



10 OCT 1990

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HAEMOPHILIA CENTRE AND HAEMOSTASIS UNIT

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PK/cf/netraid

8 October 1990

Dear Rita,

The NETR, AIDS Allocations, and Haemophilia

Further to our previous discussions and correspondence, I now enclose for your interest a copy of the recently issued Regional Haemophilia Centre Directors' consensus document on the treatment of haemophilia.

You will see that the issue of the use of 'high purity' factor VIII is discussed in some detail, and I can only reiterate my view that the additional funding needed for such products is a legitimate call on Regional AIDS allocations. This has been accepted by other Regions, and to argue otherwise is all too reminiscent of the position taken by NETR five years ago, when the issue was the extra cost of heat-treated concentrates. Prevarication at that time is now a central issue in litigation.

Unfortunately, this lack of Regional understanding of the needs of haemophiliacs and their families is mirrored in other areas. You will know that our District included in its overall AIDS funding bid for this year a request for £82,000 to help support the cost of physical expansion of Haemophilia Centre out-patient facilities. Our HIV/haemophilia practice is probably the largest in the country, and includes not only HIV-infected patients, but also a large number of currently seronegative individuals who remain at risk by virtue of sexual contact or repeated blood product exposure. Our existing facilities are inadequate to deal with the caseload. This fully justified request was rejected by you as being 'not appropriate for earmarked HIV/AIDS resources' (your letter to my District General Manager of 11th April 1990), without further explanation. Your decision cannot have been reached on the basis of a fair assessment of the situation.

This district is faced with the problem of meeting the needs of the rapidly expanding non-haemophilia HIV/AIDS service run by Dr Margaret Johnson. Without appropriate additional financial support it is not possible to also cater for the special needs

of haemophiliacs and their families, who clearly constitute and 'extra District' responsibility. The result of these two Regional failures to make an appropriate response to the legitimate needs of this latter patient group is plain from our finally agreed Acute Unit AIDS allocation list for 1990/91, which shows that only £2,700 out of a total allocation of £278,800 (ie 1%) of regionally allocated funds are to be directed towards the particular needs of haemophiliacs. This is a situation which I view as inappropriate, to say the least. Others may see it as discriminatory.

Probably, more patients with haemophilia are looked after in NETR than in any other Region in the country; certainly, more HIV-infected patients are cared for (about 13% of the national total). One might have hoped, therefore, that this Region would be setting the standards which others would follow. Regrettably, this is not the case. The contrast with the more enlightened approaches taken by other Regions is stark. One has only to read the NETR AIDS (control) Act Report for 1989/90, in which haemophilia is hardly mentioned, to appreciate the situation. Contrast this with the recently published document on haemophilia care produced by the South East Thames Region. I quote:

"(Haemophilia)....is an area where medical technology is very likely to move faster than the decision-making ability of the RHA".

".....a much more pro-active approach (is required) on the part of the Authority".

"The Regional Health Authority needs to start planning" (for the advent of synthetic factor VIII).

"Clearly in this HIV-traumatised population, the goals of total viral safety and protein purity are of major importance" (Pierce et al, 1989).

"....a large proportion of the blood product funding in SE Thames Region comes through special allocations for HIV and AIDS"... "HIV funding should continue to be used to support haemophilia care".

"It must be considered highly likely that (use of high purity product) will become a part of this Region's clinical practice".

"Clearly, the RHA should have policy decisions formulated in advance for changes such as these that can readily be foreseen, rather than having to deal with each new situation in a piecemeal way".

I remain very willing to further discuss these matters at any mutually convenient time. In particular, Dr Christine Lee, Mrs Riva Miller and myself would be delighted to show you around our out-patient facilities, and explain exactly why it is that expansion is urgently needed.

Yours sincerely

P.B.A. Kernoff

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cc:

Dr William Kearns, RMO, NETRHA

Dr Noel Olsen, DMO, Hampstead Health Authority

Mr John Cooper, DGM, Hampstead Health Authority

Mr Martin Else, Director of Finance, Hampstead Health Authority

Dr Brian Colvin, Director, Haemophilia Centre, Royal London
Hospital

Dr Margaret Johnson, Consultant in AIDS care, RFH

enc: UKHCD Therapeutic recommendations