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NOTE OF MEETING OF SIBTS DIRECTORS AND HAEMOPHILIA DIRECTORS HELD IN
ST ANDREW'S HOUSE ON 4 OCTOBER 1976.

Present:

Dr D W A McGreadie (Chairman)	Dr G A McDonald
Dr C Cameron	Miss M R Patterson
Dr J D Cash	Dr C R M Prentice
Dr I A Cook	Dr J Wallace
Dr S H Davies	Mr J G Watt
Dr A A Dawson	
Professor Girdwood	

IN ATTENDANCE

Dr A D McIntyre SHHD

Mr R N Roberts } Secretariat
Mr J Docherty }

APOLOGIES FOR ABSENCE

1. Apologies for absence were received from Major-General Jeffrey, Professor Douglas and Dr Tudhope.

MINUTES OF MEETING HELD ON 14 NOVEMBER 1975

2. The minutes were approved as a correct record.

MATTERS ARISING

3. Dr McIntyre reminded the meeting that the result of investigation of samples of AHP 127 (a batch which had caused adverse reactions) had been sent to Professor Grist and Dr Reid of the Communicable Diseases (Scotland) Unit and it was hoped that their final report would be available for discussion at the next meeting.

SUPPLIES AND REQUIREMENTS OF FACTOR VIII

4. It was agreed that items 4 and 5 on the agenda could be taken together and Dr McIntyre spoke to the paper "Resources required for adequate treatment of Scottish Haemophiliacs", which had been prepared in co-operation with Directors and had been circulated to members before the meeting.

5. Dr McIntyre explained that the question of estimating requirements of Factor VIII had been causing concern to the recently re-convened UK Expert Group on Haemophilia, (Scottish representatives on the group are Dr Davies, Mr Watt, Major General Jeffrey and Dr McIntyre). An "average" figure for the amount of Factor VIII required by each haemophiliac was unhelpful. The total usage was related to the number of moderate/severe haemophiliacs and the ratio of mild to severe cases was not constant in all areas.

6. The importance of an accurate register of haemophiliacs in Scotland was stressed and it was agreed that the upkeep of such a register would be of great value. A practical obstacle to this however was that Haemophilia Centres lacked the secretarial staff for this extremely time-consuming task. The requirements of Factor VIII for Haemophiliacs would, of course, tend to increase, as for example child sufferers grew older (a 25% - 30% increase in needs was suggested); it was also noted that longevity would add to the number of older haemophiliacs.

7. The primary need was seen as the provision of information to help on balancing use and requirements. Use would obviously increase if patients took up and were encouraged to take part in eg skiing or other outdoor pursuits. It was becoming increasingly apparent that haemophiliacs should be advised to live within the limits of their disability and in the more severe cases this would lead to them living a more sedentary life. While it was acknowledged that this is a difficult area, impinging as it did on the question of clinical freedom, it was thought to be a realistic approach.

8. It was clear from general discussion up to this point that there was general acceptance of the view that a meeting with representatives of the Haemophilia Society would be helpful. It was accepted that the Society was not representative of all haemophiliacs but a meeting would be a means of explaining to the bulk of patients what the present situation was, how in some instances the use of scarce Factor VIII was being abused and how they would co-operate in the management of the problem. It would be important that before any such meeting was arranged, definite lines of policy had been agreed which could be used as the basis for discussion. It was considered important that an agreed policy in Scotland should also have the support of clinicians in England and Wales. It was hoped that in this way the energies of the Haemophilia Society might be guided into more productive activities. The Society might be willing for example to finance the setting up of the Haemophilia Register.

9. Dr Cash reported that the figure he had used in a recent BMJ Article as the requirement for a severe haemophiliac is 500 units per kilogram/Body Weight per annum, was now apparently being adopted by Holland, Finland and France and would perhaps help the committee in discussions on requirements. In the event of a register being built up weight would, of course, require to be included. There should however be provision in any estimate for "emergency" needs and it was suggested that about 20% of the PFC output (presently 100 bottles a week) should go into reserve to cover contingencies and also the period each year when the plant was closed for maintenance.

AHF - REPORT OF INVESTIGATIONS OF BATCH 124 AND BATCH 134

10. Mr Watt spoke to the paper, copies of which had been circulated to members, stressing that there had been difficulty in collecting information, on which the report was based, due to absences on summer holiday. There had been two batches involved originally but the results of the assays on the samples sent to Drs Dane and Cash had eliminated Batch 134. Dr Dane's conclusion had been that there had probably been one positive donation which had been missed on the initial screening or that there might have been a number of positive donations which were just below the level of sensitivity in the test used. The paper suggested 3 possible solutions to the problem and it was agreed that the best long term solution was to accept Dr Dane's offer to pass on information about his more sensitive test to Edinburgh. This process has in fact already started.

11. The question of whether or not it was of real value to investigate patients who developed jaundice following administration of Factor VIII was raised in view of the expense involved. Mr Watt did not think this could be justified on the grounds of cost effectiveness but others disagreed. Drs Cash and Cameron were agreed on the worth of the exercise and it was thought that Edinburgh in particular had benefited by changing their technology to meet the new situation.

12. The Chairman thanked Miss Patterson for her excellent report.

SUPPLY OF FACTOR VIII AND IX DEFICIENT PLASMA

13. Mr Watt reported difficulty in obtaining sufficient supplies of Factor VIII and IX deficient plasma and told members that supplies of Factor IX deficient plasma had been obtained for years from one man. PFC needed 350 ml of each per month and a new source was required. This was a point which could be put to the Haemophilia Society at their next meeting and Dr Davies agreed to raise it. Mr Watt underlined the difficulties which could arise by explaining that an entire batch of Factor VIII had had to be withheld for lack of assay material.

ANY OTHER BUSINESS

14. It was suggested that it would be helpful if the figures given in Table 2 of Dr McIntyre's paper "Resources Required for Adequate Treatment of Scottish Haemophiliacs" could be given in standard units but Mr Watt explained that the PFC were having problems in standardising vials. Some of these problems were however being resolved.

DATE OF NEXT MEETING

15. It was agreed that the next meeting be held on Monday 24 January at 2.15 pm in St Andrew's House (Conference Room "D").