

RESOLUTIONS BY THE WORLD FEDERATION OF HEMOPHILIA GENERAL ASSEMBLY
REGARDING ACQUIRED IMMUNE DEFICIENCY SYNDROME(AIDS) 29 JUNE 1983

DISCUSSION

Medical Board - Report on AIDS

Mr. Chairman I will introduce this report by quoting a portion of the Administration Report presented to the General Assembly.

Last summer AIDS began to cause alarm amongst hemophiliacs and physicians in North America. Early in 1983 the media in Europe subjected the public to sensational coverage on AIDS. Societies in Australia, Japan and Latin America have recently expressed concern. In anticipation, Montreal has become an AIDS OPERATIONS CENTRE. Every day, evenings, weekends, the Federation's President responded to communications: telephone, telex, correspondence, publications, medical journals, radio and television. The WFH AIDS Operations Centre has been in liaison with government agencies, national hemophilia organizations, hematologists, research immunologists, universities, hospitals, plasma derivative companies, blood banks, blood associations and the Red Cross.

The actions taken to date by the WFH and its Executive include:

- 1) Distribution of a background statement and information on AIDS to the National Member Organizations and Council and Medical Board Members.
- 2) Distribution of an AIDS computerized bibliography by the WFH Information Clearinghouse in Heidelberg, prepared by Professor Klaus Schimpf.
- 3) Decision to request consideration of AIDS issues at the Stockholm meeting by the Medical Board.

Before giving the Board's recommendations several points regarding AIDS and also the Medical Board's status are appropriate.

- 1) The Medical Board is an advisory body to the WFH Council.
- 2) Further AIDS topics are scheduled for presentation Thursday and Friday afternoon, including an opportunity for free discussion.

For clarity and consistency in this discussion, the definitions and terms used by the Center for Disease Control of the United States Public Health Service are employed throughout.

The Center for Disease Control conducted a survey in 1982 of United States hemophilia centers to tabulate AIDS cases, hemophiliacs with opportunistic infections and those with "incomplete" or "prodromal" AIDS signs and symptoms. The most consistent of these "incomplete" signs is generalized lymphadenopathy. It must be emphasised

that these patients are not AIDS "victims" or "cases", the prognostic significance of "incomplete" signs and symptoms remains undetermined as does the precise cause of etiology of AIDS.

Following the recognition of AIDS in hemophiliacs steps were taken to exclude high risk donors from the US blood and plasma supply. The commercial producers of concentrate acted swiftly to eliminate members of high risk groups by, 1) Closing plasmapheresis centers in high risk areas, and 2) Providing for self-exclusion by educational materials supplemented by medical screening and physical examination. Donors maybe excluded at the discretion of plasmapheresis personnel.

Similarly community and voluntary blood collection agencies have been mandated by FDA regulation to initiate educational and self-exclusion systems.

Research

Since the recognition of AIDS approximately 2 years ago, research efforts have greatly intensified. As yet efforts to develop "surrogate" donor blood tests as highly specific or sensitive markers for Aids have not been successful. Additionally intense research efforts are under way to identify the etiologic agent or agents. For the present US fiscal year the federal AIDS research budget is \$14,532,000, which will increase to \$17,691,000 in the coming year. The National Heart and Lung and Blood Institute will soon solicit applications for a multi-center international 5 year study on the long-term effects of blood and blood products on multi-transfused chronic anemia patients and hemophiliac patients.

WFH Medical Board Actions

The Medical Board meeting on June 26, 1983 was attended by more than 25 physician members and invited observers from 18 countries in North America, Central and South America, Europe, the Middle East, Asia, including Japan and the People's Republic of China, and Africa. During a mini-medical-epidemiologic symposium data on AIDS in hemophiliacs in these areas was presented.

Using the Center for Disease Control definition(opportunistic infection or malignancy) the current tabulation is:

United States:	16 cases
Canada:	2 (1 homosexual)
Europe:	3
Total	21 - all with opportunistic infections

Many participants also reported preliminary results of clinical and immunological studies in progress, which indicate laboratory identified immune changes are frequent in hemophiliacs irrespective of the source of blood product.

Medical Board discussion focused on questions of choice of blood products and intensity of treatment. No consensus could be reached in these areas.

RECOMMENDATIONS

The Medical Board reached agreement on 2 issues and wish to advise the Council and General Assembly accordingly:

- 1) There is insufficient evidence to recommend at the present, any change in treatment; therefore present treatment, of hemophilia should continue with whatever blood products are available, according to the judgement of the individual physician.
- 2) Longitudinal studies are urgently needed on the questions already mentioned, as well as better definition of the relative risk/benefit ratios of various treatment regimens.

ACTIONS

The WFH actions in response to AIDS now include:

- 1) Planning for a major plenary AIDS symposium on AIDS at the Rio de Janeiro meeting in 1984.
- 2) Establishment of the WFH AIDS Operations Center at the Orthopedic Hospital, Los Angeles, United States, whose objectives will include:
 - a) Communications with patients, physicians and the public to answer questions, dispel myths and prevent rumors.
 - b) Dissemination of information to all WFH member organizations and concerned professionals at regular intervals.
 - c) Initiation of AIDS case finding and reporting using Center for Disease Control definitions and standardized forms.
 - d) Establishment of a public relations program to provide information on hemophilia and AIDS and counter the current media hysteria.
 - e) Establish WFH medical liaison with Centre for Disease Control, World Health Organization, voluntary blood collection agencies and the plasma fractionation companies.

- f) Continue close collaboration and cooperation with the WFH Information Clearinghouse in Heidelberg.

It should be noted that both the voluntary and commercial institutions involved in blood and blood products are deeply concerned over the present situation and with the cooperation and support of industry the WFH AIDS Operations Center will open lines of communications to all parties concerned.

Your help and involvement as individuals and National Member Organizations is crucial. You are requested to cooperate in case reporting, in clarifying misinformation, in preventing rumors and hysteria, and to continue active support of the goals of improving diagnosis and treatment of persons with hemophilia.