hemophilia, such an expectation seemed impossible. Now, with the cracking of the DNA genetic code, eventually the known family hereditary pattern will be controlled. A scientist at the University of California told me this could happen within our lifetime.

Although tomorrow is full of prospects, it is today that is significant. This celebrated group has gathered here in Paris to expedite the awareness of existing knowledge and facilities so as to alleviate the pain and plight of the hemophiliacs throughout the world. We, the World Federation of Hemophilia delegates, wish to express our gratitude.

Dr. Frank Schnabel