5th December, 1983

Dear Haemophilia Centre Director,

We are attempting to determine the prevalence of the ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) in haemophiliacs especially in relationship to the use of blood products. I would be most grateful if you would complete the enclosed simple questionnaire and return it to me as soon as possible. Please return the questionnaire even if you have no patients with AIDS or related syndromes or have not treated any patients with haemophilia during the last few years. I hope to analyse the data and present it for discussion at a meeting of haemophilia experts which is being held at the end of February. The meeting is a small one and is being held because of the concern about the risk of AIDS to sufferers from haemophilia. In view of the short period of time available to me to analyse the results I would be most grateful to receive your reply just as soon as possible. The replies from individual Centres will of course be considered strictly confidential and will not be divulged. Only results from individual countries will be classified.

I will be happy to send to all those who respond the results of the survey together with any recommendations that may emerge from the meeting.

Finally may I take this opportunity to wish you a very Happy Christmas and every success and happiness for the New Year.

Yours sincerely,

A. L. Bloom
Director, Haemophilia Centre

[Enclosures]
PREVALENCE OF AIDS IN EUROPEAN HAEMOPHILIACS

CENTRE: EDINBURGH

ADDRESS: Royal Infirmary

DIRECTOR: C. A. LUDCAM

COUNTRY: UK.

Section A

TREATMENT

1. How many haemophiliacs are treated each year at your centre? (e.g. in 1982)

| Haemophilia A | 60 |
| Haemophilia B | 16 |
| von Willebrand's disease | 7 |

2. During the last four years what products have you used to treat:

Severe haemophilia A: SNBTS VIII Cryo Arrow VIII Cultur VIII (Feiba Defix)
Severe haemophilia B: Defix
Mild haemophilia A: Cryo
Mild haemophilia B: Defix
von Willebrand's disease: Cryo SNBTS VIII

3. (a) Have you changed treatment policy during the last year? YES/ NO
(b) If the answer to 3(a) is YES, how have you changed? :-

- Ceased using freeze dried FVIII YES/ NO
- Ceased using imported (USA) FVIII YES/ NO
- Increased use of cryoprecipitate YES/ NO
- Ceased using freeze-dried FIX YES/ NO
- Ceased using imported (USA) FIX YES/ NO
- Increased use of fresh (frozen) plasma YES/ NO
- Reduced use of imported (USA) concentrates YES/ NO
- Ceased prophylactic therapy YES/ NO
- Ceased elective surgery YES/ NO
- Advised patients to avoid dangerous pursuits YES/ NO
- Do you think that concentrate prepared from paid donors is safer than that from voluntary donors? YES/ NO
Section B

AIDS and related conditions

On page 3 are listed criteria for suspecting AIDS. Categories 1, 2 and 3 are very suggestive of AIDS. Categories 4, 5 and 6 could indicate a pre AIDS syndrome.

1. (a) How many patients have you with AIDS - positive categories 1, 2 or 3? 0

    Alive  Dead  Died of AIDS

(b) Which items in categories 1, 2 and 3 are/were positive. Please list and indicate cause of death (if appropriate).

Patient 1  Patient 2  Patient 3  Patient 4  Patient 5

Age:

2. (a) How many patients have you in pre AIDS categories 4, 5 or 6?

   Category 4 and/or 5
   Category 6 only

(b) Please indicate number of patients in categories 4, 5 or 6 who are positive:

3. How many, if any, of the above patients are in risk category 7?

Please return to:

Professor A. L. Bloom
Haemophilia Centre
Department of Haematology
University Hospital of Wales
Heath Park,
Cardiff CF4 4XW
U.K.

as soon as possible before 20th January, 1984 (addressed envelope enclosed).