

0020

Note of meeting of Directors of the Scottish National Blood Transfusion Service and Haemophilia Directors held in St Andrew's House, Edinburgh on 24 January 1977.

PRESENT:

Dr D W A McCreadie (Chairman)
 Dr C Cameron
 Dr J D Cash
 Dr I A Cook
 Dr S H Davies
 Dr A A Dawson
 Professor R H Girdwood

Dr H B M Lewis
 Dr G A McDonald
 Miss M R Patterson
 Dr C R M Prentice
 Dr J Wallace
 Mr J G Watt

PROJECTIONS DEPARTMENT CENTRE

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Action taken

Mr J G Watt

IN ATTENDANCE:

Dr A D McIntyre (SHHD)
 Miss V Howie (ISD) - For item 4

Mr R N Roberts) Secretariat
 Mr J Docherty)

At the beginning of the meeting the Chairman paid tribute to Major-General Hugh Jeffrey, for his invaluable work for the Scottish National Blood Transfusion Service as National Medical Director. His death would be a great loss to the Service.

The Chairman introduced Miss Howie, Information Services Division, who was present for the discussion on the Haemophilia Register.

APOLOGIES FOR ABSENCE

1. Apologies for absence were received from Professor Douglas and Dr Tudhope.

MINUTES OF MEETING HELD ON 4 OCTOBER 1976

2. The minutes were approved subject to the inclusion of Dr Lewis's name to those tendering apologies for absence.

MATTERS ARISING

3. Mr Watt reported that in November he had attended a meeting of a Workshop in Oxford which had been very successful. The Workshop in Oxford was thought to be the single most important development in recent years and when all data had been collected and published this would be of great value. It was interesting that the results being achieved were comparable to those of the PFC.

HAEMOPHILIA REGISTER

4. Dr McIntyre spoke to the paper relating to resources required for adequate treatment of Scottish Haemophiliacs which had been circulated previously and briefly re-capped on the history of the Register. In 1966 a central register had been held by the Medical Research Council but later it had been agreed that SHHD should maintain the Scottish register. The value and propriety of a central register containing names and addresses was then questioned and cards containing the relevant information were sent to all Regional Haemophilia Directors in 1967. The last meeting of Haemophilia Directors and SNBTS Directors had however accepted that there was value in having a Register of Haemophiliacs to assist inter alia in the estimating of Factor VIII requirements. The questions now being asked were who should maintain the register and what information should it contain. One of the major problems in connection with the maintenance of such a Register was thought to be confidentiality: some haemophiliacs were concerned that a leakage of information might lead to their employers finding out about their disability and it was agreed that this desire for confidentiality must be respected.

Miss Howie was able to assure the meeting that if ISD were given the task of maintaining the register, and they were by no means keen to do so, security would not be a problem as they were extremely security conscious. There was no question of records being accessible to the public and in any case, computer codings could be used. Dr Wallace confirmed that in the West of Scotland, donor information was kept on computer tapes by means of computer codings and the master tape was held in BTS Headquarters. The meeting was reminded that the purpose of the Register would be to help the Group and guide PFC in production matters by showing the numbers of mild/severe haemophiliacs to enable more accurate estimates to be made of Factor VIII requirements; the names of individuals was not important centrally but the information should relate to individual patients.

It was suggested that this problem of confidentiality would probably have arisen in Oxford in connection with the register being set up there and Dr McIntyre agreed to enquire how it was being overcome. He would also prepare a draft for the next meeting showing what information the register might usefully contain. The proposal to keep this Register could at a later date be put to the ICSAG Privacy Sub-Group for their views relative to confidentiality.

ADVERSE REACTIONS TO FACTOR VIII

5. Dr McIntyre reminded members of the discussion of this item at the last meeting and reported that he had since met Dr Reid and Professor Grist. A discussion of the circumstantial evidence relating to Batch 127 seemed to indicate that it was implicated in the outbreak of hepatitis even although by the most sensitive methods of testing available it was negative for HBs Ag. It was also suggested that if a register of haemophiliacs was kept, this could show the hepatitis antigen status of patients and that consideration could be given to administering "doubtful material" to those who had antibodies. The meeting was unanimous in their opposition to this on ethical and moral grounds. The point was also made that this would create great difficulties in any legal case which might subsequently be raised.

It was agreed, that Transfusion Directors should meet to discuss new developments in methods of testing and the many connected difficulties and report back their views. On the question of a drill which might be put into operation when it was suspected that a patient had suffered an adverse reaction to a PFC product it was agreed that each circumstance would differ and it was not possible to prescribe a fixed drill. The point was made however that a "false alarm" notified in plenty of time to the PFC would result only in a product being shelved for later issue whereas late notification of a suspicious batch caused a great deal of trouble and extra work for all staff concerned. There is no question of clinicians being dictated to but any reasonable suspicion should be reported to Regional Transfusion Directors and hence the PFC as early as possible. Similarly it was suggested that the PFC Scientific Director be given a pre-publication copy of any papers being prepared for publication which impinged on the use of PFC products to avoid any misunderstanding especially when the question of adverse reactions arose.

TESTING FOR HBs AG

6. The Chairman reported that the Maycock Report had been issued under cover of an SHHD Circular and copies were handed to Directors for information.

SUPPLIES OF FRESH PLASMA

7. Mr Watt reported that thanks to increased supplies from the Blood Transfusion Centre at Law, the position had improved greatly towards the end of 1976. Dr Wallace said that he had only been able to supply extra plasma to the PFC because Glasgow Royal Infirmary had purchased a substantial amount of commercial concentrate to help overcome the initial transitional phase, and in addition he had managed to persuade his colleagues not to use fresh plasma if they possibly could. He hoped to be able to maintain supplies to the PFC and was optimistic about the future. Dr McDonald

complimented Mr Watt and his staff on their achievements over the past 12 months and was glad to hear that Albumin production was also being improved. It was suggested that it would be helpful to Haemophilia Directors to get statistics showing production and distribution of blood products and it was agreed that RTDs could pass these statistics on. The point was made that before the supplies of blood from donors in the North East could be increased, extra staff would be required but this was not possible because of the present restrictions on the recruitment of Administrative and Clerical staff.

LETTER FROM DR MARKOVA

8. Dr McIntyre read to the meeting, for their information, a letter from Dr Markova, Department of Psychology, Stirling University, concerning research on ways of improving counselling services to haemophiliacs and their families. The letter suggested that some haemophiliac children were at a disadvantage because they received advice from several sources and this was sometimes conflicting. One source of advice in each region was postulated. A reply had been sent to Dr Markova saying that there was some doubt about the value of a separate counselling service for each handicapping condition and suggesting that coming to a conclusion should be delayed until the result of the research was known. It was generally agreed that any move which would destroy the excellent relationship which existed at present between haemophiliac patients and Regional Directors should be strongly resisted. This was not to say that Directors would pre-judge Dr Markova's research and if any recommendations were made, these would be studied most carefully.

DATE OF NEXT MEETING

9. It was agreed that the next meeting be held on Monday 6 June at 2.15pm in St Andrew's House (Conference Room 'D').