



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE EIGHTH MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on 11th December 1975 at the Society's offices, 16 Trinity Street, London, S.E.1.

Those present: Rev. Tanner (in the Chair)
Mrs. Britten, Mrs. Hunter, Mrs. Stopford
Dr. Kuttner, Messrs. Hunter, Leven, Morris,
Polton, Prothero, Rosenblatt

Also in attendance: Mr. A. Turner (Oxford & District Group)

Apologies: Mr. Abrahams

Agenda

1. Minutes of the Meeting held on 13th November 1975.
2. Matters Arising.
3. Case Committee Report.
4. Honorary Treasurer's Report.
5. Honorary Secretary's Report.
6. Report on Meeting with DHSS.
7. Group Matters.
8. Oxford Hostel.
9. World Federation and Overseas Matters.
10. Any Other Business.

1. Minutes of Previous Meeting

The Minutes were signed as a correct record after the following amendment had been made:-

Page 2. Item 4 'Kelly's Director' amended to read 'Kelly's Directory'

2. Matters Arising

Page 2. Appeals letters signed by Lord Willis to go with 'Journey' had now been received.

Mrs. Britten now hopes to be in France at the end of January 1976 to work on the 'Guide for Travelling Haemophiliacs' with Dr. J-P. Allain.

Page 4. The European Advisory Board Meeting had been postponed and was now to be held on 12th-14th December 1975.

The Council and Group Representatives meetings had been held. It was agreed to review the 'Notes for the Guidance of Groups' as to the financial and other activities of the Groups and to prepare a draft for Group use in local papers.

3. Case Committee Report

The Case Committee had made a grant of £50 towards the travelling expenses of the parents of a young haemophiliac visiting their son in hospital after complications following an operation.

The Executive Committee were delighted to learn that Mrs. Stopford was expecting a baby in March. It was agreed that this would afford the opportunity to take stock of the Social Work project and the lessons to be learned. It was agreed that as from 1st January 1976, Mrs. Stopford will work only part time, the hours to be agreed between the Honorary Treasurer and Mrs. Stopford.

4. Honorary Treasurer's Report

The bank balances were:-

Current Account	£ 3,889.96
Deposit Account	£28,000.00
RPH Account	£ 422.96

Approximately £800 had been raised by the Annual Draw.

It was agreed to give the office staff a Christmas Bonus of £45 for GRO-D and £20 for GRO-D. In addition, the Honorary Treasurer was to pay GRO-D £25 towards her out of pocket expenses.

5. Honorary Secretary's Report

Various people had suggested that the Society should produce a film showing an up to date picture of Haemophilia, and preliminary talks with an independent film producer had been held. It was agreed that further enquiries should be made.

A meeting had been held with John Osborne MP. Roddy Rugman and Angus King of the "Yorkshire Post" to discuss the help we might get in Parliament for our concentrate campaign.

A letter had been received from Serfological Products Ltd. expressing interest in supporting various research projects we had put to them.

6. Meeting with DHSS

The Honorary Chairman and Honorary Treasurer met Dr. David Owen, Minister of State, DHSS, and two of his administrative staff. Three topics had been discussed, the Attendance Allowance, Mobility Allowance and the availability of concentrates.

It was agreed that fuller details of the discrepancies on the granting of Attendance Allowances would be sent to Dr. Owen.

Dr. Owen was not aware of the campaign the Society had waged over invalid tricycles and no satisfactory conclusions were reached, although it was agreed we would let the Minister have full details of the Society's claims.

Dr. Owen stated that in 1977 we would be fully self-sufficient in concentrates. The whole question of commercial concentrates, plasmapheresis, the regional structure of the BTS and other matters were fully discussed. Regular contact was to be maintained in the future and annual meetings held to discuss haemophiliacs' problems.

The Committee felt the meeting had been most constructive and augured well for future co-operation.

7. Group Matters

Dr. Kuttner reported on the visits he had made and the activities of the following Groups:- Birmingham, Bristol, Jersey, Norfolk, Northampton, Northern Ireland, North East, North West, Scottish, Southern and South Wales.

8. Oxford Hostel

Mr. Turner reported that the County Estates Office, after inspecting the hostel, were prepared to grant a new 5-year lease from 25th December 1975 at £450 p.a. The present rent was £380 p.a. The Oxford Committee had considered the matter and recommended that the hostel continue, as it was fulfilling a useful purpose, but that the individual rents should be increased to £5 a week.

The difficulties that had been encountered in the past and the steps taken to overcome them were outlined and it was agreed that the new lease should be taken up and the recommendations as to rent increases be implemented.

Mrs. Britten leaves for Paris on 20th January and anticipates returning on 26th January.

