

APPENDIX 9

DOCUMENTS THAT CONTAIN INFORMATION/ADVICE TO CLINICIANS AND/OR HAEMOPHILIACS

Print in bold is advice or information contained within the documents

3. Advice Issued to Haemophiliacs by the Haemophilia Society in
"Haemofact: AIDS" releases

Document No
in CBLA's List
11.06.80 [N.B. an asterisk denotes a document not listed by CBLA]

* 04.05.83
Haemophilia Society Letter quoting Professor Arthur Bloom's Statement. Because so little is known about AIDS and the number of cases reported in American haemophiliacs is small, and that there are no proven cases amongst the British haemophiliac population, no precipitate action should be taken until those experts who are responsible have a chance to assess the situation.

* 22.09.83
"Haemofact AIDS" Release No 2.

The advantages of treatment far outweigh any possible risk. Balance the risks for yourself but we would state again that the risk of aids is tiny compared to the risks from untreated bleeding episodes. The advice continues that treatment should continue, that the Centre Directors' advice should be taken and states "risk has always been a feature of haemophilia and in time this risk too will diminish especially given the volume of research being conducted around the world." The advice continues that you personal position should be discussed with your Centre Director. You are urged to remain on treatment and follow the advice given by your medical advisors.

* 11.05.84
"Haemofact AIDS" Release No 3

No advice, merely an update.

* 24.09.84
"Haemofact AIDS" Release No 4.

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After an update on the current situation on AIDS, it goes on to deal with Hepatitis B Virus (HBV) and says that vaccination is now available.

1891

Dec 1984: Haemofact: AIDS, Release No 5

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 at 1.a-e.
 - a. The IMMEDIATE introduction of heat-treated product by importing this from the U.S. and the release forthwith 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 "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.
- c) We also suggest that you monitor the advice being given to donors at your local BTS - let the Co-Ordinator know there are no AIDS leaflets etc on display.

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22.04.85

"Haemofact AIDS" Release No 6

After a brief update it says that they suggest it would be inappropriate for sexual partners of haemophiliacs to donate blood. Members are also urged to continue to write to their MP and to

the Minister on the subject of the introduction of plasmapheresis programmes. The earlier advice, which was to continue to accept medication, is endorsed and members are advised to enquire about their own position, to speak to their Centre Director and ends with an outline of what current practice guidelines that major haemophilia centres use ie:-

- a) cryoprecipitate is used in newborn infants and children under 4 and newly-identified patients never treated with Factor VIII concentrates;
- b) FFP is used in Factor IX deficient patients in the same categories; and
- c) desmopresin DDAVP, wherever possible, is used in patients with mild haemophilia and Von Willebrand's Disease.

The Society's recommendation that heat treated product be made available as quickly as possible for all other groups with haemophilia is repeated.

* 22.05.85
"Haemofact AIDS" Release No 7

Members are urged to co-operate with their doctors in tests which will indicate HIV antibodies. It then goes on to recommend "continue to treat bleeding episodes wherever possible with heat treated material whether imported or British. Maintain good hygiene. Adopt safe sexual practices ie use condoms even if your partner is pregnant or male. Discuss any problems or anxieties with your Centre staff".

* 29.08.85
"Haemofact AIDS" Release No 8

The main body of the advice is exactly the same as Release No 7 in every respect.

* 24.09.85
"Haemofact AIDS" Release No 9

The advice given is that:-

your antibody status is private, confidential, medical information and should not be given to anybody apart from family, a centre director and doctor and dentist. As long as

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the safe sex advice in Haemofact 8 is followed, you are no threat to anybody and members are advised not to share the information about children's antibody status with anyone outside their immediate family."

* October 1985
 "Haemofact AIDS" Advice on Safer Sex - Special Issue

* February 1986
 "Haemofact AIDS" Release No 10

The advice is that the evidence that shows that some HTLVIII virus has been found in heat treated concentrates is based on very scanty and slender evidence and the Government's Chief Medical Officer advises that heat treated concentrates are safe.

It continues suggesting that pregnancy should be avoided as there is evidence that antibody positive babies have been born to antibody positive mothers. In all cases where concentrate therapy has been used couples should appreciate the importance of taking effective steps to avoid conception and follow the safe sex practices outlined in the Haemofact Special Edition on that subject.

If parents find there is a problem with their children's education because their HTLVIII antibody status becomes known in a school they should discuss the matter with their Centre and with the Society.

* November 1986
 "Haemofact AIDS" Release No 11

This issue gives advice on obtaining life cover, borrowing money or buying a house.

* March 1987
 AIDS and Compensation

This covers the legal position on claims for compensation arising from HIV infection.

* May 1987
 "Haemofact AIDS"

This reviews the position on compensation and insurance for haemophiliacs.

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* June 1987
"Haemofact AIDS and Recompense for People with Haemophilia"
Release No 14

This gives various items of advice on unemployment, supplementary benefits, mobility allowances and invalidity benefit.

* August 1987
"Haemofact AIDS" Release No 15

Campaign for Recompense

* 17.11.87
"Haemofact AIDS" Release No 16

Successful Recompense Campaign

* 14.12.87
"Haemofact AIDS" Release No 17

The Campaign Continues

2329 February 1988
The Haemophilia Bulletin

A private newsletter expressing Dr C.K. Kasper's advice on choosing a concentrate.

* 01.03.88
"Haemofact AIDS" Release No 18 Aspects of HIV Infection.

This contains advice on countries where HIV tests are carried out at the point of entry, on avoiding vaccination with live viruses, keeping up safe sex practices, to contact solicitors immediately if they intend to pursue a course of action against the medical authorities and obtaining DHSS benefits.
