



A.I.D.S.

THIS FACTSHEET CONTAINS IMPORTANT INFORMATION

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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HAEMOFACT is produced regularly to keep people with haemophilia up-to-date on matters such as AIDS.

In view of the widespread publicity about AIDS arising from the tragic death of Mr **GRO-A**, a patient at the Haemophilia Centre, Royal Victoria Infirmary Newcastle upon Tyne and elsewhere, the Society wishes to give members a factual update on AIDS, on the responses to the current publicity of the DHSS and the NBTS and to outline the action which the Society has taken. IT IS ESSENTIAL TO NOTE THAT, DESPITE THE CURRENT PUBLICITY, LITTLE HAS CHANGED. In fact the position on AIDS remains substantially as outlined in HAEMOFACT 4, namely:-

- (1) that the probable causative agent for AIDS is a virus known as HTLV-III or LAV.
- (2) that tests to establish the presence of antibodies to HTLV-III have been developed.
- (3) that about one third of a group of english haemophilic patients studied were found to have antibodies to HTLV-III.
- (4) that the presence of antibodies is usually taken as evidence of immunity to infection, although in the case of AIDS this is not yet certain.
- (5) the level of publicity about AIDS is new but the known facts remain as outlined in HAEMOFACT over the past year or so (changes have been and will be noted in HAEMOFACT when necessary).
- (6) DHSS guidance to blood donors indicating the 'at risk' groups who should not donate blood do not currently include the sexual partners of people with haemophilia. Blood donors in this situation should contact their Blood Transfusion Centre for advice about this and their Centre Director about all matters concerning their treatment.
- (7) Heat treatment appears to destroy the HTLV-III (AIDS) virus. Heat-treated factor VIII has become available in the United States over the past few months and is now in universal use there.

The Minister, Mr John Patten and the DHSS have issued the following statements on AIDS:-

Heat treated products will be available from Elstree in April 1985.
The UK will be self-sufficient in blood products from 1986.

The NBTS has issued the following statements on AIDS:-

The Elstree plant will produce heat-treated products by April 1985.

THE SOCIETY HAS TAKEN ACTION AS FOLLOWS:-

- (1) A meeting has been arranged with Lord Glenarthur, Parliamentary Under Secretary of State on December 7th at which we shall press for the following measures:-
- (a) The IMMEDIATE introduction of heat-treated product by importing this from the United States and the release of additional funding to the regions to enable this to happen forthwith.
 - (b) Immediate consideration be given to the introduction of plasmapheresis programmes on such a scale that the UK may become self-sufficient in factor VIII by 1986.
 - (c) More stringent measures be taken by the Blood Transfusion Service to ensure that 'at risk' donors are made fully aware of their position.
 - (d) That no financial constraints be allowed to stand in the way of developing HTLV-III tests in both donors and donated blood.
 - (e) That all Supra-Regional Centres be given adequate staffing and resources to cope with the AIDS situation.
- (2) WE HAVE
- (a) kept in close touch with our own Medical Advisors, other health care professionals, the DHSS, the NBTS and other charities and organisations with interests in the problem of AIDS.
 - (b) continued to monitor AIDS developments overseas especially through the **World Federation of Hemophilia** and **World Haemophilia AIDS Centre** in Los Angeles.
 - (c) launched a major fund raising initiative to enable us to continue the provision of our information services which have been seriously strained by the AIDS problem.
 - (d) made a major effort to provide the media with the facts about AIDS.
 - (e) dealt with literally hundreds of phone calls received from members and others concerned about AIDS.

We ENDORSE our earlier advice to everyone with haemophilia, however mildly affected, to continue to accept medication as prescribed by medical staff. However, we make the following additional RECOMMENDATIONS:-

- (a) That you ask your Centre Director to make heat-treated product available as soon as possible.
- (b) That you write to your MP (and to Norman Fowler) pointing out your anxieties and urging them to take all the steps which are set out above at (2) a-e.
- (c) We also suggest that you monitor the advice being given to donors at your local Blood Transfusion Service - let the Co-ordinator know if you find that there are no AIDS leaflets, etc, on display.

CURRENT PRACTICE at major Haemophilia Centres in the UK is that *cryoprecipitate* is used in factor VIII deficient newborn infants and children under 4 years of age and in newly identified patients never treated with factor VIII concentrates; whenever possible *fresh frozen plasma* is used in factor IX deficient patients in the same categories, and *desmopressin (DDAVP)* wherever possible, is used in patients with moderate or mild haemophilia and von Willebrand's Syndrome. It is, as already stated, the Society's recommendation that heat-treated product be made available as quickly as possible for all other groups of people with haemophilia.

IF YOU HAVE ANY ENQUIRES ABOUT YOUR OWN POSITION YOU SHOULD SPEAK TO YOUR CENTRE DIRECTOR WHO WILL BE ONLY TOO ANXIOUS TO ASSIST YOU.

HAEMOFACT is a leaflet series produced by the Haemophilia Society.
They are issued from time to time on topics of interest
and concern to people with haemophilia.

For further details of Society membership please write to us at 16 Trinity Street, London, SE1 1DE.

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