Dr. Kuttner in his latest letter to Groups had asked them to forward any queries or suggestions they may have regarding the 'Notes for the Guidance of Groups'.

Page 4. The Christmas Party had been a great success with over 350 people present. A coachful had come from both the Northampton and the Nottingham & Derby Groups. The Committee expressed their appreciation of the work of GRO-D in buying the gifts; to ladies who worked so hard to prepare the food, and to the other helpers who contributed to its success. It was agreed that the Christmas Party be put on a future agenda for consideration to be given to its future organisation.

3. Case Committee Report

Mrs. Stopford reported that three grants had been given:-

£20 had been given to assist with the expenses of a family where the parents were separated and the mother and son suffered from von Willebrands disease. The local social worker was to give continuing support.

On the recommendation of the Scottish Group, £4.00 had been granted towards the Christmas expenses of the family of a member in difficulty.

£5 had been granted to a member to help with Christmas expenses in view of an added physical handicap from which he was suffering.

Mrs. Stopford had not yet given up full-time working and the Executive Committee agreed that the matter of her exact hours should be left for flexible arrangements to be made between the Honorary Treasurer and herself. The Executive Committee looked forward to Mrs. Stopford's reflections on her job, the future, her conclusions and recommendations for the future.

4. Honorary Treasurer's Report

The balances at bank were:-

Current Account	£ 3,490.29
Deposit Account	£28,000.00
RFH Account	£ 535.66

The Executive Committee were pleased to learn of a donation of over £250 from a member in Shetland.

The Honorary Treasurer reported that GRO-D was disputing the notice given to him. There appeared to be some dispute about the amount of notice to which he felt he was entitled, and all the Honorary Officers had been involved and the Committee endorsed the action in terminating his retention as from 31st December 1975. The Committee observed that GRO-D was not advancing his chances of being retained for future projects by his behaviour.

5. Honorary Secretary's Report

The Honorary Secretary had met the Managing Director of Serological Products Ltd. to discuss their interest in the two projects we had put to them. As a result, the company had made a donation of £1,100 to the Society, of which £1,000 was to meet the cost of the laboratory technician to be employed at the IHTC under Prof. Ingram. The Executive Committee was delighted to learn of this, and to learn of Serological Products Ltd.'s interest in the prophylactic trial at Lord Mayor Treloar College.

A member had requested a meeting with the Honorary Secretary, as he felt he had been hindered in putting forward information to the Society. It was agreed that more precise details should be requested.

6. Group Matters

Dr. Kuttner reported on the meetings and Christmas Parties he had attended recently and on the activities of the following Groups who had been in touch with him:- Great Ormond Street, Jersey, Norfolk & Norwich, North East, Scottish and Southern.

The Honorary Treasurer had been contacted by the Birmingham & Midland Group. The recent gales had wrecked the Group caravan and only some of the contents were salvageable. Although the caravan was fully insured, all the work and effort put into it was of course lost. The Committee were very sorry to learn of this and endorsed the Honorary Treasurer's offer to help.

7. Organisation of Office

Mrs. I. Watson was invited to join the Committee for this part of the meeting.

The situation with regard to the distribution of work was discussed. It was agreed that alternatives must be found to enable the Society's increasing work to be organised in the most efficient manner. It was pointed out that a lot of work that used to be handled in the office was now being done through Committee Members, but this was not the most efficient way to the good management of the Society's offices.

The possibility of recruiting further help and making Mrs. Watson more of an Executive Secretary was discussed and it was agreed that she should discuss the position with the Honorary Officers and the matter further reported to the Executive Committee.

It was also agreed that Mr. Rosenblatt should look at the Society's accommodation to see if the money paid as rent was being used in the best way.

8. World Federation and Overseas Matters

The Honorary Chairman reported on the meeting of the European Advisory Board in Amsterdam. The Board had concentrated on four topics which were to be further pursued between the member countries:-

Insurances - with which Mr. Rosenblatt agreed to assist.

Treatment Costs when Travelling - which would need rationalisation of legislation.

Concentrates - representations could be made to the Council of Europe.
The available information would need to be collated internationally both by doctors, patients and blood transfusion staffs.

Funds - the possibility of raising money from the Council of Europe to pay for the Board's actions.

The Honorary Secretary had been prevented from attending the meeting as planned, by a severe bleed.

The budget for the April Congress was presented to the Committee and accepted, and the arrangements for publicity, speakers etc. was discussed.

9. Any Other Business

Mr. Knight outlined the position with regard to the new format for the News Bulletin and exhibited a mock-up of the new format. The matter was still under discussion and he will report further in due course.

GRO-C

12/11/76