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21st September, 1989

Dear Colleague,

RE: Reorganisation of Haemophilia Care and Recommendations
on Choice of Therapeutic Products.

This is a further progress report and a request for your help. I regret to say that our choice to remain as we are without a designated Regional Haemophilia Centre was given a frosty reception at the first meeting of Haemophilia Centre Directors Regional Representatives last week. It was pointed out to me by everyone, including the Archangel Gabriel that our stance is against the spirit of the document "Organisation of Haemophilia Centres" circulated by Dr. Rizza to all Haemophilia Centre Directors in June. This is not how I understood the document and I hasten to add that we are not the only Region who have not as yet reorganised along these lines. Despite my protestations I have been asked to come back to you to obtain some commitment towards Regional organisation. The decision was taken to rename the "Club" the "U.K. Haemophilia Centre Directors Committee" and to put it bluntly, it will be expected that at the next meeting (February, 1990) all representatives will be Regional Centre Directors, actual or designate. My presence, as your representative, will no longer be acceptable. I know it all boils down to resources, and if it is necessary to establish a Regional Centre we must at the very least pass this document on to Region. Clearly we need to discuss this matter all over again and if there are no objections I will ask for some time during the morning of the next Haematology Sub Group meeting at Taunton on 4th October. It would be useful to have had some discussions before the A.G.M. of the Haemophilia Centre Directors on 9th October.

Another matter which I require your help with, which is not of quite such pressing importance, is the choice of therapeutic products. All Haemophilia Centre Directors have been circulated with the recommendations (31st May, 1989, second edition). The Committee wishes to update this with a third edition and have asked for comments. There is a feeling that the current recommendations show an unfair bias against certain products such as the solvent detergent treated concentrates and third generation products (monoclonally purified). No doubt legal considerations weigh heavily in the equation and at the moment none of these products have licences, but for that matter neither do N.H.S. 8Y and 9A. Another worry is over DDAVP and Tranexamic Acid, both of which have had adverse publicity recently following thrombotic events in previously fit individuals. I would be grateful if members of the Haemophilia Treaters Group

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could give me their comments in writing by early November.

Yours sincerely,

GRO-C

RICHARD LEE
Consultant Haematologist