

NOTE OF MEETING OF HAEMOPHILIA DIRECTORS AND SNBTS REPRESENTATIVES ON
29 NOVEMBER 1984 IN ST ANDREW'S HOUSE

PRESENT: Dr B Bennett
Dr C Forbes
Dr B Gibson
Dr C Ludlam
Dr B McClelland
Dr T MacDonald
Dr R Perry
Dr T Taylor
Dr G A McDonald

SHHD Dr A Bell (Chairman)
Mr A J Murray
Mr G M Thomson
Mr A Morrison

1. Dr Bell thanked the participants for attending at such short notice and extended a particular welcome to Dr G McDonald on his recent return following a period of illness.
2. The meeting had been convened to discuss the implications of the recent finding of HTLV III antibodies in Scottish haemophiliacs, measures being taken by the SNBTS to prevent the transmission of AIDS by blood products, and the media attention associated with these developments. It would also be useful for these matters to be aired in the Scottish context prior to the forthcoming meeting of UK Haemophilia Reference Centre Directors at EPL Elstree.
3. Dr Ludlam explained the circumstances in which it had been discovered that 16 haemophilia patients treated exclusively with SNBTS factor VIII had developed antibodies to HTLV III, leading to the presumption that a Scottish plasma pool had been contaminated by a donor carrying HTLV III. Various aspects of the epidemiological, pathological and ethical problems were discussed.
4. Dr Forbes described the findings relating to HTLV III antibody sero-conversion in a comparative study of haemophilia patients in Glasgow and Denmark. This study would shortly be published in the Lancet.
5. Dr Gibson reported the anxiety felt by parents of haemophiliac children treated at RHSC Glasgow, where imported factor VIII had been used until relatively recently. Five out of 10 of these patients were HTLV III antibody positive.

6. Dr Perry explained that the PFC had for some time been developing methods of heat treating factor VIII, aimed particularly at preventing transmission of NANB hepatitis. However it would be some months before these developments would result in routine wet heat treatment of all PFC product. Having regard to the established sensitivity of retroviruses to heat, and corresponding reports of the efficacy of heat treatment at 68°C in countering HTLV III activity, PFC had commenced, as a short term measure, heat treating lyophilised factor VIII at 68°C for 2 hours. This was not expected to cause significant deterioration in the product and clinical trials were already in progress. Assuming these trials revealed no unexpected problem, all PFC factor VIII being issued from about the beginning of January 1985 would be heat treated in this way. The possibility of batch dedication of factor VIII was being considered but difficulty was foreseen. Dr Perry confirmed that the licensing authorities were aware of, and did not take exception to, this procedure.

7. Dr McClelland discussed how the SNETS was tackling the problems of plasma acquisition in the context of the AIDS threat. Copies of the latest leaflet to donors, discouraging those in AIDS high risk groups, were tabled and it was explained that all donors now had to sign a statement that they had read the leaflet and were not members of the high risk groups. Some of the problems in introducing HTLV III antibody screening of all blood donors were discussed. Screening could probably not be introduced until well into 1985.

8. Views were exchanged on the very difficult ethical problems which had arisen. These included whether patients and patients' relatives should be informed and perhaps subjected to ~~unnecessary worry~~ whether publicity additional to that already provided should be given, and how directors should respond to direct enquiries or requests for advice. The chairman advised members that ministers had been informed and that SIO had been briefed. While a press statement would not be issued by the Department at present any enquiries would be answered. It was agreed that every effort should be made for patients to have the situation explained to them before the impending publicity.

9. Dr Ludlam drew attention to the safety factors that had to be considered in laboratories handling sera from patients at risk, and the inadequacy of the present facilities.

10. It was noted that the annual meeting of haemophilia and transfusion directors was due to be held on 7 February 1985, and agreed that that date should continue to be reserved for a meeting. [The meeting was subsequently postponed till 7 March].

Scottish Home and Health Department
February 1985