



The Haemophilia Society

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FAC

AJT/IH

28th November 1984

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The Lord Glenarthur
Parliamentary Under-Secretary,
Department of Health & Social Security,
Alexander Flemming House,
Elephant & Castle
London SE1

Dear Lord Glenarthur,

We are most grateful to you for agreeing to meet us on Friday, December 7,
at ~~3.30pm~~ now 10.00 am

We list below the points which we wish to discuss with you in relation to
AIDS and haemophilia.

- (1) The principle point which we wish to emphasis concerns the heat-treatment of blood products used by people with haemophilia. We note that Dr. Lane has stated publicly that he expects the Elstree products to be heat-treated from April 1985. Several points emerge from this:-
 - (a) Our first comment must be to welcome this news although this leaves a gap between now and April 1985.
 - (b) We are also concerned that this reduces the yield of factor VIII and that, coupled to the projected shortfall in plasma supply to BPL, this will lead to a widening of the 'gap' between plasma produced and product required.
 - (c) We therefore urge that heat-treated commercial concentrates be introduced forthwith.

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- (d) In connection with the 'plasma gap' we wish to stress our deep concern that there is insufficient funding available to make adequate supplies of plasma available to bring Elstree's production within reach of predicted levels of treatment. As a matter of priority we would ask the Minister to re-inforce his statements of 1983 when he emphasised that there would be NO financial constraints on the availability of plasma.

As the Society see the matter, there is a need for major investment in plasmapheresis programmes throughout the United Kingdom.

- (2) BLOOD COLLECTION: we have already expressed our deep concern about the laxity of a number of BTC's throughout the UK in making information available about risk-groups at donor centres. We RECOMMEND the practise adopted in Edinburgh where all donors are sent confidential letters outlining the risk groups and giving them the opportunity to consider the implication in private.
- (3) HTLV-III testing of donated blood: we very simply urge the most speedy possible progress on this topic. We understand that the test is in an advanced state of development and would ask that no financial constraints impede its progress to the stage of implementation.
- (4) STAFFING OF SUPRA-REGIONAL CENTRES: we are concerned to learn that not all Supra-Regional Haemophilia Centres are adequately staffed to perform their duties competently during the present crisis. We would mention in particular St Thomas' Hospital in London.
- (5) THE HAEMOPHILIA SOCIETY

See at funding

It will be readily appreciated that the Society has been under extreme pressure because of the current AIDS situation. We were encouraged to hear the Minister describe the Society as a 'responsible body' on 'The World at One' on 19 November. This level of responsibility has only been maintained at very great cost to the other activities of the Society, in particular that of fund-raising. While it is true that the Society has a 'cushion' of money held in reserve for research funding, we regret to say that this will have totally disappeared by December 1985 in supporting the service and administrative role of the Society. It will be understood that we are the only organisation in the United Kingdom which is in a position to advise people with haemophilia and their specialist advisors, both generally and specifically on the questions surrounding AIDS. We wish therefore to formally request grant aid from the Department to carry on this vital role which has been totally funded from voluntary sources for the past 34 years.

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We look forward to discussing those points in greater detail when we meet.
I would add that there will be four people from the Society attending.
These are Mr Kenneth Milne, Mr Clive Knight, Mr David Watters and myself.

Yours sincerely,

GRO-C

The Revd. A J Tanner
Chairman

Personally dictated by the Revd. A J Tanner but sent in his absence.