

# HEMOPHILIA NEWSNOTES



December 21, 1982

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## MEDICAL BULLETIN #4 CHAPTER ADVISORY #5

- AIDS: - IMPLICATIONS REGARDING BLOOD PRODUCT USE; AND  
- SUMMARY OF NATIONAL HEMOPHILIA FOUNDATION ACTIVITIES

Chapters -- Please distribute this notice to all chapter members.

Physicians -- Please distribute this notice to all providers who treat patients with hemophilia in your area.

The National Hemophilia Foundation AIDS Task Force met to review CDC's December 10th Mortality and Morbidity Weekly Report, and unpublished scientific data related to AIDS. The number of hemophiliacs who have contracted AIDS has increased -- now a total of eight and two highly suspect cases. Based on this review, the NHF AIDS Task Force wishes to provide the additional advisory information concerning the use of blood products.

There is an increased concern that AIDS may be transmitted through blood products. Patients and parents should be aware of the potential risks. There is no conclusive evidence that cryoprecipitate or fresh frozen plasma will reduce the risk of AIDS. We feel, however, that this is no time to introduce concentrates to patients who have never used them before, except when there is an overriding medical indication. Examples of patients who have not, and therefore, should not be introduced to concentrates at this time are as follows:

- newborn infants (through age 4);
- newly diagnosed cases of hemophilia; and
- those with mild disease.

At this time, the NHF AIDS Task Force does not recommend a change in treatment to those who have received concentrates in therapy. And, by all means, one should not withhold the use of clotting factor therapy when needed.

If you have any questions regarding these issues, they should be directed to your treating physician and/or NHF.

Issues surrounding AIDS remain extremely complicated. There are no easy answers because there are still so many unknowns about this disease with respect to how it is and how it is spread. A summary of NHF AIDS activity is on the reverse side of this bulletin advisory.

## ● INVOLVEMENT WITH GOVERNMENT AGENCIES

NHF Chairman, Charles J. Carman, and NHF Medical Co-Director, Louis M. Aledort, M.D., are NHF's representatives on the multi-agency Public Health Task Group established by the Assistant Secretary for Health of the U.S. Department of Health and Human Services to consider the risks and consequences of AIDS for hemophilia patients, for concentrate manufacturers, and for physicians. They will be representing NHF, along with NHF's Medical and Scientific Advisory Council Chairman, Leon W. Hoyer, M.D., at a meeting of this Task Group on January 4, 1983 in Atlanta, Georgia. NHF is maintaining on-going contact with the Centers for Disease Control (on a daily basis), Food and Drug Administration and the National Institutes of Health on AIDS. NHF participated at FDA's Blood Advisory Committee meeting in December on blood infectivity and AIDS.

## ● NHF/CDC STUDY

Collaborative work with CDC on the design, distribution, and analysis of data from a nationwide epidemiologic survey of all hemophilia treatment centers and affiliates. Preliminary findings of this survey will be reviewed at a January 4th meeting (indicated above).

## ● GOVERNMENT RELATIONS

Increased NHF activity concerning funding support for AIDS-related surveillance and research activity. With the help of Washington representative, John T. Grupenhoff, Ph.D., NHF succeeded in requesting special AIDS-earmarked federal support for the CDC, as well as increased funding for NIH.

## ● NHF RESEARCH

Under the direction of NHF Medical Co-Director, Louis M. Aledort, M.D., NHF will be funded by the Division of Blood Diseases and Resources, through CDC, to develop a data base on populations at risk for AIDS. This will complement on-going CDC work.

## ● PUBLIC INFORMATION

- periodic advisories to chapters;
- periodic medical bulletins;
- preparation and distribution of special AIDS-related publications;
- information to national news media;
- information and referral (chapter and individual patient inquiries); and
- rumour control clearinghouse.

## ● BLOOD INDUSTRY RELATIONS

NHF has offered specific recommendations to the commercial and voluntary blood community with respect to the development of more restrictive blood donor criteria that would screen out high risk groups. NHF Chairman, Charles J. Carman, has been invited by AABB to represent NHF at a meeting of its Transfusion Transmitted Disease Committee that will focus on the AIDS problem with the involvement of industry and government agencies. NHF is maintaining an on-going liaison with the blood industry on this matter.

## ● MEDICAL AND SCIENTIFIC ADVISORY COUNCIL

NHF will be convening its MASAC in January to seek a broad national perspective concerning treatment implications for hemophiliacs as it relates to newly reported data.

## ● AIDS POLICY MANAGEMENT

Day-to-day AIDS-related policy issues are reviewed by an NHF AIDS Task Force (comprised of physicians and laymen). The direction being followed is reviewed monthly by the NHF Executive Committee.

## ● AIDS FUND

Due to an unprecedented drain on scarce NHF resources that are urgently needed to address AIDS matters, a special AIDS Fund has been established at NHF to receive AIDS-restricted