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REPORT ON MEETING OF UK REGIONAL HAEMOPHILIA DIRECTORS 11 SEPTEMBER 1989

INTRODUCTION

Most of the meeting was devoted to the second item on the agenda: Document "Recommendations on choice of therapeutic products .....". The subsequent reports of the Working Party chairmen were very brief and basically said that more information would be available at the AGM in October.

1. REVIEW OF DOCUMENT

The discussion at this time was wide ranging over the current issues of FVIII supply, quality and safety. The following points were of note:

- 8Y is charged at 24p per unit
- BPL to make 100 x 10^6IU 8Y, but have no planned stock. A small unplanned stock has built up as production has exceeded demand (and one RTC cancelled their quarterly order: a hospital in this region had complained to BPL that the 8Y they had received had a one month shelf life - this was due to holding time at the RTC).
- BPL receiving 480-490 tonnes of plasma per annum - they expect to get 500 tonnes next year which should give them 90 million IU at current yields. (This year's production has reduced the plasma stock which was built up over the last few years).
- Dr Savidge pointed out that this meant that BPL planned to reduce production and enquired if the SNBTS planned to do so also. (I) stated that we intended to increase production.
- Dr Savidge enquired (agressively) when BPL were going to introduce solvent/detergent treatment. Dr Gunson said that, while he was not involved in internal discussions at BPL, he was unaware of any plans. Indeed, in his opinion, the currrent data suggest that 80C heating is sufficient. It was proposed that a representative of BPL be invited to attend the future meetings of the group. This was agreed.
- Professor Bloom said he was unaware that 8Y was available and said he would have used it in preference to commercial if he had known. He also commented that the blood bank made an estimate of the haemophilia director's needs and ordered accordingly. He pointed out that he was unaware of any evidence that monoclonal purified products were any better, and he found 8Y perfectly acceptable.

- Dr Rizza stated that he always used 8Y for virgin patients. He also raised European self-sufficiency and pointed out that the French are self-sufficient and have 'shelf-loads' of material which they would be willing to export.

- Concern was expressed that BPL (and SNBTS) would find regulatory authorities more stringent after 1992.

- Dr Kernoff commented that demand had gone up by 15% per annum in the last 15 years and such increases would be expected to continue as there was more short term prophylaxis being undertaken.

- Dr Rizza pointed out that FVIII usage in the UK was moderate by Western standards and that average usage would be some 130 x 10^6 iu per annum.

- Dr Savidge complained that the formulation of BPL Factor IX had been changed (increased heparin to comply with European standards) without discussion with the users. He also was concerned that this change had taken place in the middle of the 'safety study'.

- Dr Kernoff stated that the current arrangements of getting 8Y via the RTC's caused delays and ordered needed to be placed three months in advance.

- Dr Savidge complained that the BTS is 'financially managing' haemophilia patients by deciding which FVIII is to be purchased, as 8Y is being chosen in preference to other products.

- Professor Bloom did not encounter this difficulty and had recently bought HAEMATE for a vWD patient.

- It was agreed that an ad hoc group should be set up between the HD's, CBLA and BPL to discuss 8Y production and demand.

- It was agreed not to rewrite the Recommendation Document at present, but HD's should supply their comments to Dr Kernoff by the end of November and he will draft a new document.

- Dr Rizza raised the point that Professor Cash had written to him suggesting that as part of the 1992 package, commercial blood products would not be permitted in the EC. Dr Gunson stated that the directive required EC governments to move towards unrenumerated donor products and EC self-sufficiency, but without a time-limit.

Wane ?
Delhi ?

2. ANNUAL RETURNS FOR 1988

. Dr Rizza stated 21 centres (of which 4 were regional centres) had not yet sent in their 1988 returns.

. Without the above centres, the following were the results of the returns:

80 million IU of Factor VIII replacement used
37% NHS FVIII
61% commercial FVIII
2.5% cryoprecipitate

14.3 million IU FIX
66,000IU of which were commercial

3. CHRONIC HEPATITIS IN HAEMOPHILIA

Professor Preston outlined the objectives of the Working Party:

1. to determine prevalence of chronic liver disease in haemophiliacs.

2. to establish the percentage sero-prevalence of anti-HCV.

3. to establish the importance of HCV.

4. to examine effect of HIV and HCV co-infection.

5. to encourage trials of anti-viral agents.

4. UPDATE ON 8Y STUDY

See attached Appendix A.

5. FUTURE MEETINGS

1. 1989 AGM - 9.30am 9 October 1989
Lecture Theatre 1 (Academic Building)
John Radcliffe Hospital
Oxford (Cost £12)

2. 1990 AGM - 20/21 September 1990 - Sheffield
(one day business/one day science)

3. Next meeting of Regional Representative Group
12 February 1990
Royal Free Hospital
London