



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE TENTH MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on Thursday, 12th February 1981 at 7 p.m. at the Society's offices, 16 Trinity Street, London S.E.1.

Those present: Revd. A. Tanner (chairman), H. Abrahams, Mrs. M.I. Britten, J.R. Hunter, C. Knight, Dr. L. Kuttner, K. Milne, J. Prothero, D. Rosenblatt, J. Ritchie

Apologies: Mr. K. Polton

The Minutes of the Special Meeting of the Executive Committee of the Haemophilia Society held on Wednesday 28th January 1981 were signed as a correct record.

AGENDA

1. Minutes of the meeting held on 8.1.81.
 2. Matters arising.
 3. Case Committee.
 4. (a) Blood Products Sub-committee.
(b) Executive/Administrator Sub-committee.
(c) Group Seminar Sub-committee.
 5. Group Liaison Officer's Report.
 6. Honorary Treasurer's Report.
 7. Honorary Secretary's Report.
 8. (a) European Liaison Officer's Report.
(b) WFH Matters.
(c) Payment of dues to WFH.
 9. Any other business.
1. Minutes of the meeting held on 8.1.81

The Minutes were signed as a correct record.

2. Matters arising

The Honorary Secretary had responded to the invitation to amend the text for the programme on Capital Radio in connection with the Blood Transfusion Service. Some members of the Committee had heard the programme and it would seem that the suggestions made had been accepted.

Mr. Ritchie said that he hoped to be able to attend the Ministry of Transport Conference and Reception on ~~Wednesday~~, 12th March 1981.

Thursday.

3. Case Committee

Two letters had been received for consideration. The application for a grant for half the payment of the installation of a telephone was approved and it was decided that more information was required in respect of the second letter.

4. (a) Blood Products sub-committee

Mr. Prothero and Mr. Milne met Dr. Lane at the Elstree Blood Products Laboratory and had a discussion lasting over two hours. As the work connected with Factor VIII takes place early in the morning they were invited to see the plant at a later date. It appears that the DHSS has accepted that the laboratory will have to be replaced and plans are being considered for a building programme spread over 3 or 4 years, with probable investment of £20 million. It was thought that 80 million units could be supplied in 1985 but this was at the lower end of present needs. There was a great need to improve the technology of fractionation in order to increase the amount of Factor VIII derived from the total blood donated. As present methods were satisfactory for most blood products the cost of improvements would have to be set against supplying Factor VIII. It was thought that there was little the Haemophilia Society could do at the moment but Dr. Lane agreed to keep in touch with the Society and will advise us if he feels we can take any action. The next step seemed to be a visit to the Minister as soon as possible, the Chairman stressed the need for all the correct statistics to be available including the discrepancy between the present and optimum supply level. Mr. Prothero said that the sub-committee was to meet members of Travenol in ten days time. The Chairman thanked the sub-committee for a very full progress report.

(b) Executive/Administrator sub-committee

After some discussion it was agreed that the title should be 'Administrator'. After the interview on 28th January 1981 Mr. David Watters was offered the post through Mr. **GRO-D** and he has accepted. The time to be spent by Mr. Watters on his work as a J.P. and on the Supplementary Benefits Appeals Committee will be 4 days a month. **GRO-A** is giving his advice on the legal terms of the contract. **GRO-A** will be starting work with the Society on Monday 16th February and the Chairman and Treasurer will introduce him to the office staff. References had been taken up and seen by the officers of the Society and copies will be kept in the office. Mr. **GRO-A** suggested that a letter of thanks for all his work should be sent by the Chairman to Mr. **GRO-D** on behalf of the Committee. This was agreed.

4. (c) Groups Seminar sub-committee

Mr. Prothero said the response so far was extremely good - 37 names had already been received from the Groups and most of the members were coming on Friday - the Hotel arrangements had been made. Mr. Knight outlined the programme which would be circulated. The Council Meeting would take place on Sunday morning. Chairmen for sessions had yet to be arranged. The Committee agreed to underwrite an expenditure up to £2500 for the expenses of the Seminar but it was hoped that the main cost of the Seminar would be met by commercial resources.

