

4th July 1979

Association of Haematologists (North East Thames Region)

HAEMOPHILIA WORKING PARTY

Meeting held at the Brentwood Regional Blood Transfusion Centre,  
April 4th 1979, 2.30 p.m.

Members Present:        Dr. P. Kernoff (Chairman)  
                             Dr. O.H.A. Baugh  
                             Dr. D. Carmichael  
                             Dr. B. Colvin  
                             Dr. W.J. Jenkins  
                             Dr. J.W. Nicholas  
                             Dr. A. Rankin

Apologies for Absence:  
                             Sister Anne George, Dr. R. Lane, Dr. J. Oakey

2/79

Matters arising from the minutes.  
9/76 Central Funding of Commercial Factor VIII concentrate purchase.

Dr. Jenkins reported the reply from the Regional Treasurer stating that "all pharmacists in the region should refuse to supply Factor VIII concentrate except in North Camden and Tower Hamlets Districts". Only the Directors of the Royal Free Hospital and London Haemophilia Centres would have access to Commercial Factor VIII concentrate and then through an Area Supplies Officer at Barking and Havering.

Dr. Jenkins pointed out that this proposal was contrary to the advice put forward by the Haemophilia Working Party. It was generally agreed that the suggestion was unacceptable and demonstrated lack of understanding at Regional level of the nature and problems of the Haemophilia Centre and Associate Centres both in funding and day-to-day treatment.

Dr. Carmichael asked that the Regional Treasurer's proposal should be rejected. He felt that it was fundamental that Directors of all Haemophilia Centres and Associate Centres must be able to prescribe and treat their patients without such restrictions. He emphasised that care must be taken at District level to ensure responsible use of the Factor VIII concentrate available so that funding for NHS Factor VIII concentrate could go ahead.

Dr. Jenkins agreed that funding of NHS Factor VIII concentrate was essential. He re-iterated the cheaper cost of the NHS product at 5p/unit, and supported the aims of self sufficiency. He emphasised the need to avoid the risk of hepatitis from U.S.A. Products.

Dr. Carmichael suggested that the proposals of the Haemophilia Working Party should be re-stated and that the economic and ethical arguments should again be presented to the Regional Board. He said that a 'position paper' should be prepared and taken to the Specialist Committees for support.

It was agreed that the Chairman should draft a letter to the Regional Treasurer declaring that the recent proposal was unacceptable. It was agreed that this letter should be circulated to interested parties, initially to the Association of Haematologists.

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HEPATITIS RISK WITH FACTOR VIII CONCENTRATES

Dr. Kernoff reported the increased recognition of Non A/ Non B Hepatitis as a risk of Factor VIII concentrates.

He suggested that until a diagnostic reagent is available, sera from all vulnerable patients should be stored, together with an aliquot of the concentrate used, for the retrospective study.

Dr. Jenkins suggested that all sera from possible post-transfusion hepatitis could at present be examined at Brentwood Regional Transfusion Centre for Hepatitis B.

Dr. Colvin said that Haemophilia patients on regular Factor VIII concentrate treatment may have abnormal liver function tests, and that three groups have been identified:-

1. No abnormality
2. Temporary disturbance of LFT's
3. Permanent disturbance of LFT's.

He suggested that there should be an attempt to evaluate treated patients.

It was agreed that regular testing for Hepatitis B, LFT's, and storage of sera for the retrospective study for NonA/NonB Hepatitis should be arranged. However the question of liver biopsy was problematical. It was important to assess liver changes on treatment, but the question of costs and ethics was also involved.

The Associate Haemophilia Centre Directors present agreed that they would not be prepared to undertake investigative liver biopsies. Drs. Kernoff and Colvin agreed to present a working paper on the feasibility of liver biopsies and a rough draft proforma for a Regional Haemophilia Hepatitis survey.

It was agreed to set out:-

- a. A Regional Policy for investigation of Home Treatment Patients for treatment induced liver disease.
- b. A Regional Policy outlining the indication for liver biopsy.
- c. A Regional Proforma to follow-up patients new to Factor VIII (or IX) concentrate therapy.

The next meeting was not arranged. Now fixed for 1st August 1979  
2.30 p.m. at Brentwood Regional Blood Transfusion Service.