Coleg Meddygaeth Prifysgol Cymru

University of Wales College of Medicine

Department of Haematology,
Heath Park, Cardiff CF4 4XN
Tel. 0222-755944

Professor A. L. Bloom

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Mr. D.G. Watters
Co-ordinator
The Haemophilia Society
P.O. Box 9
16, Trinity Street
London SE1 1DE.

Dear David,

Thank you for your letter of 20th December, 1984. I think that our meeting went reasonably well although some patients and families may have had their worries increased. I can't see any realistic way of avoiding this. However like you I am glad that the meeting was held before all the publicity.

I was also glad to receive the copy of HN (83) 36 regarding supraregional services. In point of fact this possibility has been discussed in detail at the last meeting of the Reference Centre Directors in September in the presence of Dr. Alison Smithies of DHSS. It was decided that each Reference Centre Director would write to me setting out his/her ideas for the case for supraregional funding so that a general case could be put forward under the terms of the above HN. Copies of individual specific applications were also to be sent to me. So far however no proposals have been received by me even from the most vociferious Directors, probably because everyone is so overworked by the AIDS crisis. However your letter and enclosures will certainly come as a timely reminder and I will make sure that this is discussed at an extra January meeting as well as at our normal meeting in February.

With regard to the general situation regarding AIDS the whole thing is worrying. We are in a catch 22 situation. In the past my committee has always been under pressure from patients and from the Society to seek increased funding for the purchase of commercial factor VIII. It is perhaps natural that the useage of factor VIII for patients in the UK was compared unfavourably with the greater useage in some other countries. Some more conservative UK haemophilia specialists felt themselves under criticism even from some of their colleagues in spite of a feeling that it would be unwise to increase treatment levels ad lib with potentially dangerous concentrates. These considerations of course predated the AIDS crisis.

Contined.....

We are now in a situation in which we are being driven to administer large volumes of heat treated factor VIII without adequate clinical trial. We do not know the short or medium term effects leave alone the long term effects of such treatment. For instance, immunological effects on inhibitor development, immune complex disease, liver and kidney impairment. We do not know if these effects, or indeed protection from AIDS, may be dose-related. I am therefore writing in my private capacity, not as Chairman of the haemophilia directors organisation, to ask you to draw the attention of your colleagues to my fears. Perhaps you could consider the advisability of introducing a note of caution concerning dosages of factor VIII and free useage of heated materials until more experience is obtained with their use. You may like to solicit the views of your other Medical Advisors on these aspects.

It is salutory to note that problems have recently been encountered with biogenetically synthesised growth hormone. This is a much more simple molecule than factor VIII but it appears that a slight difference in its structural analyses has resulted in the synthesis of a product which stimulated the development of growth hormone inhibitors in patients. The possible analogies with factor VIII are obvious and as with heated products counsel the need for caution in the mass introduction and "consumer" demand for these new materials even when they are available.

As a haemophilia physician I feel somewhat guilty that my therapeutic endeavours have resulted in exposure of patients to this newly discovered HTLV III virus. I do not wish to see this type of process repeated in the future albeit with a different hazard. For this reason I wish to draw your attention to the need for caution. I realise the desire of haemophiliacs to lead a normal life but at the same time one must realistically conclude that ideal treatment is not available. If I were to act as devils advocate I would suggest that it is reasonable to steady out at levels of treatment attained during the last five years, say at an average of 25,000 units per patient per year giving overall useage of 50 to 60 million units per annum. In the light of present knowledge I am not convinced that it is wise to push for steady increase to 100 million units per year, although we are right to ensure that the necessary potential is available. Expectations must be balanced against informed reality. I leave it to you and your colleages to consider the best ways by which this particular nettle may be grasped; always accepting that, there is in fact a nettle.

With all best wishes for the New Year.

Yours sincerely,

A.L. BLOOM