5. Group Liaison Officer's Report

Dr. Kuttner reported that he had received letters from the Tayside Group which had been addressed by Dr. Forbes on 'Social Problems of Haemophilia'; N.Wales Group; Jersey Group; Oxford Group; Sheffield Group which had made excellent fund raising efforts; North Eastern Group - parts of Mrs. GRO-A's letter was read to the Committee with details of the Annual Draw with profit of £150; Sussex Group - enclosing a very good News Letter; and the Northampton Group which had asked Dr. Kuttner if he could arrange for members to visit Lord Mayor Treloar college and this had been done. A letter from Mr. GRO-A of the Northampton Group was read to the Committee giving details of a meeting of representatives from the Northampton, Birmingham, Oxford and Notts & Derby Groups and outlining resolutions to be put to the Council on 15th March 1981. Dr. Kuttner was asked to thank Mr. GRO-A for this letter.

6. Honorary Treasurer's Report

<u>Bank Balances:</u>	Current Account	£2,170
	Ordinary Deposit A/c	£18,909
	Special Deposit A/c	£51,000

Research Appeal Fund to date: £86,682

The following donations had been received:- Refuge Assurance Co. £100; Queen Anne P.H. £100; United Grand Lodge, England £500; Solicitors Law & Stationery Society £50; Stewart Wrightson Charity Trust £250; Selection Trust £400; De la Rue Co. £250; Lord Samuel of Wych Cross £50; Unigate Dairies £100; Brown Boverie, Kent Ltd. £450, (all to the Research Fund) Merseyside Group £500 to the Research Fund and £100 to the General Fund; Double Century P.H. £500 to the General Fund. The Treasurer said most of these resulted from Mr. Polton's work on appeal letters.

The Treasurer proposed that Mrs. Watson's salary should be increased by £15 per week from 16th February 1981. This was agreed unanimously.

The Treasurer proposed and Mrs. Britten seconded that the Account for £575 (including VAT) for the expenses of Mr. GRO-D in connection with the appointment of the Administrator should be paid. It was pointed out that no Fee had been charged. This was agreed.

7. Honorary Secretary's Report

A letter from Mr. [GRO-A] was read by the Chairman. The Committee learned with deep concern that Mr. [GRO-A] would probably be undergoing surgery which would mean a period of about three months in hospital and recovery. It was agreed that during this period Mr. Prothero should be Acting Honorary Secretary.

Mr. [GRO-A] had sent in a written report which the Chairman read -

re AGM Dr. Tuddenham had booked the Royal Free Lecture Theatre for the whole day and has advised that it will be possible to provide a buffet lunch for which there will be a charge. He has agreed to take part in the afternoon session on Synthesising of Factor VIII and suggested that Dr. Brownlee, who is an expert on Genetic Engineering, be asked to take part. This has been done and an invitation also sent to Dr. Preston at Sheffield.

re Oxford Hostel The last two tenants have left and the hostel is now empty. The offer to help the tenants with moving was taken up by one of them and the Committee approved the grant of £40 being made. Mr. [GRO-A] suggested that a vote of thanks should be given to Mr. [GRO-A], Chairman of the Oxford Group, who has given invaluable practical help and support in finalising matters. Mr. Milne proposed and Mr. Ritchie seconded that this should be done and the Committee agreed unanimously.

8. (a) European Liaison Officer's Report
(b) WFH Matters

Mr. Prothero said that arrangements for Group Travel had been made. The cost for travel to Costa Rica and Hotels would be about £535 so that with incidental expenses, meals, etc. the total cost would be £600 - £650 each. Mr. Milne and Mr. Ritchie both expressed their willingness to represent the Society and it was decided to leave the decision about representation to the next meeting of the Committee when the response of possible sponsors had been obtained.

(c) Payment of dues to WFH

After some discussion it was decided that the following resolution should be sent to Mr. Frank Schnabel as Chairman of WFH -

'The Haemophilia Society expresses its disquiet that some National Member Organisations have had their arrears waived and their full voting rights restored. We consider this to be unfair to those countries which do regularly meet their full dues'.

9. Any other business

Members of the Committee were asked to send in reports as soon as possible to Mr. Clive Knight to help him with the Annual Report.

Date of next meeting: Thursday 5th March 1981

GRO-C

5th March 1981